THE PHONE IS MY LIFELINE: IMPACT OF THE CEDAR PROJECT WELTEL MHEALTH PROGRAM FOR HIV TREATMENT AND PREVENTION AMONG YOUNG INDIGENOUS PEOPLE WHO HAVE USED DRUGS

by

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The Phone is My Lifeline: Impact of The Cedar Project WeITel mHealth Program for HIV Treatment and Prevention Among Young Indigenous People Who Have Used Drugs

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Abstract

Indigenous scholars have called for responses to substance use and HIV among young Indigenous people that acknowledge ongoing colonization, structural violence, and the impacts of intergenerational traumas, while building on cultural strengths and resilience. This mixed method dissertation took place within The Cedar Project cohort involving young Indigenous people who have used drugs in Vancouver and Prince George, British Columbia (BC). The purpose was to examine experiences of engagement with the HIV cascade of care, and evaluate The Cedar Project WeITel mHealth program for HIV-related health and wellness, among young Indigenous people who have used drugs living in British Columbia, using both qualitative and quantitative approaches. Findings support understanding of how a wholistic perspective of health and wellbeing, as well as experiences of ongoing colonial violence including child apprehension, inform engagement with the HIV cascade of care among Indigenous peoples. Results add to mounting evidence that state-based apprehensions of Indigenous children are a negative determinant of health for Indigenous families. Findings further illustrated how mobile phones can be a tool to support family (re)connections, relationships with health and social services, and self-determination within young Indigenous people who have used drugs' health and wellness journeys. Moreover, this dissertation demonstrates that a supportive two-way texting mHealth initiative integrated into existing wraparound care from trusted case managers is acceptable and valued by young Indigenous people who have used drugs. Study findings provide evidence that the Cedar Project WelTel mHealth program may be an effective approach to support engagement in HIV care for young Indigenous people who have used drugs, and should be considered for application in other program settings as well. Four overarching recommendations for policy makers and health providers were developed in collaboration with Cedar mentors, committee members, and investigators: (1) uphold a wholistic perspective to walk with young Indigenous people who have used drugs on their health and wellness journeys; (2) urgently address ongoing apprehensions of Indigenous children; (3) offer the Cedar Project WelTel mHealth model for HIV health and wellness; and (4) explore integrating mHealth with healing modalities for substance use and other aspects of wholistic health and wellness.

Lay Summary

The Cedar Project is a long-term study following over 700 young Indigenous people who have used drugs in BC to better understand their health related to HIV and hepatitis C. The first aim of this dissertation was to understand experiences of HIV care and treatment among Indigenous people, including Cedar participants living with HIV. The second was to determine if a mobile phone 'mHealth' program would be helpful for young Indigenous people who have used drugs living with or at-risk of HIV. We found that family disconnections resulting from colonization were detrimental to HIV health and wellbeing, but that Indigenous culture, resilience, and social support promoted engagement in HIV care. We showed that supportive culturally-safe mHealth, including ability to call and connect with family and circles of care, as well as weekly texting with a case manager, was feasible, valued, and effective among participants living with and at-risk of HIV.

Preface

This statement is to confirm that the work presented in this dissertation was conceived, conducted, analyzed, and written by Kate Jongbloed (KJ). KJ designed the research program, established the research objectives, collected significant parts of the data, conducted all the data analyses, and wrote each chapter of this dissertation, all with the governance of the Cedar Project Partnership which provides oversight for Cedar Project's research, ethical, and knowledge translation activities. Guidance was provided by two Indigenous mentors who are members of the Partnership (Ms. Sherri Pooyak and Mr. Lou Demerais), and the thesis committee (Dr. Patricia M. Spittal, Co-Supervisor; Dr. Martin T. Schechter, Co-Supervisor; and Dr. Richard T. Lester, Committee Member). The research protocol for the project presented in this dissertation was approved through by the UBC Providence Health Care Research Ethics Board, certificate # H15-01192.

Chapter 3. A version of this material has been published in *AIDS & Behavior*: Jongbloed K, Pooyak S, Sharma R, Mackie J, Pearce ME, Laliberte N, Demerais L, Lester RT, Schechter MT, Loppie C, Spittal PM, For the Cedar Project Partnership. Experiences of the HIV cascade of care among Indigenous peoples: A systematic review. AIDS & Behavior. 2019; 23(4):984–1003. I was the lead investigator, responsible for all major areas of concept formation, data collection, and analysis, as well as manuscript composition. SP, RS, JM, MEP, and NL were involved in assessing articles for inclusion, verifying data extraction, and providing feedback on the review protocol and manuscript. SP and LD provided mentorship and guidance at all stages in their role as Cedar Project Partners and Indigenous mentors. RTL, MTS, CL, and PMS provided feedback on the review protocol, interpretation and presentation of results, and manuscript. Figure 3.1, which I created, was also previously published in Jongbloed, K., Parmar, S., Kop, M. v. d., Spittal, P. M., & Lester, R. T. (2015). Recent Evidence for Emerging Digital Technologies to Support Global HIV Engagement in Care. Current HIV/AIDS Reports, 12(4), 451-461.

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Glossary

ART	Antiretroviral Therapy
BC	British Columbia
Child apprehension	Removal of children from their biological parents according to provincial and federal laws.
	Imposed state actions (including legislation and policies) that
Colonial violence and trauma	physical, emotional, and spiritual harm.
	Culturally-safe services are those which respect and honour
	Indigenous identities and perspectives, and are free from racism
	engagement that supports people seeking care to find paths to
	wellbeing. Reaching cultural safety requires an ongoing process of
Cultural safety & humility	cultural humility.
	An approach to service delivery which recognizes and responds to
Healing-centered	the impact of colonial violence and trauma on health and wellness.
HIV	Human Immunodeficiency Virus
	Framework for understanding HIV treatment success. Steps along
	the cascade continuum include: diagnosis, linkage and retention in
	care, initiation and adherence to ART, and viral suppression. The
HIV cascade of care	term 'HIV care cascade' is also used here.
	Descendants of the First Nations Peoples of North America;
	including Indigenous, Aboriginal, Metis, First Nations, and Inuit.
Indigenous people	Includes both Status and non-Status "Indians" under the Indian Act.
IPHA	Indigenous person living with HIV/AIDS
MCFD	BC Ministry of Children and Family Development
	Use of mobile devices, including phones, smartphones, and tablets,
mHealth	for health.
	Odds ratio. Also, unadjusted odds ratio (uOR) and adjusted odds
OR	ratio (aOR).
Resilience	Ability to cope despite adversity
	Research and programmatic approaches which focus on sources of
	strength and resilience that nurture health and wellbeing, as
Strengths-based	opposed to suppressing disease, sickness, or symptoms
TRC	Truth and Reconciliation Commission of Canada
	When the copies of HIV virus in the blood reach undetectable levels
Viral suppression	(≤ 40 copies/ml)

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Throughout this research I was a visitor, including living as an uninvited guest on unceded Coast Salish territories. I am a visitor in Indigenous spaces and drug use spaces. Thank you to the Cedar Project Partnership and all the Cedar participants for allowing me to spend time as a visitor, teaching me how to behave, and accommodating my accidental rudeness and many blunders. I am grateful for how you have showed me different ways to see and be in the world. To Sherri and Lou and Vicky and Earl and Kukpi7 Christian and Mary who have been kind hosts and thoughtful guides – you don't know just how much you have taught me. And to my teachers at the FNHA, Janene, Joe, Katie, Qut-same, Te-ta'in, Syexwaliya, your willingness to help me learn has been both humbling and transformative.

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Dedication

For my family – Mum, Dad and Ingo.

Chapter 1 Introduction & Literature Review

Young Indigenous¹ people who have used drugs face significant barriers to health and wellbeing as a result of historical and lifetime traumas stemming from ongoing colonization and structural violence, especially related to substance use and HIV. Indigenous leaders and scholars have called for responses to substance use and HIV that acknowledge the ongoing impacts of intergenerational traumas while building on Indigenous perspectives, identities, and cultural strengths (Assembly of First Nations & Health Canada, 2015; Assembly of First Nations, National Native Addictions Partnership Foundation, & Health Canada, 2010; Barlow & Reading, 2008; Christian & Spittal, 2008; Duran & Walters, 2004; FNHA, 2017b; FNHA, BC Ministry of Health, & Health Canada, 2013; McKenzie, Dell, & Fornssler, 2016; Myhra & Wieling, 2014; Pearce, Jongbloed, et al., 2015; Walters, Simoni, & Evans-Campbell, 2002; Walters & Simoni, 1999).

This mixed-method dissertation took place within The Cedar Project, a prospective cohort study involving young Indigenous people who have used drugs in Vancouver and Prince George, British Columbia (BC). The purpose was to examine experiences of engagement with the HIV cascade of care, and evaluate The Cedar Project WeITel mHealth program for HIV-related health and wellness, among young Indigenous people who have used drugs living in British Columbia. This introductory chapter locates me (the doctoral researcher), describes the conceptual framework underpinning the dissertation, reviews relevant literature, and provides an overview of the chapters that follow.

1.1 Researcher location

My name is Kate Jongbloed. I am a white first-generation descendant of European immigrants and have been living as an uninvited guest on the traditional Coast Salish territories of the X^wməθk^wəỷəm (Musqueam), Sə'lilwəta?+ (Tsleil-Waututh), and Skwxwú7mesh (Squamish)

¹ A note about terminology: For the purposes of this dissertation, 'Indigenous' refers to those who are descendants of the First Peoples of North America including Métis, Aboriginal, First Nations, and Inuit peoples. Included in this definition are those who both do and do not have 'status' as per the *Indian Act*. I acknowledge that Indigenous peoples in BC, Canada, and globally are diverse, made up of many nations and communities. Where possible, I have tried to honour the identities of Indigenous scholars, knowledge keepers, and Cedar Project participants by using specific terms. However, this is not always possible, especially where data are aggregated or the sample includes a diverse group of Indigenous people. In these cases, I use the term "Indigenous". I use "Indigenous peoples" when referring to a group of populations and "Indigenous people" when referring to a group of individuals. When referring to individual Indigenous people living with HIV, I use the acronym IPHA. Finally, I have adhered to the terms used in external sources when they are quoted directly.

Nations for close to 10 years. Some of my life experiences mirror those of the Cedar Project participants whose voices are represented in this study, as we are similar in age, and many are daughters, wives, and friends like I am. In other ways, they do not. My identity as a non-Indigenous person with limited experience using illicit drugs are key ways our life experiences diverge. While I carry many unearned social privileges with me to this work, the focus of this dissertation centers specifically around Canadian structures of settler-colonialism that result in both unfair disadvantage (oppression) and unfair advantage (privilege) (Nixon, 2019). It is important to recognize that I am embedded as part of this system that creates health inequities, and that I unfairly benefit from it in many ways (Nixon, 2019).

As a non-Indigenous researcher, guidance and governance from the Cedar Project Partnership – an independent body of Indigenous Elders, leaders, scholars, and health and wellness experts – has been fundamental to remaining accountable to the participants in this study. In particular, I have received direct mentorship from two Cedar Project Partners, Ms. Sherri Pooyak (Cree) who is a Community Based Research Manager for the Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre) and Mr. Lou Demerais (Cree and Métis) who has served as the founding Executive Director of Vancouver Native Health Society. Throughout this dissertation, I have tried to use "I" to refer to actions taken by me in my role as doctoral candidate, and "we" to refer to collective actions by The Cedar Project Partnership and investigators, though these are not always distinct.

Being involved with the Cedar Project and this piece of work has been a personal learning journey for me. As you will see, an important theme of this dissertation is family – disconnection, reconnection, identity, and foundations of wellness. I relate to some of these experiences in that I was adopted and in recent years have worked to connect with my own birth family or to "stitch the pieces of my quilt back together". This process was supported by my adoptive parents, two immigrants who left their own families as young adults to seek a new life in a faraway country. My family's experience was not rooted in colonial laws and policies that seek to dismantle families and Nations as the Indigenous participants in this study. Still, the lessons I learned from participation in ceremonies, hearing participants tell their stories, and witnessing Cedar staff and partners at work, have helped me immensely on my own journey. I am very, very grateful.

Engaging in a process of reflexivity has provided the opportunity to recognize and make explicit several values I bring to this research (LeCompte & Schensul, 2010, p. 65; Watt, 2007):

- Cedar Project participants and partners are the experts. I worked to maintain a "learner orientation" and be open to the lessons participants and partners had to teach me about their knowledge and experiences. I am grateful for participants who spent time sharing their cultural expertise with me including how to smudge, how to say words in Indigenous languages (e.g., correct pronunciation of *Bah'lats*, the Carrier word for what is known in English as Potlatch), how to make a dream catcher, as well as inviting me to eat traditional foods such as eulachon grease.
- Striving for cultural safety and humility. Cultural safety refers to respectful engagement with Indigenous people which seeks to address power imbalances to create an environment free of racism and discrimination (First Nations Health Authority, n.d.; Papps & Ramsden, 1996). Cultural humility is a lifelong process of self-reflection where one's own biases and privileges are continually interrogated, unpacked, and addressed (Barlow et al., 2008; First Nations Health Authority, n.d.). Key to cultural humility is acknowledging oneself as a learner when it comes to understanding another's experience (First Nations Health Authority, n.d.).
- Change is urgent. Cedar participants are profoundly impacted by ongoing colonization and the effects of colonial violence and trauma. Their strengths, smarts, and resilience allow them to navigate untenable terrain. However, we know that Cedar participants are dying at an alarming rate – 13 times Canadians their age (Jongbloed et al., 2017). Real lives are at stake and there is urgent need to end and address the harms caused by colonial legislation, unresolved colonial traumas, and culturally unsafe services.

1.1.1 Transformative paradigm

It is also important to briefly make explicit the worldview (paradigm) I hold as a researcher, and the related philosophical assumptions that have shaped this dissertation. My academic training and life experiences have led me to identify strongly with a transformative paradigm, rooted in critical theory (LeCompte & Schensul, 2010, p. 62; Mertens, 2007, 2009). According to a transformative paradigm, reality is shaped by socially constructed power structures that result in discrimination and oppression, such as those related to race, gender, and economics (LeCompte & Schensul, 2010, p. 64; Mertens, 2007; Mertens, Bledsoe, Sullivan, & Wilson, 2010). Power, discrimination, and oppression perpetuate inequalities, while resilience and

resistance oppose them (Mertens, 2009, pp. 3, 10). As a result, transformative research focuses on inequities that result in asymmetric power relationships, as well as the strategies used to resist, challenge, and subvert these constraints (LeCompte & Schensul, 2010, p. 63). It is explicit in its action agenda for reform, rooted in social justice and human rights (Mertens et al., 2010). Further, it requires that research cannot be stripped of these contexts of structural inequities (LeCompte & Schensul, 2010). Transformative researchers acknowledge that power dynamics shape what is considered 'knowledge' and also whose 'reality' or 'truth' is privileged (LeCompte & Schensul, 2010, p. 63; Mertens, 2007; Mertens et al., 2010). Therefore it is the role of the researcher to help shift the balance of power by making visible and challenging oppressive structures (Mertens, 2007; 2009, p. 5). Transformative researchers use the tools of research to illuminate inequities and find ways to bring about change in inequitable distributions of power (LeCompte & Schensul, 2010, p. 63). Collaboration is imperative so as to not further marginalize participants as a result of the inquiry (Mertens et al., 2010). Methodologically, this requires that communities represented in the research must be involved at all stages of the research process, from identifying research priorities, generating the research question, planning the design and methods, and interpreting the results (LeCompte & Schensul, 2010, p. 65; Mertens, 2007; 2009, p. 3). Researchers must also maintain a self-reflective stance to examine their own biases, privileges, and power relationships in relation to the research context (LeCompte & Schensul, 2010, p. 64). Throughout, the voices of those reflected in the research are privileged and amplified (Mertens et al., 2010). In addition, the transformative paradigm challenges a deficit perspective that contributes to pathologizing groups of people and upholding harmful stereotypes (Mertens, 2009, p. 17).

A requirement of being rooted in the transformative paradigm is privileging the worldview(s) of the Indigenous people who participate in and govern the Cedar Project. This has required active and ongoing learning through working closely with my mentors, spending time with Cedar Project Partners, attending ceremonies and cultural events, as well as seeking out learnings from other Indigenous scholars and Knowledge Keepers. In the last few years of this dissertation, I also began to work with the First Nations Health Authority which has offered significant opportunities for learning that are also reflected here. Much of this experiential learning related to Indigenous understandings of health and wellness has taken place outside of classrooms, journals, and textbooks (Chansonneuve, 2005, p. 8). I have tried to capture some of these learning moments in Figure 1.1. However, many have been informal and are not easily captured.



Figure 1.1: Examples of experiential learning during the dissertation research

1.2 Conceptual framework & related literature

Nêhiyaw (Cree) and Saulteaux scholar Margaret Kovach states, "Conceptual frameworks make visible the way we see the world" (Kovach, 2009, p. 41). They represent the 'thinking' behind the 'doing' (Kovach, 2009, p. 39; Maxwell, 2012, p. 39). This section details the theories that are foundational to this dissertation and how they come together to form an overall conceptual framework. It also provides a review of the literature related to each element that appears within the dissertation conceptual framework. The framework is informed by the transformative paradigm. Additional relevant details are provided in the chapters that follow. Visualizing the conceptual framework (Figure 1.2) has been an iterative process, which I returned to frequently over the course of my PhD journey. It has evolved and shifted as I engaged with experiential learning, study data, and academic literature.

Embedded in the dissertation conceptual framework is a commitment to acknowledging and emphasizing existing strengths of young Indigenous people who have used drugs, as well as their families and communities, while also recognizing the impact of ongoing systemic oppression on their health and wellness (Van Uchelen, Davidson, Quressette, Brasfield, & Demerais, 1997). Throughout this section, relevant Cedar Project findings are presented to provide specific context. Key calls to action from the Truth and Reconciliation Commission of Canada (TRC) Report are highlighted (Truth & Reconcilliation Commission of Canada, 2015). Finally, 'real life' examples of the issues under discussion, such as those brought forward in the media and through the voices of Indigenous leaders, Elders, and scholars, have been explicitly incorporated. This is important to me as it demonstrates that these ideas and concepts operate in both the past and present to impact real live people, their wellbeing, and that of their families, communities, and Nations.



1.2.1 Indigenous perspectives of health and wellness

Indigenous peoples in Canada have long histories of health and wellbeing, including traditional healing and wellness systems, which have supported individuals, families, communities, and nations for thousands of years. Despite the diversity of Indigenous peoples in BC, Canada, and globally, a common thread is a wholistic² perspective of health and wellness that includes mental, physical, emotional, and spiritual dimensions of wellbeing (Brant Castellano, 2008, p. 384; 2015, p. 33; FNHA, n.d.; King, Smith, & Gracey, 2009; Kirmayer, Sehdev, & Isaac, 2009;

² This spelling is explicit as it implies "whole" instead of "hole" (deficit focused), as recommended by Mi'kmaq Elder Murdena Marshall (Marshall, Marshall, & Bartlett, 2015). As a result, it is used throughout this dissertation.

Loppie Reading & Wien, 2013; Waldram, Herring, & Young, 2006, p. 74). Wellness is conceptualized as balance and harmony between interconnected aspects of individual and collective wellbeing (Van Uchelen et al., 1997) or what Cree scholar Jeffrey Ansloos refers to as 'wholistic relationality' (Ansloos, 2017, p. 17). In this way, health and wellness extends beyond the individual to include all relations including family, community, and nation, as well as kinship connections to land, water, and other living things (Hovey, Delormier, & McComber, 2014; King et al., 2009; McCormick, 1997; Sinclair, Hart, & Bruyere, 2009). Making and maintaining good relationships is the foundation of a healthy sense of self and balanced wellbeing (Chansonneuve, 2005, p. 43). Fulfilling a reciprocal role as a helper or healer is another component of interconnectedness, belonging, and cultural identity, which contributes to resilience and wellbeing (Brant Castellano, 2008, p. 389; Evans-Campbell, 2008; Kirmayer et al., 2009; McCormick, 1997). This is closely tied to being able to fulfill ones relational, cultural, and spiritual roles and responsibilities, including to land, family, and all relations (Freeman, 2017; Ka'opua, 2001; Pooyak, 2009). The teaching that everyone has a gift to share and the spirit grows weak if their gift is not being offered has been shared with me many times as I worked to complete this dissertation (FNHA et al., 2013). Indigenous perspectives of health and wellness are rooted in Indigenous cultures and ways of life, including languages, traditional laws, ceremonies, and healing approaches (Dion Stout, 2015; Gracey & King, 2009; King et al., 2009). These perspectives are powerfully articulated in the words of these three BC First Nations Elders and leaders:

"First thing about wellness is to know who you are. Who you come from. Your history. Your ceremonies. Your language. Your community." – Elder Larry Grant, X^wməθk^wəỳəm Nation (Grant, 2017)

"Health to us is actually the result of having a sense of belonging, of knowing who you are, of knowing who your relatives were, of knowing what your place is in community. It's about social responsibility, it's about a whole complex network of relationships. So, health is not the absence or presence of disease. It's a way of relating...and of being." – Gwen Philips, Ktunaxa Nation (First Nations Health Council, 2010).

"It's our connection to the land that has been severed, and that's why a lot of our health is not there. A lot of communities were removed and relocated as an example, and those are the communities that have the biggest issues with suicide, social issues, addictions, alcohol. Because they were taken away from where their ancestors lived for thousands of years. And so, I think the more that we understand that our connection is to the land and to the water, and that it is that connection that has kept us healthy – not only for ourselves to re-learn and revisit and reinvigorate that but for society as a whole to recognize it, that

we do have that connection to the land." – Kukpi7 (Chief) Wunu'xtsin Wayne Christian, Splatsin te Secwepemc (First Nations Health Council, 2010).

Self-determination is fundamentally tied to Indigenous health and wellness (Ansloos, 2017, p. 16; Gallagher, 2016; King et al., 2009; Reading, 2015). Indigenous scholars Jeff Corntassel (Cherokee Nation) and Cheryl Bryce (Songhees Nation) describe Indigenous self-determination as, "unconditional freedom to live one's relational, place-based existence, and practice healthy relationships" (Corntassel & Bryce, 2011). Athabascan scholar Dian Million emphasizes that the meaning of self-determination is defined by each nation themselves, citing an example from the north-west coast of BC: "Nuxalk sovereignty is an active responsibility that intertwines our history, language, families, and connection to the land through complex and strict laws as related through our *smayustas*, songs, dances, and potlatches" (Jacinda Mack quoted in Million, 2013, p. 142). Self-determination manifests at multiple levels, from the individual (e.g., respect for patient decision making), family and community (e.g., freedom to engage in ceremony and culture), all the way to the nation (e.g., traditional laws, self-government, control over services), and has implications for health and wellbeing each level (Browne & Fiske, 2001; Chandler & Lalonde, 1998; Chandler & Lalonde, 2009; Million, 2013, pp. 136-142).

Indigenous rights to self-determination are enshrined in Canadian and International Law. In 1763, the Royal Proclamation was signed by King George III at the end of the Seven Years War. In addition to setting out the terms of governance of French-held territories "acquired" by the English during the war, it recognized Indigenous peoples as self-governing entities and has formed the basis of treaty making since Canadian confederation in 1867 (Milloy, 1999, p. 12; Towtongie & Stevens, 2015, p. xvii). The Proclamation has been characterized as the "Indian Magna Carta" (Towtongie & Stevens, 2015, p. xvii). Over 200 years later in 1982, the Canadian Constitution was patriated from British Parliament to Canada's federal and provincial legislatures. Pressure from BC First Nations leaders who led the Constitutional Express, traveling by train to Ottawa to address then Prime Minister Pierre Trudeau, ensured the new document included Indigenous peoples' right to self-determination (Union of BC Indian Chiefs, 2005). As a result, Section 35 (1), which recognizes and affirms Indigenous peoples' inherent right to self-govern, was included in the Constitution Act of 1982, and has formed the basis of important legal challenges in the last 35 years (Borrows, 2005; Waldram et al., 2006, p. 12). Internationally, the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) outlines Indigenous rights to self-determination and self-government (UN General Assembly, 2007). UNDRIP was adopted in 2007 by a majority in the UN General Assembly with 144

states voting for, and four votes against (Mitchell & Enns, 2014). Canada was one of four countries that voted against, along with Australia, New Zealand, and the United States (Mitchell & Enns, 2014). It was not until 2010 that Canada reversed its position and supported UNDRIP (Mitchell & Enns, 2014). In 2015, the TRC released its findings and called for UNDRIP to form the foundation of reconciliation in Canada (Sinclair, Littlechild, Wilson, & The Truth and Reconciliation Commission of Canada, 2015). Specifically, TRC Call to Action 43 recommends the full adoption and implementation of UNDRIP by all levels of government in Canada (Truth & Reconcilliation Commission of Canada, 2015). In 2016, Canada removed its official objector status, nearly a decade after UNDRIP's adoption (Fontaine, 2016). Both the current federal and provincial governments have committed to renewing a nation-to-nation relationship with Indigenous peoples and upholding UNDRIP (BC NDP, 2018; Trudeau, 2018). In May 2018, Bill C-262, which provides a legislative framework to bring Canadian law into alignment with UNDRIP, was approved by the Canadian House of Commons (209 to 79 votes) and was read in the Senate; however it was not passed into law prior to the 2019 Federal Election (Parliament of Canada, 2019b). These are hard won and positive developments made possible through hundreds of years of resistance and advocacy by Indigenous leaders (Union of BC Indian Chiefs, 2005). However, in the next section I examine how colonial institutions have historically, and in the present, undermined Indigenous rights, freedoms, sovereignty, and nationhood, and the consequences for Indigenous health and wellbeing. As settler historian Mary-Ellen Kelm states, Indigenous "health problems have roots in the material conditions of wardship and therefore can be fixed once those conditions are removed" (Kelm, 1999, p. xvii).

1.2.2 Colonization and legislated genocide of Indigenous peoples in Canada

"In this part of the world we've had 150 years of colonial rule where everything from birth to death were ruled by government legislation." – Kukpi7 (Chief) Wunu'xtsin Wayne Christian, Splatsin te Secwepemc (First Nations Health Council, 2010)

Indigenous health and wellbeing were forcibly disrupted through colonization by European settlers persisting to this day (Dion Stout, 2015; Kelm, 1999, p. xvii). Ongoing colonization and its intergenerational effects are considered fundamental and underlying determinants of Indigenous peoples' health (Greenwood & de Leeuw, 2012; King et al., 2009; Loppie Reading & Wien, 2013; Reading, 2015; Smylie & Firestone, 2016). Colonization is rooted in racist ideology viewing Indigenous peoples as inferior to European settlers (Loppie, Reading, & de

Leeuw, 2014). The harmful aim of Canada's assimilation policies was the deliberate destruction of family, social, and political systems that sustain Indigenous wellbeing (Christian, 2010; Million, 2013, p. 20; Richmond & Cook, 2016; Sinclair, 2007; TRC, 2015a). Self-determination is undermined by the imposition of foreign laws that dispossess Indigenous peoples of their land, rights, and freedoms (Milloy, 1999, p. 9; Reading, 2015). In particular, there are five Canadian institutions I will highlight, which have historically, and continue to, oppress Indigenous peoples:

- Indian Act³
- Residential school system
- Child apprehension system⁴
- Criminal justice system
- Healthcare system

It is vital to note that with the exception of the residential school system, the laws and policies of these imposed systems persist. Canada's current Prime Minister, Justin Trudeau, has acknowledged in a recent speech to the House of Commons that this legislation has resulted in "generations of harm" (Trudeau, 2018). The majority of these individual and collective harms have not been fully addressed. Yet, as we examine the health and wellness impacts of each of these institutions, it is important to remember that Indigenous peoples, Nations, and ways of being have survived and in many ways, continue to thrive.

Indian Act

"I think it's critical that non-Indigenous Canadians be aware of how deeply the Indian Act penetrated, controlled, and continues to control, most aspects of the lives of First Nations. It is an instrument of oppression." – Bob Joseph, Gwawaenuk Nation (Joseph, 2018)

The *Indian Act* lays out the Government of Canada's policies of assimilation and appropriation of Indigenous lands, and positioned Indigenous people as legal wards of the Canadian state (Bennett, Blackstock, & De La Ronde, 2005; Richmond & Cook, 2016; Smylie, 2009, pp. 13-14). It was unilaterally imposed in 1876 and <u>remains in effect</u>. The *Indian Act* includes broad controls that undermine Indigenous rights and freedoms, including those related to governance,

³ Indian Act (R.S.C., 1985, c. I-5)

⁴ Though the terms 'child welfare' and 'child protection' are common when referring to government infrastructure and legislation that seeks to respond to harms faced by children, they do not reflect the colonial dynamics of wide-spread apprehension of Indigenous children by the BC government discussed here. Therefore, the term 'child apprehension system' is used.

land, identity, spirituality, and family ties (Borrows, 2008; Joseph, 2018; Milloy, 1999, p. 21; RCAP, Erasmus, & Dussault, 1996b, p. 584; Union of BC Indian Chiefs, 2005). Million describes the *Indian Act* as a form of normative or regulatory violence which has controlled every aspect of Indigenous life in Canada for approaching 150 years (Million, 2013, p. 6). Anishinaabe legal scholar John Borrows, who is of the sixth generation of his family to be affected by the *Indian Act*, states it is "anti-family" as a result of inclusion of legislative provisions that sever future relationships, in contrast to recognizing and affirming life-giving family connections and kinship bonds (Borrows, 2008).

Under the Indian Act, Canada's reserve system carved up traditional territories and closely controlled where Indigenous people were allowed to live and travel (Adelson, 2005; Union of BC Indian Chiefs, 2005; Ware, 1975). Today, reserves persist as a visible reminder of racebased segregation of Indigenous peoples (Loppie et al., 2014). Additional policies created a 'pass system' which required written permission from the Indian Agent to travel outside of reserve lands, which was used to control Indigenous resistance and limit visits by parents to children in residential schools (Joseph, 2018, pp. 50-52). The Act imposed foreign governance systems (bands, elected chiefs, and councils) intended to undermine Indigenous sovereignty and traditional governance. In addition, important governance mechanisms and ceremonies such as the potlatch and sun dance were outlawed between 1885-1951 (Joseph, 2018; Union of BC Indian Chiefs, 2005, pp. 47-49). The Act defines who is and is not an 'Indian'. Previous versions included enfranchisement policies which encouraged assimilation by withholding rights from those who did not give up their 'Indian' status (Loppie et al., 2014). Sexism in the Indian Act is apparent as women were not allowed to vote in band elections until 1951 and those who married non-Indigenous husbands (and their children) were disenfranchised until 1985 and denied membership in their own communities (Joseph, 2018, pp. 19-23; Million, 2013, p. 59). The 1985 amendment (Bill 31-C) did not fully address the sex discrimination; while women's status was reinstated, their band membership was not (Million, 2013, p. 130). Further, the grandchildren of these women are denied status ('second generation cutoff') while the grandchildren of their brothers are not (Joseph, 2018, pp. 21-22). Finally, particularly relevant for this dissertation, previously the Act also directly controlled access to healthcare, as Indigenous people were required to get the permission of the Indian Agent before visiting a physician or hospital, and prior to any medical procedure (Kelm, 1999, p. 111).

Resistance. Since contact, Indigenous peoples have resisted the dispossession of their lands, imposition of colonial laws, and restrictions on culture under the *Indian Act* (TRC, 2015a, p. 116; Union of BC Indian Chiefs, 2005; Wesley-Esquimaux & Smolewski, 2004). A powerful illustration is the way BC First Nations leaders have engaged directly with settler governments to uphold their rights in the context of the unanswered land question since 1763 (Ignace & Ignace, 2017; Union of BC Indian Chiefs, 2005). For example in 1906 and 1908, BC First Nations chiefs travelled to London and Ottawa, speaking to King Edward VII and Prime Minister Wilfrid Laurier to contest the dispossession of their lands (Ignace & Ignace, 2017, pp. 462-463; Union of BC Indian Chiefs, 2005). This legacy of resisting attempts by settlers to undermine Indigenous land rights in this province has continued into the present day. As soon as the *Indian Act* ban which prevented Indigenous people from retaining legal counsel was lifted in 1951, Indigenous people began to use the courts to fight for and protect their inherent rights (Joseph, 2018, pp. 73-74; Union of BC Indian Chiefs, 2005; Union of BC Indian Chiefs & Tsilhqot'in National Government).

Some of the most discriminatory policies of the *Indian Act* have been redressed; however, Canada's Federal Government, currently led by Prime Minister Justin Trudeau, continues to implement and administer this colonial legislation. Health consequences of the *Indian Act* are complex and far reaching (Richmond & Cook, 2016). On one hand, the *Indian Act* has restricted access to traditional approaches to health and wellness, including land, family, cultural traditions, and spirituality, which have sustained Indigenous peoples for thousands of years. On the other, the *Indian Act* has imposed foreign systems that have actively caused physical, mental, emotional, and spiritual harm, both directly (morbidity and mortality) and indirectly (contributing to negative determinants of health).

<u>Related Cedar Project findings – connection to reserves:</u> Measuring the complex impacts of *Indian Act* legislation on individual health and wellness is difficult. In the context of Cedar, one way to understand its impact is through participants' connection to Indian Reserves. Though Cedar study sites are based in urban areas (Vancouver and Prince George), in a cross-sectional analysis involving 260 Cedar participants, more than a quarter had visited a reserve in the past six-month period, including 38% of those living in Prince George (Jongbloed, Thomas, et al., 2015). It is important to remember that both cities are located on unceded Indigenous territories of the Lheidli T'enneh and Coast Salish nations. As a result, many

participants living there continue to live on traditional territories their ancestors occupied for centuries, even though they do not live on reserve.

Residential School System

"We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties." – TRC Call to Action 18

Wellbeing is undermined and eroded when Indigenous children are forcefully removed from their families and communities, as they were through the residential school system (Aquiar & Halseth, 2015; Milloy, 1999, p. xxxvii; TRC, 2015a). Between 1874-1996, over 150,000 Indigenous children were removed from their families and placed in residential schools (RCAP, Erasmus, & Dussault, 1996a; TRC, 2015a). The system was an assimilationist strategy designed to sever the link between children and their families, languages, customs, and beliefs, in order to 'kill the Indian in the child' (Chansonneuve, 2005, p. 5; Milloy, 1999, p. 42; TRC, 2015c, p. 4). Children were taught to feel shame about their cultural heritage, ancestors, families, and spiritual traditions (Chansonneuve, 2005, p. 5). Sections 113-122 of the Indian Act (repealed in 2014) legally removed the rights of Indigenous parents to make decisions related to their children's school attendance, essentially giving the government total control over children's lives (Chansonneuve, 2005, p. 43). When parents did not want to send their children, school attendance was enforced by the Royal Canadian Mounted Police (RCMP) (Chansonneuve, 2005, p. 43; TRC, 2015a). It is essential to recognize that this statesanctioned abduction of Indigenous children in and of itself constitutes a severe form of abuse as well as a violation of Indigenous self-determination (Chansonneuve, 2005, p. 44). The system has been described as "cultural genocide", involving physical, sexual, emotional, and spiritual abuse; institutionalized neglect; medical experimentation; devaluation of cultural identity; harsh punishment; and exposure to serious illness (Chansonneuve, 2005; Milloy, 1999; Mosby, 2013; TRC, 2015a). Million has explained that the residential school system and its intergenerational effects on Indigenous peoples in Canada constitute a, "wound to their most basic relations: in family between men and women, between mothers and fathers and children, extending outward in the relations that are community, and finally, nation" (Million, 2013, p. 7).

There were 18 residential schools in BC (Kelm, 1999, p. 60). Survivors and their descendants are part of the fabric of Indigenous communities throughout the province.

Consequences for health and wellness. Physical, mental, emotional, and spiritual health consequences of residential school attendance have been profound, including while children were attending the schools, after they had left, and for their descendants. Reports from the residential school era demonstrate conditions (e.g., overcrowding, shoddy construction, poor ventilation, inadequate nutrition) at the schools contributed to spread of illnesses such as tuberculosis, while also lacking medical services or facilities to deal with health concerns (Milloy, 1999, p. 84; TRC, 2015a, p. 98). Per capita federal funding was kept low with the intention that it would be supplemented by the church; however, this resulted in schools being dangerously underfunded (Milloy, 1999, p. 118). In the early 1900s, Dr. Peter Bryce, the first federal official responsible for 'Indian' health, published findings demonstrating that 25 to 35% of children attending residential schools died (Lux, 2016, p. 8; Waldram et al., 2006, pp. 188-189). Parliament rejected his repeated requests for funding to address disease and lack of medical services within schools (Waldram et al., 2006, pp. 188-189). Estimates determined during the TRC process suggest that residential school attendees were 4-8 times more likely to die than the general population of Canadian school-age children (TRC, 2015a). However, this is likely a substantial underestimate, given mass destruction of documents coupled with reports by families of children who went missing (TRC, 2015a, 2015b). In a recent scoping review of the literature published since the last school closed, Wilk et al. identified 61 articles examining associations between attending residential school (42 studies) or being a descendant of someone who attended (38 studies), and both physical and mental health outcomes, (Wilk, Maltby, & Cooke, 2017). They found evidence of poorer general and self-rated health, increased rates of chronic and infectious diseases, mental distress, depression, addiction and substance use, stress, and suicidal behaviours associated with intergenerational residential school attendance (Wilk et al., 2017).

Specific mention of the intergenerational health and wellness consequences of wide-scale sexual abuses in the residential school system is necessary. Residential school survivors have testified to pervasive experiences of sexual abuse by staff, only some of whom have been prosecuted (TRC, 2015a). Though the full extent of the abuse cannot be quantified, as part of the Indian Residential Schools Settlement Agreement Independent Assessment Process, over 30,000 former students were awarded claims in recognition of physical and sexual abuse

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experienced at the schools (TRC, 2015a, p. 108). Abuses in residential schools, as well as disruptions of traditional ways of life, have had severe and enduring repercussions for the health and wellbeing of Indigenous families as some survivors unintentionally re-created their own abuses at home (Pearce, 2014).

Resistance. Indigenous families and leaders have actively resisted Canada's attempts at assimilation and cultural genocide via the residential school system (Dion Stout & Kipling, 2003). Many parents refused to send their children, and when it became mandatory under the Indian Act, resisted sending their children despite threat of violence (TRC, 2015a, pp. 116-118). Survivors' courage to speak up about abuses led to creation of the Aboriginal Healing Foundation in 1998 to administer \$350 million from the federal government to support community initiatives to heal the legacy of residential schools (Brant Castellano, 2008, p. 385). More recently, over 80,000 residential school survivors took the Government of Canada to court, which resulted in the largest class action settlement in Canadian history, the Indian Residential Schools Settlement Agreement. The settlement included a \$2 billion compensation package and creation of the Truth & Reconciliation Commission of Canada (TRC). It also prompted public apology to survivors in 2008 by then Prime Minister Stephen Harper (Harper, 2008). During Canada's TRC process, survivors and their descendants publically testified about their experiences in the schools and the consequences for themselves and their families (TRC, 2015a). In its final report shared in 2015, the TRC put forward 94 Calls to Action and a guiding framework for reconciliation in Canada (TRC, 2015a).

<u>Related Cedar Project findings – residential school:</u> Cedar participants are intergenerational survivors of the residential school system (Pooyak et al., In press). At baseline, more than half (55.9%) reported that they had a parent who attended residential school (Craib et al., 2009). Many others reported that they were "unsure" if their parents went to residential school, which may reflect survivors who have chosen to keep silent about their experiences or disconnection from family (Pearce, Jongbloed, et al., 2015). Second-generation residential school survivors in Cedar were more likely to have experienced childhood sexual abuse, have been involved in the child welfare system, have experienced sexual assault in adulthood, and be living with hepatitis C (Clarkson et al., 2015; Craib et al., 2009; Pearce, Blair, et al., 2015; Pearce et al., 2008).

Child Apprehension System

"Removing children from their homes weakens the entire community. Removing First Nations children from their culture and placing them in a foreign culture is an act of genocide" – Patricia Monture-Angus, Mohawk (Monture, 1989).

"We call upon the federal, provincial, territorial, and Aboriginal governments to commit to reducing the number of Aboriginal children in care" – TRC Call to Action 1

As the residential school era came to a close, wide-scale apprehension of Indigenous children into the child welfare system perpetuated removal of Indigenous children from their families and communities (Blackstock, 2003, 2007; TRC, 2015a). The TRC has argued that through its impact on families, the residential school system created conditions that facilitated the next wave of apprehensions during what is known as the Sixties Scoop (TRC, 2015c, p. 11). Between 1951-1991, tens of thousands of Indigenous children were removed from their homes and placed – often permanently – with non-Indigenous families ("Sixties Scoop Settlement Agreement," 2017). Like with the residential school system, the removal of Indigenous children from their homes and families was anchored by imposed settler government legislation and policy. In 1951, Section 88 of the Indian Act was amended and effectively delegated responsibility for Indigenous health, welfare, and education to the provinces (Bennett et al., 2005, p. 45; Sinha et al., 2011, p. 7). Funding arrangements incentivized apprehensions as per capita amounts were only released once a child was in custody, and little was available to support families to stay together (Sinclair, 2016; TRC, 2015c, p. 14). Between 1955-1964, the proportion of children in foster care who were Indigenous increased dramatically from less than 1% to over 34%, and continued to climb in the 1970s and 1980s (Johnston, 1983, p. 23; RCAP et al., 1996a, p. 3:22).

The Sixties Scoop era was followed by what is now being termed the 'Millennium' or 'Millennial' Scoop beginning in the early 1990s (Foster, 2018; Sinclair, 2007). A new federal funding formula policy known as "Directive 20-1" was instituted for First Nations child and family services, and again incentivized removal of children by only providing funds for those "in care" with no funds to support families to maintain custody (TRC, 2015c, p. 21). Directive 20-1, which remains in effect in BC, has led to profound funding disparities as on average, on-reserve First Nations child welfare expenditures were 22 to 30% less than those for non-First Nations

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children, despite higher levels of need (Blackstock, 2016). Shortfalls have led to denials, disruptions, and delays in services, especially lack of funding for prevention services aimed at stabilizing families and keeping them intact, as well as culturally-safe services to address the context of intergenerational trauma stemming from the residential school system (Blackstock, 2016). Since the early 1990s, Indigenous child and family service agencies have been created and taken more control over the welfare of children in their communities; however, they remain bound by provincial child protection laws, and face barriers such as funding constraints for prevention initiatives (Blackstock & Trocmé, 2005). Today, Indigenous children continue to be overrepresented within child welfare systems across Canada, including in BC. Over half of children in foster care in Canada are Indigenous, despite making up less than 8% of children in the country (Statistics Canada, 2018c). For many years, the number of Indigenous children in care has exceeded the number enrolled in residential schools at their peak; estimates suggest the number of Indigenous foster children is three fold higher (Blackstock & Trocmé, 2005; Picard, 2018). Here in BC, although only 10% of children in the province are Indigenous, they comprise 60% of children in custody of BC's Ministry of Children and Families (MCFD) (Special Advisor on Indigenous Children in Care, 2016). Indigenous children are 15 times more likely to be in care than non-Indigenous children in BC (Special Advisor on Indigenous Children in Care, 2016, p. 11).

Consequences for health and wellness. Involvement in the child apprehension system is a key determinant of mental, physical, emotional, and spiritual health of Indigenous children – during, after, and across generations (Tait, Henry, & Walker, 2013). A key assumption underlying the settler child welfare approaches across the country is that when children are apprehended they are placed in "nurturing, stable, and supportive foster home environments where they are able to thrive," (Tait et al., 2013). However, considerable evidence exists that this presumption has not been realized. Context of the apprehension itself, especially if it includes witnessing parental distress and conflict, can be traumatic (Tait et al., 2013). Then there are experiences while in care which often includes multiple transitions and placements (Tait et al., 2013). Indigenous survivors of the child apprehension system have testified to experiences of violence while in custody of the state (Fournier & Crey, 1997, pp. 32, 37-39, 42-43, 85; TRC, 2015c, p. 17). Ansloos described that violence experienced during periods of apprehension includes bullying, sexual abuse, physical restraints by staff, criminalization, and lack of permanency in placements (Ansloos, 2017, p. 8). The TRC experienced challenges accessing comprehensive national data on deaths of Indigenous children in care, but identified
evidence of disproportionate risk of death among Indigenous children in care in Alberta and Ontario (TRC, 2015c, pp. 36-38). Further, they identified significant concerns in Manitoba and BC where all foster children are at increased risk of death, and Indigenous children are at drastically higher risk of being in foster care. Children in care in BC (Indigenous and non-Indigenous) are 3.7 times more likely to die than other BC residents the same age, with suicide, homicide and infectious disease among the leading causes of death (Provincial Health Officer for BC, 2006). Alarming reports of deaths of young Indigenous people in government care across Canada continued to make headlines while this dissertation was underway, including Tina Fontaine (age 15) found in Winnipeg's Red River (died August 2014), Alex Gervais (age 18) who fell to his death from the Abbotsford hotel room where he was living alone (died September 2015), and Danny Francis (age 18) who took his own life in Port Alberni (died December 2015). Two other young Indigenous women died from overdose within months of aging out of care in Burnaby (Patricia Evoy, age 19, died March 2016) and Surrey (Santanna Scott-Huntinghawk, age 19, died November 2016), highlighting heightened vulnerability among young Indigenous people that continues after available MCFD supports and services come to an end.

In addition, involvement with the child apprehension system has been linked to severe health and social outcomes across the life course which are cause for tremendous concern (Ansloos, 2017, p. 38). Impacts of being placed with non-Indigenous families, and/or transitioning through multiple placements, on culture and identity are profound. As explored throughout this dissertation, cultural identity and belonging are important assets which support health and wellbeing for many Indigenous peoples. Mohawk lawyer Patricia Monture-Angus stated, "The effect of the child welfare process is to remove and then seclude First Nations children from their cultural identity and their cultural heritage" (Monture, 1989). While in residential schools, Indigenous children were at least surrounded by other Indigenous peers, this was often not the case in the foster care and adoptive system as the majority of placements were with non-Indigenous families (Sinha et al., 2011, p. 7). Especially when combined with experiences of violence, disconnections from family and identity can contribute to barriers to relational attachment and reinforce experiences of rejection and shame (Ansloos, 2017, p. 8; Tait et al., 2013). The future and survival of Indigenous cultures and traditional systems depend on children (Milloy, 1999, p. 9; Monture, 1989). Like the residential school system, the child apprehension system has intergenerational repercussions for transmission of Indigenous parenting values and skills, as well as cultural transmission more broadly (Varley, 2016).

Further, former foster children who have had negative experience may become parents themselves without having the chance to heal, and unwittingly contribute to stress or traumas in their own children's lives. Finally, while much of the literature focuses on the impact of child apprehension on the child, it is also vital to recognize the impact of apprehensions on parents and extended family from whom the child is removed – a fact which comes up repeatedly in the subsequent chapters of this dissertation (Tait et al., 2013).

Resistance. As with the residential school system, Indigenous peoples have resisted the apprehension of their children in a myriad of ways, including protest and legal action. It is worth stating explicitly that this resistance stems from Indigenous peoples' love for their children, as well as acknowledgment that Indigenous peoples are in the best position to make decisions affecting Indigenous children, youth, families, and communities (Blackstock, Cross, George, Brown, & Formsma, 2006). Throughout the colonial period, Indigenous peoples have sought to uphold traditional child safety laws and practices (Blackstock, 2007; Christian, 2010; Sandy, 2011). One example of successful action to protect this right was the Indian Child Caravan in 1980 (Christian, 2010; Sandy, 2011). Spallumcheen Indian Band made the decision to exercise their jurisdiction over child welfare in their community; however, the provincial and federal governments were resistant (Sandy, 2011, pp. 68-69). The Band and their supporters organized a march from Prince George through the province to Vancouver, where they camped on the front lawn of then Minister of Social Services Grace McCarthy (Sandy, 2011, pp. 68-69). The Caravan resulted in meetings with the province that led to agreement that the band has sovereign jurisdiction over their children (Sandy, 2011, pp. 68-69). Spallumcheen drafted a bylaw which has been frequently contested in the courts, but remains the only example of success in exerting First Nations jurisdiction over child welfare in Canada to date (Bennett, 2004; Sandy, 2011, pp. 68-69). Another example is recent legal actions taken against the Government of Canada. In January 2016, the Canadian Human Rights Tribunal ruled that the Government of Canada is racially discriminating against 163,000 First Nations children as a result of inequities in funding for on-reserve child welfare services (Blackstock, 2016; "First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada, CHRT 2," 2016). After receiving four non-compliance orders, Canada finally agreed to respect the ruling in 2018 (Picard, 2018). Further, a number of class action suits have been brought against the government in provincial and federal courts in connection with the Sixties Scoop ("Sixties Scoop Settlement Agreement," 2017). In August 2017, an agreement was reached between parties setting out the terms of a single national settlement for Sixties Scoop survivors, which includes individual payments and creation of a foundation dedicated to healing and reconciliation ("Sixties Scoop Settlement Agreement," 2017). Most recently on November 30, 2018, after years of work and lobbying by Indigenous leaders, then federal Indigenous Services Minister Jane Philpott made a new commitment to transfer child welfare to Indigenous governments (Tasker, 2018). As of June 2019, Bill C-92 *An Act respecting First Nations, Inuit and Metis children, youth and families* has been read three times in the House of Commons and received Royal Assent (Parliament of Canada, 2019a).

In sum, removal of children from their parents through both the residential school and child apprehension systems is a reflection of racist attitudes to Indigenous parenting and culture more broadly (Christian, 2010; Tait et al., 2013; TRC, 2015c). Current policies, 'do not account for or respect Indigenous child welfare practices' (Christian, 2010) and therefore undermine Indigenous peoples' inherent right to self-determination (UN General Assembly, 2007). The effects of over 140 years (Figure 1.3) of child apprehensions are intergenerational and impact individuals, families, communities, and nations (Christian, 2010; Varley, 2016). State-enforced family disconnections contribute to ongoing traumas impacting the lives of Indigenous peoples across BC (Christian, 2010).



Figure 1.3: Timeline of over 140 years of state apprehension of Indigenous children

<u>Related Cedar Project findings – child apprehension experiences:</u> Cedar participants have been profoundly affected by the Sixties Scoop, which continued into the 1980s. A majority (65%) reported having been taken away from their biological parents; median age of first being removed was 4 years old (Clarkson et al., 2015). Those who had been apprehended were 2.6 times as likely to have experienced sexual abuse and 2.4 times as likely to have been living with HIV at baseline (Clarkson et al., 2015). Participants who had been apprehended were also more likely to have been homeless, paid for sex, diagnosed and hospitalized with mental illness, self-harmed, thought about suicide, and attempted suicide (Clarkson et al., 2015). Among participants who used injection drugs, those who had been apprehended were more likely to have shared needles and overdosed (Clarkson et al., 2015). Further, Cedar participants are the parents of children who have been apprehended through the Millennial Scoop. Among 293 women involved in Cedar between 2008-2016, 78 (27%) of participants reported a combined total of 136 child apprehensions during the 8-year study period (Ritland et al., 2019). The incidence rate was 6.64 (95% CI: 5.25-8.29) child apprehensions per 100 person-years (Ritland et al., 2019). Mothers who reported having recently had a child apprehended were twice as likely to have attempted suicide (aHR: 2.0; 95%CI: 1.0-4.1), adjusting for other factors (Ritland et al., 2019).

Criminal Justice System

"We call upon federal, provincial, and territorial governments to commit to eliminating the overrepresentation of Aboriginal people in custody over the next decade, and to issue detailed annual reports that monitor and evaluate progress in doing so." – TRC Call to Action 30

Mass incarceration and extreme punishment of Indigenous people persist and are a significant barrier to health and wellness. It has been suggested that Indigenous people are over-policed when it comes to criminalization, but *under*-policed when it comes to protection (Dhillon, 2015; The Lancet, 2016). Monture-Angus has linked these experiences with other colonial systems: "Indeed, the over-representation of First Nations peoples within institutions of confinement – be they child welfare institutions, provincial jails, or federal prisons - is part of a vicious cycle of abuse" (Monture, 1989). Further, Million stresses that incarceration of Indigenous people must be seen not simply as a 'barrier to health' but as another example of state-based violence (Million, 2013, p. 5). The police and courts operating in BC and Canada have been externally imposed on Indigenous peoples by, "a government they have not authorized and do not have effective participation within" (Dhillon, 2015). Understanding present-day relations between Indigenous people and the criminal justice system requires recognition of historic criminalization of Indigenous cultural practices and institutions through colonial law, as well as the role of Canadian police in carrying out these laws (Comack, 2013, p. 219; Dhillon, 2015). Distrust of the RCMP persists as a result of their role in enforcing the Indian Act, including apprehension of children to residential schools (LeBeuf, 2011, p. 8). According to the TRC, the residential school system has contributed to over-incarceration of Indigenous people (TRC, 2015c, p. 7). Children were forcibly removed from home, kept in prison-like institutional settings, and treated like offenders (TRC, 2015c, p. 7). In addition, residential school experiences contributed to substance use among survivors and descendants; ongoing criminalization of drugs thus results in those who use them being in conflict with the law (TRC, 2015c, p. 8). Indigenous and non-Indigenous legal scholars have argued that over-incarceration of Indigenous peoples in Canada is a result of failure to recognize sovereignty, self-determination, and Indigenous legal perspectives (Monture, 1989; Ross, 2014).

In the present day, Indigenous adults accounted for more than a quarter of admissions to provincial or territorial correctional services in 2016/17, while representing just 4.1% of the Canadian adult population (Malakieh & Canadian Centre for Justice Statistics, 2018). This proportion has increased steadily over 10 years, from 20% to 27% (Malakieh & Canadian Centre for Justice Statistics, 2018). Overrepresentation of Indigenous people in the criminal justice system is especially pronounced among women (43% of all incarcerated women) and youth aged 12-17 (46% of all incarcerated youth) (Malakieh & Canadian Centre for Justice Statistics, 2018). Within BC, Indigenous people accounted for 30% of admissions to custody in 2016/17 (Malakieh & Canadian Centre for Justice Statistics, 2018). Indigenous women represent nearly half (47%) of incarcerations in BC (Malakieh & Canadian Centre for Justice Statistics, 2018). Both male (44%) and female (60%) Indigenous youth are significantly overrepresented among those incarcerated in the province (Malakieh & Canadian Centre for Justice Statistics, 2018). Researchers determined that in 2011, 305.1 (95%CI: 277.9-332.3) Indigenous people in BC per 100,000 were incarcerated, a rate 4.54 (95%CI: 4.52-4.57) times higher than among non-Indigenous people (Owusu-Bempah et al., 2014). Deeply concerning differences in life years lost to incarceration have been identified among Indigenous people compared to non-Indigenous people (Owusu-Bempah et al., 2014). On average, Indigenous men spend 3.75 times longer in BC custody and 6.18 times longer in federal custody than non-Indigenous men (Owusu-Bempah et al., 2014). Indigenous women spend on average 6.4 times longer in BC custody and 9.0 times longer in federal custody than non-Indigenous women (Owusu-Bempah et al., 2014). These disturbing disparities endure among street-involved youth in Vancouver: A longitudinal (2005-2013) analysis involving 1050 (24% Indigenous) participants in the At-Risk Youth Study (ARYS) observed that controlling for other factors, Indigenous participants had increased odds of incarceration (aOR: 1.4; 95%CI: 1.09-1.80), compared to non-Indigenous participants (Barker et al., 2015). Dhillon reminds us that incarceration is just one part of a "continuum of violence" in the criminal justice system as a whole, which begins

with initial police contact, followed by arrest, detainment, court, sentencing, jail, and probation (Dhillon, 2015).

Indigenous people involved in the criminal justice system also face disproportionate experiences of extreme punishment. Recent news coverage about Adam Capay, a young man from Lac Seul First Nation who spent more than four years in solitary confinement awaiting trial is an extreme example (Porter, 2016). Indigenous people in the Federal system are over represented in maximum security institutions, serve disproportionately more of their sentence behind bars before first release, and are disproportionately involved in institutional security incidents, use of force interventions, segregation placements, and self-injurious behaviour (Office of the Correctional Investigator, 2012). Diverse health consequences of incarceration have been well documented. Higher all-cause mortality, mental disorders, infectious disease, and suicide have been identified as negative health outcomes associated with incarceration in a comprehensive review of the health of prisoners globally (Fazel & Baillargeon, 2011). Many voices – both Indigenous and non-Indigenous – continue to call for a shift from a retributive to restorative approach to justice (Ansloos, 2017, p. 7; Ross, 2014, p. 202).

While Indigenous people are over-represented in the criminal justice system, it is also important to recognize the ways in which the system fails to protect and provide justice for them. Perhaps most visibly, the RCMP and other Canadian police forces have been severely criticized for failures to protect Indigenous women in the context of murder and disappearance, including lack of follow-up in the case of BC serial killer Robert Pickton, which would have prevented additional deaths (Eby, 2012; Oppal, 2012). As another example, while this dissertation was under way, two all-white juries failed to convict white men who killed Indigenous individuals in high-profile cases in Canada. In 2015, one jury agreed that Cindy Gladue – who was killed in the context of sex work in 2011 – had consented to sex rough enough to result in fatal internal bleeding, but that her client bore no responsibility in her death (Razack, 2016a, 2016b). In 2018, another all-white jury – from which Indigenous people were deliberately excluded – acquitted Gerald Stanley of both murder and manslaughter after he shot and killed 22-year-old Cree man Colten Boushie in 2016 (Roach, 2018).

BC also has a long and horrific history of abuses within the context of policing and criminal justice, including in the present day (Union of BC Indian Chiefs, 2005). Most recently, attention has been paid to serious concerns in Northern BC. In 2004, Prince George-based provincial

judge David Ramsay was convicted of buying sex from minors and sexually assaulting four young Indigenous women involved in sex work ("R. v. Ramsay 2004 BCSC 756," 2004). The Ramsay investigation led to additional sexual assault allegations against ten police officers, but ultimately no formal charges were issued, as a result of statute of limitations and internal investigation delays (Eby, 2012; Pan et al., 2013). A 2011 BC Civil Liberties study and a 2013 Human Rights Watch study both documented multiple reports of abuses by law enforcement from community members living near the Highway of Tears (Human Rights Watch, 2013). These include racist and sexist comments, excessive use of force, rape, and sexual assault by police officers (Human Rights Watch, 2013). In 2013, a Cedar paper was the third report to raise serious allegations of police misconduct in Northern BC (Pan et al., 2013). Despite this attention, complaints against police and criminal justice are still coming to the fore. In July 2017, Dale Culver, a young man from Wet'suwet'en and Gitxsan First Nations died in the back of an RCMP vehicle in Prince George after being pepper sprayed. The BC Civil Liberties Association has filed a complaint to the RCMP expressing concerns that officers may not have acted appropriately following the use of pepper spray, including by possibly failing to assist him after the incident, failing to provide immediate medical attention, and/or failing to follow procedures (Paterson, 2018). In addition, in 2018 during the overdose public health emergency, Alex Joseph, a young man from Nak'azdli Nation died of an overdose after being ignored by guards while he was in the back of a BC Corrections van despite the fact that his fellow inmates pounded on the walls and shouted for help for more than an hour (Bolan, 2018).

Resistance. One critical way that Indigenous peoples have resisted imposition of the criminal justice system is through upholding Indigenous legal and justice traditions (Borrows, 2005). An example is recent efforts by Marianne and Ronald Ignace to gather the shared knowledge of the Secwepemc people into a single source to make these laws and teachings accessible to community and public, as they have done so in *Secwépemc People, Land, and Laws: Yerí7 re Stsq'ey's-kucw* (Ignace & Ignace, 2017). Another example is the use of circles to address family violence in a number of Indigenous communities across the country (Ross, 2014). Resistance is also exemplified in Indigenous peoples' use of protest, prayer, and ceremony when injustice is carried out in the name of justice, as I witnessed while attending rallies for Cindy Gladue and Colton Boushie while this dissertation was under way. Further examples of this resistance include when descendants of Indigenous peoples who endured miscarriage of justice in the past speak up for their ancestors so they are remembered and recognized, such as the

relatives of the five Tsilhqot'in chiefs who were executed following the 1864 war who have recently been exonerated by the BC government (2014) and federal government (2018).

Related Cedar Project findings – policing and incarceration: Cedar participants continue to be profoundly affected by the criminal justice system. Nearly 18% of participants had been incarcerated for over seven days in the six months prior to their baseline interview (Clarkson, 2009). Recent incarceration was significantly associated with current self-harm, injection drug use, ever having been in juvenile detention, and being male (Clarkson, 2009). Many participants have been stopped by police (73%), experienced physical force by police (28%), and had drug equipment confiscated (31%) (Pan et al., 2013). As expected, participants who reported dealing drugs (40%) were significantly associated with syringe sharing, rushed injection, and reusing syringes (Pan et al., 2013). Because of personal experience, practical concerns, and intergenerational legacies of unfair policing practices, most participants did not want a positive relationship with police (57%) (Pan et al., 2013). Desire for a good relationship with police was positively associated with having been helped by police, and inversely associated with having been helped by police, and inversely associated with having been stopped by police and/or experiencing physical force by police (Pan et al., 2013).

Healthcare system

"First Nations people have a right to access a healthcare system that is free of racism and discrimination and to feel safe when accessing healthcare. This means people are able to voice their perspectives, ask questions, and be respected by the healthcare professional on their beliefs, behaviours, and values. As partners in their own care, First Nations are entitled to be a part of their healthcare decision-making." (FNHA, 2016a)

The healthcare system has also played a significant role in the colonization of Canada. Harmful health-related experiences have occurred in the past and in the present. Indigenous peoples continue to remember, witness, and experience harm within the healthcare system, with consequences for engagement with care and services. Further, the systems and legislation discussed throughout this chapter have suppressed and denied access to traditional health and wellness systems (Kelm, 1999; TRC, 2015c, p. 139). In contrast to Indigenous perspectives of health and wellness articulated above, a mainstream settler perspective of health tends to center on disease and infirmity – a 'sickness' perspective, which predominates within, and

orients the approach of, Canadian provincial healthcare systems (Gallagher, 2018; Howell, Auger, Gomes, Brown, & Leon, 2016). By failing to reflect the values of Indigenous peoples, and also actively causing harm, the healthcare system has and continues to contribute to health disparities experienced by Indigenous peoples (Adelson, 2005).

It is important to briefly outline the legislative backdrop of healthcare for Indigenous peoples in Canada and BC specifically. Provincial and territorial governments hold authority over healthcare under the Canada Health Act (Martin et al., 2018). However, the special relationship between Indigenous people and the federal government has also shaped the provision of healthcare, which has operated at a federal level (Martin et al., 2018; Waldram et al., 2006, p. 219). Throughout the 1900s, the Indian Health Service within the Department of Indian Affairs provided some medical services for Indigenous peoples. Settler historian Maureen Lux has suggested that these services grew primarily out of "deep anxieties about Aboriginal people and their perceived threat to the public's health" (Lux, 2016, p. 19). In 1979, the federal government's responsibility for healthcare for Indigenous peoples was formalized through creation of the Indian Health Policy (Martin et al., 2018). This has resulted in a semi-segregated and fragmented system of care for Indigenous people, as follows. On-reserve services were funded by the federal government, and Indigenous people with status are covered by a federal Indigenous-specific insurance plan (i.e., non-insured health benefits) (Gallagher, 2018; Loppie Reading & Wien, 2013; Reading & Halseth, 2013). In addition, Indigenous people also access mainstream health services offered by provincial health systems (Gallagher, 2018; Loppie Reading & Wien, 2013; Reading & Halseth, 2013). The degree of segregation has shifted over time; however, in all manifestations, the system has contributed to healthcare inequities (Martin et al., 2018; Reading & Halseth, 2013; Waldram et al., 2006, pp. 210-235). Allan and Smylie argue that, "race-based legislation has normalized the uneven distribution of health funding, resources, and services" (Allan & Smylie, 2015, p. 26). Currently, major changes are taking place as BC First Nations have entered into agreement with the federal and provincial governments to reclaim control over health funding and services for First Nations in this province, under the Indigenous-controlled BC First Nations Health Governance Structure (Gallagher, Mendez, & Kehoe, 2015; O'Neil, Gallagher, Wylie, Bingham, & Lavoie, 2016). Of note, transfer took place in 2013, while this dissertation was underway, and therefore the information presented here predominantly reflects the period prior to this shift.

One of the first collective memories of healthcare-related harm among Indigenous peoples in BC includes mismanagement and failure to provide vaccines that would have contained the spread of smallpox which resulted in drastic population declines in the 1800s (Union of BC Indian Chiefs, 2005). Some argue this denial of care was a purposeful act of genocide and paved the way for settlement of the province (Ostroff, 2017). In fact, when then BC Premier Christy Clark apologized to the Tsilhqot'in people for the wrongful execution of five of their chiefs in 1864, she acknowledged that, "reliable historical accounts" indicate that smallpox was spread intentionally (Clark, 2014). Painful memories of healthcare experiences in settler staterun institutions, including residential schools and Indian Hospitals, also continue to shape present day experiences of the healthcare system (Lux, 2016; Milloy, 1999, p. 84; TRC, 2015c). In many cases, 'medical care' in these contexts was underfunded, racially segregated, and coerced (Waldram et al., 2006, p. 196). In total, there were 22 segregated Indian Hospitals operating in Canada between the 1920s to 1980s (Lux, 2016, p. 3). Of these, three were in BC. Former patients have spoken out about hospital stays that lasted years. Human rights abuses experienced by Indigenous peoples within government-run health and educational institutions, such as coerced sterilization, medical experimentation and excessive use of restraints, continue to come to light (Boyer & Bartlett, 2017; Lux, 2016, p. 44; Mosby, 2013; Sterritt & Dufaitre, 2018). Like the intergenerational traumas of residential schools, traumas experienced within the context of 'healthcare' are also passed through generations. Recently, I have spent time with residential school and Indian Hospital survivors and their descendants who spoke powerfully of their memories of harmful healthcare experiences. While attending the University of Victoria's Centre for Indigenous Research and Community-Led Engagement (CIRCLE) 2016 Gathering, I listened to Songhees Elder Joan Morris share her experiences at the Nanaimo Indian Hospital where her mother was sent two weeks after her birth and stayed for 17 years (Morris, 2016). She recounted memories of sterilization, electric shock therapy on genitals, mutilation, experimentation, and of her uncle being sent to the morgue before he was dead (Geddes, 2017; Morris, 2016). I use this example to illustrate that these experiences, which can seem so far in Canada's past, are in fact within the living memory of the Indigenous peoples and families who we interact with in our day-to-day lives.

If we recognize that racism has shaped most of Canadian-Indigenous relations in BC for the past 150 years, including forming the foundation of the *Indian Act* and residential school systems, it becomes clear that encounters between Indigenous patients and non-Indigenous healthcare providers are also affected by deep-rooted racial bias, stereotypes, and racism that

thus far remain unaddressed in settler society (Harding, 2018; Reading, 2015; Waldram et al., 2006, p. 231; Wylie & McConkey, 2018). Resulting negative experiences can include instances when: concerns are discounted, assumptions are made about behaviour, someone is blamed or belittled, cultural health practices are diminished, and/or rights and agency are undermined (Allan & Smylie, 2015; Brian Sinclair Working Group, 2017; Goodman et al., 2017; Loppie Reading & Wien, 2013; Loppie et al., 2014). Indigenous people also witness family, loved ones, and other Indigenous people experiencing harm within the health system, which likely contributes to a perception that the system is unsafe and should be avoided. The Health Council of Canada suggests there is interplay between lack of trust in mainstream health services, combined with feeling alienated by a foreign system (Health Council of Canada, 2012).

Research documenting the impact of racism and discrimination experienced by Indigenous peoples seeking healthcare in BC is growing, including numerous studies by Browne and colleagues. Among 10 First Nations women living on-reserve in Northern BC, participants described experiencing dismissal by healthcare providers during which their concerns were not taken seriously, as well as feelings of being a 'outsider' in healthcare settings (Browne & Fiske, 2001). Participants felt that experiences of being dismissed by healthcare providers reflected judgement and negative stereotypes about Indigenous people, and that this was compounded by lack of understanding about coping mechanisms learned in residential schools leading survivors to avoid outward expressions of suffering (Browne & Fiske, 2001). In a gualitative study involving 35 participants including healthcare providers and First Nations patients (n=14). beliefs / assumptions about social and cultural differences between Indigenous and non-Indigenous peoples that were not viewed through the lens of settler colonial history and power dynamics contributed to differential treatment (Browne, 2007). Another qualitative study involving 44 Indigenous people attending an emergency department in a large teaching hospital in a Western Canadian city found that participants anticipated dismissal or diminishment of their health issues as a result of racialized stereotypes (Browne et al., 2011). Building on Browne et al.'s work, Goodman et al. explored the intersections of discrimination related to race and substance use in healthcare settings through talking circles involving 30 Indigenous participants who used illicit drugs in Vancouver (Goodman et al., 2017). Participants recounted experiences where they had been treated differently, including feeling demeaned, dismissed, threatened, and discharged without treatment by healthcare personnel (Goodman et al., 2017). In response to these harmful experiences, participants engaged

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strategies to mitigate discrimination, which often amounted to avoiding care (Goodman et al., 2017). Concerns were also raised about healthcare interactions that failed to account for personal circumstances and determinants of health, such as if a late-night discharge resulted in inability to secure a shelter bed, leading to a night outside during a period of illness (Browne & Fiske, 2001; Goodman et al., 2017).

Further, experiences of racism and discrimination in the healthcare system have been gaining attention in the media. The story of Brian Sinclair, an Indigenous man who died of a bladder infection having never received care following a 34-hour wait in the Winnipeg Health Sciences Centre ER waiting room in 2008, is one high-profile example of how racism in the healthcare system can be fatal (Allan & Smylie, 2015; Brian Sinclair Working Group, 2017; Indigenous Health Working Group of the College of Family Physicians of Canada & Indigenous Physicians Association of Canada, 2016; McCallum & Perry, 2018). Similarly, recent news stories have documented instances of Indigenous people seeking emergency care in BC who experienced horrific and harmful delays in diagnosis that appear to result from racism and stereotypes related to substance use. Michelle Labrecque (Oneida Nation) presented to Victoria's Royal Jubilee Hospital emergency department with a fractured pelvis three times prior to being diagnosed and treated (McCue, 2015). This experience reminded her of a previous ER visit at the same hospital when the doctor had given her a prescription, but when she got home she found that it was a crude drawing of a beer bottle circled with a slash through it (McCue, 2015). In August 2017, Gitxan father and husband Chuck Gray required four visits to Wrinch Memorial Hospital in Hazelton over four days before being diagnosed with a stroke and receiving treatment (Fundal, 2017). In September 2017, Mary Stewart (Skwah First Nation) sought help at Chilliwack General Hospital after being hit by a truck but was soon ordered to leave at threat of police involvement without treatment (Johnston, 2017). As she and her partner had no means of transportation or phone, they spent the rest of the night outside nearby (Johnston, 2017). They returned to the hospital the next day at the recommendation of her pharmacist, at which time she was diagnosed as having multiple fractures and a broken femur (Johnston, 2017). At present, no systematic investigation into the scope of the issue of racism in BC and Canada's health system is available, and patient safety reviews continue to deny the role of racism in these events (Allan & Smylie, 2015; Brian Sinclair Working Group, 2017). Further, little research has been done about Indigenous peoples' experiences with discrimination within healthcare, but outside of hospital contexts, such as at labs and pharmacies (Goodman et al., 2017).

Consequences for health and wellness. Collective remembering, witnessing, and experiencing harm in the healthcare system are intertwined and have a cumulative impact on Indigenous health and wellness. The impacts are felt through generations as Indigenous children witness their parents' and grandparents' own negative experiences and learn that healthcare is unsafe. Consequences of these systemic harms include: not receiving care required to prevent illness and death; re-traumatization; delays or avoidance of care until severely ill; emotional and social harm (e.g. anticipating harmful experiences; expecting not to be believed; engagement of stress response to cope with discrimination); and worse health outcomes (Allan & Smylie, 2015; Loppie et al., 2014; Tang & Browne, 2008). When Indigenous perspectives are not respected in healthcare settings, when legislation and lack of self-determination uphold a fragmented, imposed, and segregated health system, and when racism continues to be hard-wired in, the cycle of harm continues and health disparities between Indigenous and non-Indigenous people are maintained and reinforced (Allan & Smylie, 2015; Loppie et al., 2013).

Resistance. Indigenous people have always contested the negation of Indigenous health systems and practices, as well as the pathologizing of Indigenous bodies (Kelm, 1999, p. xvi). One example is that Indigenous peoples have maintained their health and healing traditions despite colonial onslaughts (FNHA, 2014). Today, change is evident as Indigenous peoples across the country seek to assert their individual and collective rights to self-determination over healthcare through creation of Indigenous-led health organizations such as BC's First Nations Health Authority (Gallagher, 2016, 2018; Gallagher et al., 2015; O'Neil et al., 2016). Communities and individuals are also beginning to seek redress for past harms. In 2018, a class-action lawsuit was filed in relation to forced detainment and abuse among former patients at Indian Hospitals (Pelley, 2018). As examples of racist treatment of Indigenous people in the current health system are given more weight, they must begin to be addressed through formal channels such as courts and regulatory bodies.

Section Summary

The overwhelming lesson that I take away from the scholars and teachers cited in this section is that Canadian laws and institutions – including the *Indian Act*, residential schools, child welfare, criminal justice, and healthcare – have been imposed on Indigenous peoples and constitute ongoing state-based violence. While public discourse often views colonization as

something that has happened in the past, I cannot emphasize enough that the story of colonization (and not just its 'legacy') in Canada continues to unfold in the present moment. Ongoing impacts of these systems on the health and wellbeing of Indigenous peoples in Canada is profound, as discussed in the following section.

1.2.3 Ongoing impacts of colonization on health and wellbeing of Indigenous peoples

Ongoing colonization resulting from the continuation of imposed settler laws and policies, has complex and multifaceted impacts on Indigenous people, families, communities, and nations. If self-determination is an important aspect of health and wellbeing, in contrast, lack of control over life circumstances contributes to a burden of stress which is known to contribute to poor health outcomes over the life course (Reading & Halseth, 2013). The following section discusses the role of colonization in contributing to historical and lifetime trauma; violence; racism and discrimination; economic hardship; housing instability; and food insecurity, each of which are well-known determinants of health (Loppie Reading & Wien, 2013; Reading, 2015; Reading & Halseth, 2013).

Colonial trauma: Historical, intergenerational, and lifetime

"When unspeakable things happen to a person and that trauma becomes buried deep within his or her soul, the soul is wounded and the body pays the price through manifestations of illnesses, substance abuse, and depression at levels dramatically exceeding those in the external, dominant society" (Duran, Duran, Yellow Horse Brave Heart & Yellow Horse-Davis, 1998 cited in Hovey et al., 2014)

"Aboriginal communities have suffered repeated shocks from epidemics, territorial displacement, and loss of control over their lives. Loss of children to residential schools laid down another layer of trauma and its distorting effects. When children returned from residential school lacking language and relationships and practical skills to reintegrate into the community, the capacity of extended families to support recovery from abusive and demeaning experiences was compromised by their own grief over multiple losses." – Marlene Brant Castellano, Mohawk (Brant Castellano, 2008, p. 387)

Trauma can be understood as a harmful disruption impacting the spirit, body, mind, and heart requiring healing (Moran & Fitzpatrick, 2008 cited in Pihama et al., 2017). Historical trauma refers to the additive effects of multiple traumatic events occurring over generations experienced by Indigenous peoples in North America as a result of colonization, which have impacts at the levels of individual, family, community, and nation (Evans-Campbell, 2008).

Duran et al. describe the legacy of colonization as a "soul wound," which is multigenerational, collective, historical, and cumulative, which contributes to a "historical trauma response" (Duran, Duran, Yellow Horse Brave Heart, & Yellow Horse-Davis, 1998, pp. 341-342). Ansloos has described the consequences of colonization as, "the alienation of many Indigenous people from their cultural traditions and identity" and that discontinuity and complex violence is perpetuated by the continuation of the neo-colonial systems described above (Ansloos, 2017, p. 5). Ansloos and others differentiate between *complex* trauma (e.g. intergenerational colonial violence) and acute trauma (e.g. witnessing an armed robbery), suggesting that colonial traumas manifest in both ways among Indigenous peoples (Ansloos, 2017, p. 8; Haskell & Randall, 2009). In addition, complex trauma can be *cumulative* (e.g., multiple unresolved traumas over the life course); *collective* (e.g., reverberate through a population, creating a universal experience); and *intergenerational* (e.g., when descendants of those who experienced colonial traumas show symptoms) (Phillips cited in Evans-Campbell, 2008; Pihama et al., 2017; Sotero, 2006). Indigenous scholar Amy Bombay (Rainy River First Nation) and colleagues further suggest that experiencing trauma contributes to risk of facing additional trauma, and also intensifies responses to traumatic stress, known as re-traumatization (Bombay, Matheson, & Anisman, 2009; Bombay, Matheson, & Anisman, 2014a).

Snohomish scholar Teresa Evans-Campbell identified three characteristics of a historical trauma event: (1) it is widespread and affects many members of a group; (2) it is perpetrated by people from outside the group, often with purposeful and destructive intent; and (3) it generates significant collective distress within the group affected (Evans-Campbell, 2008). Historical traumas may refer to different types of loss and violence, such as death of relatives; emotional suffering; forced assimilation; loss of land, language, culture, and spirituality; family and community disconnection; disruption of parenting traditions; and environmental degradation (Chansonneuve, 2005; Evans-Campbell, 2008; Whitbeck, Adams, Hoyt, & Chen, 2004; Yellow Horse Brave Heart, 2003). Haskell and Randall have emphasized that the defining feature of colonial trauma is "disrupted attachments" – to land, to self, and to others (Haskell & Randall, 2009). Put another way, trauma contributes to dismantling land-based, social, and cultural systems of care, identity, and belonging that usually keep someone safe and protected, as well as helping to maintain good family and community relations (Evans-Campbell, 2008; Wesley-Esquimaux & Smolewski, 2004, p. 4). Over 150 years of colonial assault on Indigenous families, including state-sanctioned child apprehensions, mean that some Indigenous children have

been denied the opportunity to grow and learn within responsible, loving, and caring parental and family relationships (Hovey et al., 2014).

Unresolved trauma is passed on to the next generation through a number of hypothesized pathways that may be direct or indirect (Duran et al., 1998; Evans-Campbell, 2008; Haskell & Randall, 2009; Wesley-Esquimaux & Smolewski, 2004; Whitbeck et al., 2004; Yellow Horse Brave Heart, 2003). One possible pathway is related to the family and social environment, for example the result of a community's loss of spiritual compass, interrupted intergenerational transmission of healthy child-rearing practices, or unintentional re-creation of abuses (Aguiar & Halseth, 2015; Bombay et al., 2009; Chansonneuve, 2005, p. 61; Evans-Campbell, 2008; Kirmayer, Gone, & Moses, 2014). Another is the unconscious absorption of parental trauma or stress, referred to as the psychodynamic pathway of transmission (Haskell & Randall, 2009; Kirmayer, Simpson, & Cargo, 2003). Finally, traumatic experiences may have consequences for the body that are transmitted to children within genetic memory or during pregnancy (Aguiar & Halseth, 2015; Bombay et al., 2009; Bombay et al., 2014a; Haskell & Randall, 2009; Kirmayer et al., 2014). Most colonial traumas remain unaddressed / unresolved and Indigenous peoples continue to live side-by-side with the perpetrator of their abuse (Duran et al., 1998, p. 345; Yellow Horse Brave Heart, 2003). Throughout this dissertation I use the term "colonial trauma" as it recognizes that Indigenous peoples continue to feel the effects of traumas that began in the past, but that these are not 'historic' in the sense that new traumas continue to be perpetrated by imposed colonial systems and ongoing colonial violence (Evans-Campbell, 2008; Kirmayer et al., 2014; Whitbeck et al., 2004). Within the concept of colonial trauma, I will refer to historic, intergenerational, and lifetime traumas experienced by Cedar participants, their families, their communities, and their nations.

Colonial trauma *response* refers to a dynamic constellation of collective and individual reactions to historical and contemporary colonial traumas among some but not all Indigenous people (Brant Castellano, 2008, p. 388; Evans-Campbell, 2008; Yellow Horse Brave Heart, 2003). This is closely related to the stress response as understood within a mainstream biomedical sense, in which physiological and psychological processes are activated and increase allostatic load (Bombay et al., 2009; Institute of Medicine, 2001; Kirmayer et al., 2009). Individual reactions can include: bereavement, physical and psychological stress; fear; sadness; anger; loss of meaning; learned hopelessness; guilt and shame; marginality and alienation; identity confusion; challenges with emotional regulation; loss of trust in others;

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difficulty forming/maintaining relationships: addictive or self-destructive behaviours; and mental health issues (Bombay et al., 2009; Chansonneuve, 2005, pp. 46-48; Duran et al., 1998, pp. 342-343; Evans-Campbell, 2008; Haskell & Randall, 2009; Sotero, 2006; Yellow Horse Brave Heart, 2003). Considerable evidence has linked intergenerational and lifetime trauma experiences with depression, anxiety, suicide ideation, and post-traumatic stress response (Bellamy & Hardy, 2015a, 2015b, 2015c; Bombay, Matheson, & Anisman, 2011; Bombay et al., 2014a; Kirmayer et al., 2003; O'Neill, Fraser, Kitchenham, & McDonald, 2018; Whitbeck, Walls, Johnson, Morrisseau, & McDougall, 2009). Learned hopelessness can be thought of as the result of cumulative assaults on collective and individual self-determination (Chansonneuve, 2005, p. 49; Wesley-Esquimaux & Smolewski, 2004, pp. 66-71). Through violent imposition of settler laws, Indigenous decision-making and agency have been systematically undermined (Haskell & Randall, 2009; Wesley-Esquimaux & Smolewski, 2004, pp. 66-71). Mainstream psychological research suggests that feeling powerless or lack of control over life situations and circumstances is a mediator of stress that can contribute to self-doubt, self-rejection, anxiety and depression, as well as having profound physical ramifications (Wesley-Esquimaux & Smolewski, 2004, pp. 66-71). It is important to note that many of the 'symptoms' of trauma response listed here are survival coping strategies in the context of ongoing colonization and colonial violence, and are not 'character flaws' or 'cultural differences' to be ascribed to Indigenous peoples on the whole (Evans-Campbell, 2008; Haskell & Randall, 2009; Mitchell & Maracle, 2005; Monture, 1989).

Indigenous scholars and others remind us that narrow focus on individual-level trauma response fails to address the broader relational impacts on families and nations (Bombay et al., 2014a; Evans-Campbell, 2008; Haskell & Randall, 2009; Mitchell & Maracle, 2005). Recent scholarly dialogue has problematized emphasis on 'trauma' (reaction to violence) and 'healing' (too individualized), at the expense of centering its cause (Canadian state-based violence) and collective cure (Indigenous self-determination) (Million, 2013). This is especially important given that of the five colonial laws and systems discussed in the previous section, just one – the residential school system – has come to an end. As a result, any discussion of 'healing' without seeking to dismantle, stop imposing, or address the harms of these systems does not make sense, and may in fact cause further harm (Clark, 2016; Goodkind, Hess, Gorman, & Parker, 2012; Million, 2013, p. 20). Concerns that the narrative of historical trauma may obscure the fact that Canada is in no way a 'post' colonial society are critical to keep in mind as we discuss the consequences of historical and contemporary colonization on health and wellbeing of

Indigenous people.

Related Cedar Project findings – trauma response and mental health: At baseline, 37.0% of Cedar participants reported they had ever attempted suicide (Moniruzzaman et al., 2009). Factors associated with suicide attempt included living in Prince George, ever having been sexually abused, and ever having overdosed (Moniruzzaman et al., 2009). A recent analysis involving 202 participants observed elevated psychological distress among those who had experienced severe emotional abuse in childhood and blackout drinking later in life (Pearce et al., 2018). Among women, any recent drug use was also associated with increased psychological distress (Pearce et al., 2018). Yet, being able to speak a traditional language and living by traditional culture were associated with lower psychological distress among men, and recently having tried to quit drugs was associated with lower psychological distress among men, and sex work, 67% had probable post-traumatic stress disorder (PTSD) (Sharma et al., 2018). Ever having attempted suicide was associated with higher likelihood of probable PTSD, while living by traditional culture was associated with higher likelihood (Sharma et al., 2018).

Physical and sexual violence

Multiple examples of institutional violence against Indigenous peoples in Canada have been discussed in previous sections of this chapter. Colonization has also contributed to a disproportionate burden of interpersonal violence among Indigenous peoples, including physical and sexual violence perpetrated by state-based actors (e.g., police; residential school staff), non-Indigenous people, and other Indigenous people (i.e., lateral violence). Lateral violence (violence within Indigenous families and communities) can be understood as what Ansloos terms 'relational imbalance' resulting from colonial violence and intergenerational trauma (Ansloos, 2017, p. 95; Bombay, Matheson, & Anisman, 2014b; Duran et al., 1998, p. 347). Physical and sexual violence has mental, emotional, and spiritual consequences, in addition to the more obvious physical ones. Athabascan scholar Dian Million explains that violence (and rape specifically), "interrupts and dissolves the ontological presence of a person and community, their desire to be, to go on, to endure, to have integrity" (Million, 2013, p. 37).

Colonial dynamics have resulted in Indigenous families being over-represented in child maltreatment statistics. Some survivors of residential schools have unintentionally re-created their own abuse within their families and communities after returning home, contributing to

cycles of abuse affecting multiple generations. Conditions of colonization also contribute to increased risk of abuse experiences while wards of the state. In addition, Indigenous families have been subject to disproportionate surveillance and child welfare involvement which increases their representation within the available data. In the most recent Canadian Incidence Study of Child Abuse and Neglect (CIS-2008), rates of child maltreatment investigations were 4.2 times higher among First Nations children compared to non-First Nations children (140.6 vs. 33.5 investigations per 1000 population) (Sinha et al., 2011). Rates of substantiated child maltreatment were five times higher for Indigenous families than non-Indigenous families (Sinha et al., 2011). Further, in a 2013 survey involving all Indigenous youth (12-17) attending schools on and off reserve in BC, 19% of participants reported they had been physically abused and 15% had been sexually abused (Tourand et al., 2016, p. 44). Considerable evidence demonstrates that childhood trauma impacts health and wellbeing across the life course, including through increasing risk of re-victimization and intensifying stress response systems (Bombay et al., 2009).

Indigenous adults are also disproportionately affected by violence. In the 2014 Global Social Survey, nearly one in three (30%) Indigenous people reported that they or their household had been the victim of sexual assault, violent robbery, physical assault, theft, or vandalism in the preceding year (Perreault, 2015). In comparison, fewer than one in five (19%) non-Indigenous people reported that they or their household had been victimized (Perreault, 2015). However, high-level figures can obscure the gendered dynamics of violence against Indigenous people rooted in patriarchal colonial systems (Brodsky, 2016; Smith, 2015). In BC, we have witnessed the Robert Pickton, Highway of Tears, Clifford Olson, and Cody Legebokoff murders that have disproportionately affected Indigenous women (Oppal, 2012). Of the 67 women included in the BC Missing Women Commission of Inquiry, 33% were Indigenous (Oppal, 2012). This overrepresentation is also apparent in national estimates of missing and murdered Indigenous women (MMIW). Using publicly available data, Maryanne Pearce identified 3,329 women who are missing and murdered in Canada, including 824 (24.7%) who are Indigenous. While it provides comparative data, this study represents an underestimate as a 2013 RCMP-led study across all police jurisdictions in Canada identified a total of 1,181 missing or murdered Indigenous women (RCMP, 2014). Families of Indigenous women whose deaths have been deemed suicides or overdoses continue to call into guestion official rulings claiming no evidence of foul play and urge that their loved ones be included in the National Inquiry into Missing and Murdered Indigenous Women and Girls (Moore & Troian, 2016; RCMP, 2014;

Smith, 2016). Indigenous women also continue to be disproportionately impacted by both sexual assault (Perreault, 2015) and spousal violence (Statistics Canada, 2015a). Finally, despite the media focus on Indigenous women, Indigenous men and boys also face disproportionate threat of violence over the course of their lives, including being three times more likely than Indigenous women to be a victim of homicide, and seven times more likely to experience homicide than non-Indigenous men (Statistics Canada, 2015b). As discussed previously, Indigenous men also experience concerning levels of violence within the context of the criminal justice system (Razack, 2015).

Indigenous Elders and leaders also remain concerned about high rates of suicide in some communities, particularly among young people who are involved in substance use and/or the foster care system (BC Coroner's Service & FNHA, 2017; Jongbloed et al., 2017). Chandler and Lalonde monitored suicides in 196 BC First Nations bands between 1987-2000, determining that risk of suicide was 5-20 times higher for First Nations youth compared to non-First Nations youth, but that both youth and adult suicides were not evenly distributed across BC First Nations (Chandler & Lalonde, 2009; Lalonde, 2006). Over half of the bands had no suicides, suggesting the heaviest burden is borne by a small fraction of communities (Chandler & Lalonde, 2009; Lalonde, 2009). Over half of the bands had no suicides, suggesting the heaviest burden is borne by a small fraction of communities (Chandler & Lalonde, 2009; Lalonde, 2006). Over half of the bands had no suicides, suggesting the heaviest burden is borne by a small fraction of communities (Chandler & Lalonde, 2009; Lalonde, 2009; Lalonde, 2009; Lalonde, 2009, Lalonde, 2009). Since then, youth suicide rates among Indigenous people in BC have been declining, from a high of 5.30 per 10,000 between 1993-1997, down to 2.32 per 10,000 between 2009-2013 (Provincial Health Officer of BC & First Nations Health Authority, 2015). Still, between 2010-2016, nearly one-third of unexpected deaths among First Nations youth aged 15-24 in BC were suicides (BC Coroner's Service & FNHA, 2017).

Related Cedar Project findings – childhood trauma: Almost half (48%) of Cedar participants reported being forced to have sex or molested prior to enrollment in the study (Pearce et al., 2008). Sexual abuse was reported by 70% of young women compared to 29% of young men (Mehrabadi et al., 2008). Median age of first non-consensual sex was six years old. Sexual abuse was associated with sleeping on the streets, self-harm, mental illness, high numbers of sexual partners, sex work, and overdose (Pearce et al., 2008). Among 266 participants who completed the Childhood Trauma Questionnaire between 2011-2012, significant proportions of Cedar participants reported having experienced severe levels of physical abuse (41.4%); sexual abuse (38.7%); emotional abuse (33.8%); emotional neglect (17.8%); and physical neglect (39.4%) (Pearce, 2014). Severe sexual abuse was associated with having a parent who had attended residential school, as well as experiencing sexual assault later in life (Pearce,

2014). Other factors associated with having experienced severe sexual abuse included sex work involvement, inconsistent condom use, high frequency cocaine injection, binge injection, and hepatitis c infection (Pearce, 2014).

<u>Related Cedar Project findings – sexual violence:</u> Between 2003-2010, nearly 30% (n=73) of young women in Cedar ever reported having been sexually assaulted in the previous six months (Pearce, Blair, et al., 2015). Of these, 30 (41.1%) reported experiencing sexual assault more than once in that time (Pearce, Blair, et al., 2015). Just 15 (20.5%) had received counselling (Pearce, Blair, et al., 2015). Odds of sexual assault were higher for women who had a parent who attended residential school, experienced childhood sexual abuse, been involved in sex work, been offered money to not use condoms, used injection drugs, injected cocaine or opiates daily, binged with injection drugs, and experienced difficulty accessing clean syringes (Pearce, Blair, et al., 2015). Among participants in Prince George, 4% reported having been raped by members of the criminal justice system (Pan et al., 2013).

Racism and discrimination

Racism in healthcare settings was discussed previously in this chapter, but it is also necessary to consider racism and discrimination as a determinant of health more broadly (Allan & Smylie, 2015; Loppie et al., 2014; Reading, 2015). Racism is an ideology that ascribes a hierarchy based on ethnicity or phenotype, and is used as a justification for discriminatory treatment of groups perceived as inferior (Loppie et al., 2014). Colonization and present-day systemic violence against Indigenous people is rooted in and perpetuated by racism in which Indigenous ways of life are viewed as inferior to those of settler communities (Loppie et al., 2014). Racism can be systemic (i.e. economic, social, and political institutions and processes that create and reinforce racial discrimination); *interpersonal* (i.e. acts of racism that occur between people); epistemic (i.e., racialized judgement of what is considered 'knowledge', 'normal', or 'objective'); and internalized (i.e., internalization of negative, stereotypical beliefs) (Allan & Smylie, 2015, p. 5; Indigenous Health Working Group of the College of Family Physicians of Canada & Indigenous Physicians Association of Canada, 2016; Loppie et al., 2014). Intersectionality refers to recognition that some people experience discrimination as a result of multiple and intersecting identities and life experiences, including those related to substance use, sex, gender identity, sexuality, class, etc. (Hankivsky & Christoffersen, 2008). Haskell and Randall argue that one of the most harmful aspects of Canada's systemic racism against Indigenous peoples is, "the mainstream tendency to deny any social responsibility for producing the very

conditions producing this marginalization and powerlessness, while simultaneously holding those so affected responsible for their own situation" (Haskell & Randall, 2009).

The epidemiology of racism and its health impact is complex, and few studies seeking to quantify these experiences among Indigenous peoples in Canada currently exist. One cross-sectional study involving a community-based sample of Indigenous people living in Edmonton, Alberta (n=372) observed that over 80% of participants had experienced discrimination in the past year (Currie, Wild, Schopflocher, & Laing, 2015). Researchers found that experiencing racial discrimination was associated with post-traumatic stress symptoms and prescription drug misuse (Currie et al., 2015). In another cross-sectional study involving 340 members of Kettle and Stony Point First Nation in Ontario, researchers found that racial discrimination assessed using the Measure of Indigenous Racism Experience (MIRE) Interpersonal Racism Scale was associated with significant increases in stress levels (Spence, Wells, Graham, & George, 2016). However, cultural resilience modestly compensated for the detrimental effect of racial discrimination on stress (Spence et al., 2016).

<u>Related Cedar Project findings – racism:</u> Among 321 Cedar Project participants, 255 (79.4%) experienced interpersonal racism as measured using the MIRE scale (Sharma et al., 2019). Of these, nearly half (n=102; 47.8%) had experienced high levels of interpersonal racism, most commonly from police, staff from government agencies including child welfare, health personnel and in public settings (Sharma et al., 2019). Experiencing high levels of interpersonal racism was more likely if participants were women (uOR: 2.68; 95%CI: 1.33-5.41), lived in Prince George (uOR: 3.30; 95%CI: 1.63-6.71), had had a child apprehended (uOR:3.14; 95%CI: 1.43-6.88), had been denied access to shelter (uOR: 2.15; 95%CI:1.08-4.31), had ever attempted suicide (uOR: 2.69; 95%CI: 1.27-5.71), and had traditional language spoken at home while growing up (uOR: 2.67; 95%CI: 1.23-5.80) (Sharma et al., 2019). Adjusting for other factors, the only significant predictor of experiencing high interpersonal racism was having experienced a child being apprehended (aOR: 3.58; 95%CI: 1.40-9.15) (Sharma et al., 2019).

Economic hardship, housing instability, and food insecurity

Disproportionate burden of negative social determinants of health among Indigenous peoples is a symptom of colonization (Nebelkopf & King, 2003). Colonization, particularly the *Indian Act* and residential school system, undermines land-based economies that have sustained Indigenous peoples for generations, resulting in significant material inequities (Million, 2013, p. 105). Housing, employment/income, and food security affect health in complex and interconnected ways (King et al., 2009; Loppie Reading & Wien, 2013; Raphael, 2009; Reading & Halseth, 2013). Secure and adequate housing and employment make both material and meaning contributions in peoples' lives. Their absence can contribute to negative mental, emotional, spiritual, and physical health and wellness outcomes, including stress, anxiety, depression, low self-worth, risk of violence, chronic illness, or hunger/malnutrition (Reading & Halseth, 2013). When basic necessities are not available, people may face forced compromises that negate their health, such as staying with a partner who does not keep them safe, or participating in illegal or dangerous work (Jongbloed, 2012; Jongbloed, Thomas, et al., 2015).

<u>Related Cedar Project findings – housing instability:</u> At baseline, 48 of 260 Cedar participants (18.5%) reported sleeping in six or more places ('highly transient') in the past six months (Jongbloed, Thomas, et al., 2015). Transience was independently associated with sex work, sexual assault, injection drug use, daily cocaine injection, and public injection (Jongbloed, Thomas, et al., 2015). After stratification, transience and sexual vulnerability remained significantly associated among women but not men (Jongbloed, Thomas, et al., 2015).

Section Summary

Ongoing impacts of colonization on health and wellbeing of Indigenous people include colonial traumas and trauma response; violence; racism and discrimination; and material inequality leading to economic hardship, housing instability, and food insecurity. Previous Cedar research has documented the persistence of each of these concerns within the lives of young Indigenous people who have used drugs in BC.

1.2.4 Indigenist stress-coping model

Coping with ongoing colonial violence, historical or lifetime trauma, discrimination, and material inequities contributes to high levels of mental and physical stress which takes a toll on physical, mental, spiritual, and emotional health and wellbeing (Loppie Reading & Wien, 2013; Mikkonen & Raphael, 2010; Raphael, 2009). Indigenous scholars Walters, Simoni and Evans-Campbell's 'indigenist stress-coping model' suggests that experiencing colonial trauma contributes both directly and indirectly to increased risk of substance use, as well as both mental and physical illness (Walters et al., 2002). However, these negative outcomes may be 'buffered' by the

protective functions of identity, family, community, spirituality, and traditional healing approaches (Walters et al., 2002).

Strengths-based stress coping: culture, resilience, and resistance

A growing body of literature focuses on individual- and community-level strengths, which support coping with stress stemming from historical and lifetime colonial traumas. These protective factors help to counteract risk and decrease individual vulnerability to adverse conditions (Dion Stout & Kipling, 2003, p. iii). Key interrelated strengths-based factors that I will return to throughout this dissertation include resilience, cultural connection, and resistance. Each is outlined briefly here.

Resilience refers to the ability to cope with adversity and attain good life outcomes despite emotional, mental, or physical stress (Brant Castellano, 2008, p. 395; Dion Stout & Kipling, 2003, p. iii; Fleming & Ledogar, 2008; Kirmayer et al., 2009). Others have highlighted that resilience is a dynamic and contextualized process in which internal and external resources support a person to build positive self-image, reduce the effect of risk factors, and break negative cycles (Fleming & Ledogar, 2008; Lalonde, 2006). Onkwehonwe scholar Bonnie Freeman shares, "Indigenous-based resilience is innate, spiritual, and is relational to the land and environment" (Freeman, 2017). In this way, resilience can be understood as operating at the level of individual, family, community, and Nation, and is closely entwined with personal agency and collective self-determination (Fleming & Ledogar, 2008; Freeman, 2017; Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011; Kirmayer et al., 2009; Lalonde, 2006; Lavallee & Clearsky, 2006). Supporting Indigenous resilience requires: (re)awakening concepts of self and personhood; connection to land; revitalizing language, culture, and spirituality; strengthening individual and collective agency; supporting families and healthy child development; and building social capital, networks, and support (Kirmayer et al., 2011; Kirmayer et al., 2009). Focus on resilience within Indigenous health research marks a deliberate shift from deficit-based research that incorrectly portrays Indigenous peoples as being inherently sick (the 'disappearing Indian') which has been used to justify colonial actions (Fogarty, Lovell, Langenberg, & Heron, 2018; Kelm, 1999, pp. xvi-xvii; Lavallee & Clearsky, 2006). Blackfeet/Crow scholar Iris HeavyRunner and colleague Kathy Marshall have powerfully summarized the concept of resilience:

"Resilience is the natural, human capacity to navigate life well. It is something every human being has — wisdom, common sense. It means coming to know how you think, who you are spiritually, where you come from, and where you are going. The key is learning how to utilize innate resilience, which is the birthright of every human being. It involves understanding our inner spirit and finding a sense of direction." (HeavyRunner & Marshall, 2003)

Cultural identity, continuity, and connection are considered critical foundations of wellbeing, and include embedded practices that enable Indigenous people to navigate stress and adversity (Dion Stout & Kipling, 2003; Kirmayer et al., 2009; Kishebakabaykwe, 2010). In their work for the Aboriginal Healing Foundation, Wesley-Esquimaux and Smolewski noted that despite colonization and colonial trauma, Indigenous knowledge, ceremony, and teachings have been, "spirited away and safely stored in the homes, minds, and hearts of those that survived the terrible holocaust of the epidemics" (Wesley-Esquimaux & Smolewski, 2004, p. 85). In synthesizing Indigenous-led qualitative literature on cultural connectedness and continuity, Métis scholar Monique Auger identified that identity, cultural activities, healing practices, ceremony and spirituality, self-determination and self-government, and Indigenous values (respect, wholism, relationality) were central (Auger, 2016). Further, she emphasized a perspective of culture that is dynamic and includes transmission of culture through generations (Auger, 2016). A number of epidemiological studies have identified links between measures of cultural factors (e.g., cultural continuity, cultural identity, social support, family influence, community- and individual-level resilience) and improved indicators of health and wellness (e.g., lower rate of suicide, reduced stress, reduced substance use, higher self-reported health) (Baldwin, Brown, Wayment, Nez, & Brelsford, 2011; Chandler & Lalonde, 1998; Chandler & Lalonde, 2009; Currie, Wild, Schopflocher, Laing, & Veugelers, 2013; Lalonde, 2006; Richmond, Ross, & Egeland, 2007; Spence et al., 2016). Anishinaabe scholar Kishebakabaykwe Patricia McGuire says,

"Knowing who I am and where I came from gives me a solid foundation in my life. This knowing establishes my contextual framework, that is, my perspective on how my life has been affected by social and political happenings. ... Identifying as Anishinaabe Wiisaakodewag determines who I am and how others will respond to me. It determines how I understand my past and establishes what my contextual direction for the future will be." (Kishebakabaykwe, 2010)

<u>Resistance</u> to assimilation and erasure of Indigenous rights, cultures, and identity is also critical in consideration of strengths-based factors that support health and wellness (Kirmayer et al.,

2009; Tousignant & Sioui, 2009). Anishinaabe scholar *Minogiizhigokwe* Kathleen Absolon writes, "To remember who we are and where we come from...is an act of resistance against being dismembered" (Absolon, 2011, p. 16). Since first contact, generations of Indigenous people have resisted the dispossession of their lands, imposition of colonial laws, restrictions on culture, and removal of their children (TRC, 2015a, p. 116; Union of BC Indian Chiefs, 2005; Wesley-Esquimaux & Smolewski, 2004). Indigenous scholars have argued that, whether it is through small, daily acts asserting Indigenous identity and life ways, or through more formal collective acts of protest, resistance is healing (Ansloos, 2017, pp. 15-18; Corntassel et al., 2018).

Related Cedar Project Findings – resilience: Cedar Participants have a mean resilience score of 62.04 (of a possible 100), as measured by the Connor Davidson Resilience Scale, with no differences between young men and women (Pearce, Jongbloed, et al., 2015). This score is lower than average resilience in a general population (Mean: 80.4; SD: 12.8) (Connor & Davidson, 2003), and similar to average resilience among street-involved youth (Cleverley & Kidd, 2011), young people transitioning out of the child welfare system (Goldstein, Faulkner, & Wekerle, 2013), and people with generalized anxiety disorder (Connor & Davidson, 2003). Among Cedar participants, strengths-based factors significantly associated with higher mean resilience scores included having grown up in a family that often/always lived by traditional culture and having often/always spoken a traditional language at home (Pearce, Jongbloed, et al., 2015). Knowing how to speak a traditional language, often/always living by traditional culture, and having recently sought drug/alcohol treatment were also significantly associated with higher resilience (Pearce, Jongbloed, et al., 2015). Vulnerabilities associated with diminished mean resilience scores included severe childhood emotional neglect, smoking crack daily, having been sexually assaulted, and blackout drinking (Pearce, Jongbloed, et al., 2015). Another qualitative Cedar study focused on the resilience of second-generation survivors of the residential school system (Pooyak et al., In press). The narratives of participants in this study reflected their efforts to break cycles of disconnection and reclaim connections with family and identity, including recognizing that their own experiences were an extension of trauma that had begun generations before, seeking to cope in less harmful ways, rebuilding family relationships, and stopping the transmission of trauma in their own families (Pooyak et al., In press).

<u>Related Cedar Project Findings – cultural connection:</u> Drawing together questions related to cultural connection, including language, ceremony, traditional food, and living by traditional

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culture developed by study Elders, combined with a resilience scale, we affirmed statistical links between what Indigenous people have known for centuries: that speaking traditional languages and participating in ceremonies is associated with higher resilience, regardless of abuse experiences (Pearce, Jongbloed, et al., 2015). A recent Cedar analysis involving 202 participants demonstrated elevated levels of psychological distress among participants, yet, being able to speak a traditional language and living by traditional culture were associated with lower psychological distress among young men (Pearce et al., 2018). In another Cedar analysis involving 142 women, 67% had PTSD Civilian Checklist scores indicating probable PTSD; however, living by traditional culture was significantly associated with reduced risk of probable PTSD (Sharma et al., 2018).

Negative coping strategies: harmful substance use

Experiencing trauma, including colonial traumas, can contribute to development of extreme coping strategies for managing overwhelming distress (Haskell & Randall, 2009). As discussed, colonization, including cycles of child apprehension that began with residential schools and continue today through the child welfare system, have left an indelible mark on Indigenous families, communities, and Nations across generations. Consequently, some Indigenous people engage in substance use to cope and numb the pain of trauma (Chansonneuve, 2007; Duran et al., 1998, p. 345; McCormick, 2000; TRC, 2015a; Walters et al., 2002). It is important to note that illicit substance use is relatively rare among Indigenous peoples in Canada, and the majority of Indigenous people do not use drugs (First Nations Information Governance Centre, 2018). For example, the 2015-17 Regional Health Survey in BC involving a representative sample of on-reserve First Nations people demonstrated that substantial majorities (92%) had not used illicit drugs (excluding marijuana, salvia and inhalants) in the previous year (First Nations Health Authority, 2019, p. 61). While these figures may be underestimates given the stigmatizing and illegal nature of substance use, it is vital to recognize they are more accurate than harmful, universalizing stereotypes related to high rates of substance use among Indigenous people.

A comprehensive review of diverse literatures related to substance use among Indigenous people in Canada published between 2000-2014 found that Indigenous people experience a disproportionate burden of substance use and harm, particularly Indigenous youth (Firestone, Tyndall, & Fischer, 2015). Relationships between colonial trauma, racism, material inequities, and harmful substance use have been documented in the epidemiological literature (Currie et

al., 2015). Further, more recent research has begun to address the issue of intergenerational substance use within some Indigenous families (Myhra & Wieling, 2014; Myhra, Wieling, & Grant, 2015). As a result, addressing harmful substance use is consistently ranked as a high priority by Indigenous people and communities in BC and across Canada (Assembly of First Nations et al., 2010; Firestone et al., 2015).

In contrast to the protective nature of cultural identity, resilience, and resistance discussed in the previous section, harmful substance use is identified as a negative coping strategy contributing to increased risk of injurious social impacts (e.g. incarceration, assault), illness (e.g. HIV, hepatitis c), and death (e.g. fatal overdose) (FNHA, 2017b; Jongbloed et al., 2017; Spittal et al., 2007). For example, BC has declared a public health emergency as a result of a surge in overdoses related to the introduction of fentanyl and carfentanil into the drug supply (BC Gov News, 2016 Apr 14). Data indicates that in the context of this crisis, First Nations people were five times more likely to experience an overdose event and three times more likely to die of oversdose in 2015/16, compared to other BC residents (FNHA, 2017b). Although just 3.4% of residents in BC are First Nations, 14% of all overdose events involved First Nations people and 10% of overdose deaths were among First Nations people (FNHA, 2017b). During the release of this data, Stó:lō Grand Chief Doug Kelly, shared:

"In our way, what my respected elders and my teachers have taught me, is that sometimes, physical pain is actually a spiritual pain. Sometimes, a physical pain has a mental cause, or an emotional cause. And so, when we begin to confront all of those challenges, we need to make sure that we're responding with the appropriate care." (Kelly, 2017)

The Grand Chief's words reveal that a wholistic perspective is necessary to understand and respond to substance use within Indigenous communities (FNHA et al., 2013). Many Indigenous Elders, scholars, and health and wellness experts have brought forward perspectives of substance use based in Indigenous worldviews, including that harmful substance use may reflect being out of balance or disconnection (Assembly of First Nations & Health Canada, 2015; Assembly of First Nations et al., 2010; FNHA et al., 2013; McCormick, 2000; Puckett, 2018; Wieman & Perry, 2018). It follows that dealing with substance use involves returning to a state of connection and balance in mind, body, and spirit (Puckett, 2018; Wieman & Perry, 2018).

Related Cedar Project findings - substance use patterns: At enrollment, 55.4% of Cedar

participants reported using injection drugs (Miller et al., 2011). Vancouver-based participants who inject drugs were more likely to use heroin daily, compared to Prince George participants (40% vs. 12%), who were more likely to use cocaine daily (37% vs. 21%) (Spittal et al., 2007). Using data collected between 2003-2007, the initiation rate for injection drug use was 11.5 participants per 100 person years, and this transition was associated with involvement in sex work (Miller et al., 2011). Less than half of participants who injected opiates on a daily basis had ever received methadone maintenance therapy (Yang et al., 2011). In a recent mortality analysis, overdose was the leading cause of death among Cedar participants (Jongbloed et al., 2017). Furthermore, recently experiencing a nonfatal overdose was associated with a three-fold increase in risk of death (Jongbloed et al., 2017).

Section Summary

Within the context of historical and lifetime colonial traumas and trauma sequelae, Indigenous people who use drugs may turn to substance use to cope; however, access and connection to family, cultural strengths, identity, and traditional practices, can serve as buffers to support health and resilience (Pearce, Jongbloed, et al., 2015; Walters et al., 2002; Walters & Simoni, 1999, 2002; Walters, Simoni, & Harris, 2000).

1.2.5 Substance use and HIV vulnerability

Approximately 1 in 10 people living with HIV in Canada are Indigenous (Public Health Agency of Canada, 2018). Substance use continues to be the primary driver of HIV risk among Indigenous people (Negin, Aspin, Gadsden, & Reading, 2015). Canadian surveillance data from 2016 suggests there were a total of 2,344 new HIV diagnoses overall, contributing to a cumulative total of 84,409 diagnoses in Canada since 1985 (Bourgeois et al., 2017). This represents an increase the HIV infection rate, up to 6.4 per 100,000, compared to 5.8 in 2015 (Bourgeois et al., 2017). Among cases with ethnicity data (less than half of all cases), 21.2% of diagnoses were among Indigenous people which represents a substantial overrepresentation in relation to population (Bourgeois et al., 2017). Substance use was the primary exposure category among Indigenous who were diagnosed, accounting for 59.6% of seroconversions (Bourgeois et al., 2017).

Overall, the rate of new HIV diagnoses in BC in 2015 was 5.1 per 100,000 people (239 cases), and 11.9 per 100,000 (17 cases) among First Nations people (BC Centre for Disease Control, 2017). This represents that 8% of diagnoses were among Indigenous people, who make up just 5% of the provincial population (BC Centre for Disease Control, 2017). While this proportion has decreased over the past ten years, it remains a concerning disparity. Disparities are especially pronounced among Indigenous women in BC who accounted for 27% of new HIV diagnoses among women in 2015 (12.4 vs 1.6 per 100,000) (BC Centre for Disease Control, 2017). Highest rates among Indigenous people occurred among men 25-39 years old and among women 30-39 years old (BC Centre for Disease Control, 2017). Injection drug use and heterosexual sex were the primary exposure categories among Indigenous people in BC in 2015 (BC Centre for Disease Control, 2017).

Significant disparities in mortality have been observed among Indigenous people living with HIV in BC and across Canada. Early studies in BC and Alberta observed higher rates of HIV-related mortality among Indigenous people, who were more likely to die without ever accessing HIV treatment compared to HIV-positive non-Indigenous people (Martin, Houston, Yasui, Wild, & Saunders, 2011; Wood et al., 2005). More recently, the Canadian Observational Cohort (CANOC) Collaboration, involving eight cohort studies of people living with HIV in BC, Ontario, and Quebec observed that between 2000-2012, mortality among Indigenous participants was 2.69 times that of non-Indigenous participants (Benoit (b) et al., 2017). Finally, among 546 (323 Indigenous) people attending the Vancouver Native Health Society Medical Clinic (2007-2012), Indigenous people experienced significantly higher proportions of all-cause and HIV-related mortality; however, significant declines in mortality were observed over time (Klakowicz, Zhang, Colley, Moore, & Tu, 2016).

Related Cedar Project findings – HIV & hepatitis C: Baseline HIV prevalence among Cedar participants was 12.6% in Vancouver and 3.8% in Prince George (Spittal et al., 2007). Among those who reported injecting, prevalence was 17.4% in Vancouver and 7.2% in Prince George. History of non-consensual sex, residing in Vancouver, and longer duration of drug use were associated with increased risk of HIV infection. HIV incidence among those who inject is 2.5 per 100,000 person years (Unpublished analysis). Women are more than two times more likely to be living with HIV than young men (13.1 vs 4.3%) (Mehrabadi et al., 2008). Baseline hepatitis C prevalence was 34.8% overall, and 59.4% among those who used injection drugs (Craib et al., 2009). Incidence of hepatitis C infection between 2003-2009 was 11.6 per 100 person years, with people who had been injecting for two years or less most at risk (Spittal et al., 2012). In a Cedar analysis of all-cause mortality among 40 young Indigenous people who have used illicit drugs in BC, four died of HIV-related causes despite living in a setting of

universal healthcare and free access to antiretroviral therapy (Jongbloed et al., 2017). Further, living with hepatitis C at baseline was the most significant predictor of mortality, controlling for other factors (Jongbloed et al., 2017).

1.2.6 Engagement in the HIV cascade of care

Antiretroviral therapy (ART) is a powerful tool to prevent illness and death, as well as to avert new HIV infections (UNAIDS, 2014a). However, availability of treatment alone is insufficient to end the HIV epidemic. Growing understanding that getting to "undetectable" is a process has led to development of the HIV cascade of care framework (Gardner, McLees, Steiner, del Rio, & Burman, 2011). For people living with HIV to access treatment and be engaged in HIV care, they must know their HIV status, be linked and retained in care, and initiate and remain adherent to ART medications. According to this conceptualization, the ultimate clinical goal of HIV treatment is the achievement of viral suppression, which in turn reduces HIV transmission, morbidity, and mortality (Cohen et al., 2011; Lima et al., 2007).

Criticisms of the cascade of care framework have suggested that its overly focused on the biomedical dimensions of HIV health, without adequate consideration for other aspects of health and wellness. Paparini and Rhodes explain that, "narrow focus on viral load progression (from detectable to undetectable) detracts from the broader aspects of HIV as a health and social *condition* and not only a virus" (Paparini & Rhodes, 2016). Further, they suggest that understanding of viral suppression as a 'goal' is incorrect; rather it is 'state' which must be maintained over time. Shifting to accommodate this perspective may help to avoid the emphasis on 'success versus failure' in the current framework (Paparini & Rhodes, 2016).

Emergence of the cascade of care framework has led to adoption of the global 90-90-90 treatment targets by UNAIDS (UNAIDS, 2014a). The UNAIDS 90-90-90 statement aims to end to the epidemic in 2030, with 90% of all people living with HIV knowing their HIV status, 90% of all those diagnosed with HIV receiving sustained ART, and 90% of all people receiving ART virally suppressed by 2020 (UNAIDS, 2014a). Indigenous leaders have raised concerns that this framework does not reflect Indigenous worldviews, as willingness to leave 10% of people living with HIV behind is explicitly embedded in within the targets (Pala, 2015; Poitras, 2016). Further, it is likely that those who will make up the '10-10-10', those who are left behind, are those who are most vulnerable, such as the key populations identified in UNAIDS The Gap Report (UNAIDS, 2014b).

Epidemiology of the HIV cascade of care is increasingly used to monitor HIV trends. A population study of cascade trends in BC between 1996-2011 observed significant improvements at all stages over time (Nosyk et al., 2014a). Proportion of people living with HIV reaching each stage of the cascade in 2011 are presented in Figure 1.4.



Figure 1.4: HIV cascade of care among BC residents in 2011 (Nosyk et al., 2014)

However, details of HIV cascade of care epidemiology among Indigenous people in BC remains limited. A 2016 study among 326 Indigenous people who use illicit drugs living with HIV in Vancouver observed that 72% had ever been on ART; 60% had been dispensed HIV medications in the past six months; 32% had greater than 95% adherence; and 29% were virally suppressed (Figure 1.5) (Milloy et al., 2016). This area is explored further in detail in *Chapter 3*, which presents a systematic review related to Indigenous people's experiences of the HIV cascade of care.



Figure 1.5: Baseline engagement in the HIV cascade of care among Indigenous people who use drugs in Vancouver (ACCESS Study, 2005-2014)

Adapted from (Nosyk et al., 2014b)

Adapted from (Milloy et al., 2016)

1.2.7 Responding to substance use and HIV among Indigenous peoples

"When an advocate friend spoke about the moment when he stopped dying of AIDS and began living with HIV, he taught me about the spirit of our work. A response to HIV cannot occur without responding to a person's whole being. Living well requires care to address the physical impact of the virus in a person's body, but even more living well with HIV is about mental, emotional, and spiritual health." – Renée Masching (Six Nations) (Pooyak, Amirault, & Masching, 2015, p. 239)

The previous sections have demonstrated how colonial legislation, colonial trauma response, substance use, and HIV are deeply interconnected in an Indigenous context. Therefore, Indigenous scholars have called for responses to substance use and HIV that acknowledge ongoing colonization, structural violence, and the impacts of intergenerational traumas, while building on cultural strengths and resilience (Assembly of First Nations & Health Canada, 2015; Assembly of First Nations et al., 2010; Barlow & Reading, 2008; Duran & Walters, 2004; FNHA et al., 2013; Goodkind, LaNoue, Lee, & Freund, 2012; Marsh, Cote-Meek, Young, Najavits, & Toulouse, 2016; McKenzie et al., 2016; Myhra & Wieling, 2014; Pearce, Jongbloed, et al., 2015; Walters et al., 2002; Walters & Simoni, 1999). A growing body of literature addresses interventions among Indigenous people to support: (1) healing from intergenerational traumas; (2) addressing substance use; and (3) engagement in HIV prevention and care. These literatures are presented in detail in the results chapters that follow. However, it is important to introduce a bundle of four overlapping concepts that are woven throughout these responses: 'culture as intervention' and healing-centered, strengths-based, and culturally-safe care.

Culture as intervention

Indigenous health and wellness systems have been interrupted by colonization; however, they have not been lost or forgotten (Hovey et al., 2014; Kelm, 1999, p. 83; Kirmayer et al., 2009; Poonwassie & Charter, 2001; Wesley-Esquimaux & Smolewski, 2004, p. 85). As discussed at the beginning of this chapter, these health and wellness systems are embedded in the worldviews, cultures, laws, territories, and spirituality of Indigenous peoples. For many years, Indigenous communities have used (re)connection with culture, ceremony, territory, and language as a way to heal from intergenerational traumas, address substance use, and support HIV health and wellness (Aboriginal Healing Foundation, Castellano, & Archibald, 2006; Pooyak et al., 2015, p. 239).

According to Mitchell and Maracle, "people can and do recover from post-traumatic stress and heal the mental, physical, emotional, and spiritual wounds" (Mitchell & Maracle, 2005). Summarizing the research of the Aboriginal Healing Foundation, Mohawk scholar Marlene Brant Castellano explains that healing can be understood as "restoring physical, mental, social/emotional, and spiritual balance in individuals, families, communities, and nations" (Brant Castellano, 2008, p. 383). Further, healing is both a personal and collective journey that can be viewed as a cycle which moves through finding safety, remembering and mourning, reconnection and reclamation, and giving back (Brant Castellano, 2008, pp. 388-389). Kanien'kehá:ka (Mohawk) scholar Rod McCormick further suggests that Indigenous healing comes through fostering interdependence, including connections to community, family, spirituality, and land (McCormick, 1997). In this way, healing is seen as a restoration of good relations with self, family, community, and all creation – marking a shift from disconnection to interconnectedness (McCormick, 2000).

(Re)claiming connection involves recovering traditional values, beliefs, philosophies, ideologies, and approaches, which provide identity, meaning, and support (Goforth, 2007; Marsh, Cote-Meek, et al., 2016; McCormick, 2000). Language can be healing as it provides the words to articulate these worldviews (McIvor & Napoleon, 2009). Ceremony plays an important role in restoring or strengthening relationships, including providing individuals, families, and communities structures within which to acknowledge and mourn trauma experiences (McCormick, 1997; Mitchell & Maracle, 2005). Further, the idea of 'taking care of one's self' is important to the concept of Indigenous healing as it reflects a perspective of self-determined health and wellness in which a person is in charge of their own health and wellness journey with important individual and collective responsibilities in that regard (Hovey et al., 2014; McCormick, 1997). As such, Indigenous people are not passive recipients of harm, trauma, disease, or ill health as they have often been constructed in colonial literatures (Kelm, 1999). This is articulated within the Cree concept of *nanâtawihiwêwin*, the 'daily ritual of healing and helping ourselves' shared by Cree scholar Madeleine Dion Stout (Dion Stout, 2015). In this way, taking care of oneself is an act of resistance, as colonization has sought to undermine healing activities by exerting control over ordinary aspects of daily life that impact all four dimensions of health and wellbeing. The chapters that follow offer examples of healing programs that have used culture as intervention to address both substance use and HIV (Bouey & Duran, 2000; Duran et al., 2010; Goodkind, LaNoue, et al., 2012; Marsh, Cote-Meek, et al., 2016; Marsh,

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Young, Meek, Najavits, & Toulouse, 2016; Marsh, Coholic, Cote-Meek, & Najavits, 2015; Nebelkopf & Penagos, 2005; Rowan et al., 2014; Wright et al., 2011)

It bears repeating that 'healing' is a problematic concept in a settler-colonial society where harms continue to be perpetrated and Indigenous rights to self-determination are undermined (Goodkind, Hess, et al., 2012; Million, 2013). As Brant Castellano notes, "We have a good deal of information on how First Nations, Inuit, and Métis people have been working on coming to peace within their own persons and restoring harmonious relations within their communities. There is less evidence of how peacemaking can be extended to include the Canadian populace at large" (Brant Castellano, 2008, p. 396). In this way, healing is just one piece of the work, and action on the part of Canadian settler governments to engage in meaningful truth and reconciliation that upholds Indigenous self-determination is essential.

Healing-centered

A healing-centered approach to health and social services recognizes the impact of colonial trauma and violence on mental, emotional, spiritual, and physical health. It promotes compassion for people and communities who have endured colonial trauma that has impacted their ability to cope (Mitchell & Maracle, 2005). Survivors of colonial traumas need nonjudgmental, empowering support to create strategies to overcome trauma and transform negative coping strategies into self-care (Chansonneuve, 2005, p. 48). This includes a role for "strong, vocal advocates within 'the system' who are knowledgeable about the impacts of residential abuse and the potential for re-victimization, who themselves model a healing path and who are committed to re-empowering Aboriginal people" (Chansonneuve, 2005, p. 48). Embedded in a healing-centered approach is understanding that trauma experiences may put individuals at greater risk of ill health later in life, requiring higher engagement with health and social services over the life course (Reeves, 2015). It emphasizes the need for health services to integrate responses that directly address traumatic life experiences (what the patient has experienced), rather than a sole focus on treatment of trauma symptoms and sequelae (what is wrong with the patient) (Huckshorn & LeBel, 2013; Pihama et al., 2017; Reeves, 2015). Healing, in this sense, involves "moving beyond hurt, pain, disease and dysfunctionality, and establishing new patterns of living that produce sustainable well-being" (Bopp & Lane cited in Million, 2013, p. 143). In addition, a healing-centered approach is cognizant that engagement with healthcare and social services can cause distress or re-traumatize those with trauma experiences (Reeves, 2015). For example, power imbalances between patients and providers

can be reminiscent of those in interpersonal violence, and examinations can be triggering for those whose traumatic memories are connected to physical sensations or lack of bodily autonomy (Reeves, 2015). Reeves' review of the literature found a number of common aspects of a healing-centered approach: (1) trauma screening and patient disclosure; (2) importance of provider-patient relationships; (3) minimizing distress and maximizing autonomy; and (4) multidisciplinary collaboration and referrals to other safe services (Reeves, 2015).

Use of the terms 'healing-centered' or 'trauma and violence informed" represents a purposeful shift from the term 'trauma-informed' (Browne et al., 2016; Ginwright, 2018). The latter has been criticized, especially in relation to Indigenous health, as it does not sufficiently acknowledge ongoing experiences of systemic and inter-personal violence stemming from colonization that represent the root causes of trauma, and may also pathologize those it seeks to serve (Browne et al., 2016; Ginwright, 2018; Haskell & Randall, 2009). Indigenous scholars have argued that healing-centered approaches must take the unique and specific context of colonial traumas and structural violence into account when working with Indigenous peoples (Million, 2013; Pihama et al., 2017). This includes moving away from a singular focus on individual healing to include collective healing at the levels of family, community, and nation (Ginwright, 2018; Million, 2013; Pihama et al., 2017). As discussed above, healing-centered approaches serving Indigenous peoples must also take into account Indigenous perspectives and methods of healing (Pihama et al., 2017).

Strengths-based

Strengths-based approaches are another fundamental component of Indigenous-led initiatives to respond to intergenerational trauma, substance use, and HIV by building on sources of strength and resilience (Dion Stout & Kipling, 2003, p. vi; Goodkind, LaNoue, et al., 2012). On one hand, failure to understand and address the context of colonization and intergenerational trauma within healthcare settings may serve to perpetuate harms. On the other, focusing exclusively on trauma experiences and symptoms fails to recognize the strengths that Indigenous people, families, communities, and nations bring to their health and wellness journeys (Dion Stout, 2015). Like the other concepts in this bundle, strengths-based approaches represent an emphasis on nurturing health and wellbeing, as opposed to suppressing disease, sickness, or symptoms (Fogarty et al., 2018; Ginwright, 2018). Further, Haskell and Randall suggest that shifting to a strengths-based approach is trauma and violence informed in that it recognizes a person's best attempts at coping in the context of intolerable
circumstances (Haskell & Randall, 2009). In this sense, a strengths-based response is one that supports people who have experienced trauma to develop and strengthen healthy ways of coping (Haskell & Randall, 2009). Rapp & Goscha have powerfully articulated the goal of strengths-based approaches: "People should have the opportunity to live in a place they can call home, to work at a job that brings satisfaction and income, to have rich social networks, and to have available means for contributing to others. It also means avoiding the often spirit-breaking experiences of forced hospitalization, homelessness, or incarceration" (Rapp & Goscha, 2008, p. 320). This notion of being able to lead 'a good life' is represented in many Indigenous cultures, such as the notion of *mino-pimatisiwin* in Cree or *pimaatisiwin* in Anishinaabemowin (Ansloos, 2017, p. 94; Brant Castellano, 2008, p. 384; Henderson, 2008; Poonwassie & Charter, 2001). What 'a good life' is, is up to the person living that life through the teachings they carry. It may reflect a life lived in balance, according to Indigenous values, with good relationships (Hovey et al., 2014).

Strengths-based approaches have been applied to case management. The aim of strengthsbased case management is to "assist people to recover, reclaim, and transform their lives by identifying, securing, and sustaining the range of resources—both environmental and personal-needed to live, play, and work in a normal interdependent way in the community," (Rapp & Goscha, 2008, p. 320). Hovey et al. have suggested that the role of health practitioners and the community in general involves creating conditions that "enable people to follow their journeys of self-discovery and identity" (Hovey et al., 2014). Success is hopefulness, self-efficacy, self-esteem, empowerment, and community connection (Rapp & Goscha, 2008, p. 320). Rapp & Goscha have outlined the values inherent in strengths-based case management (Rapp & Goscha, 2008, pp. 321-323). First and foremost is to continuously identify and amplify clients' strengths, including specific talents, knowledge and achievements; resources currently available to them; and dreams and aspirations they have for themselves. To support clients to connect and build on these strengths, trusting, reciprocal relationships between the client and provider are paramount. Throughout the process, the client leads the form, direction, and substance of the support they receive. As a result, an outreach model that meets people where they are at – both geographically and mentally/emotionally – is important. Both case managers and clients work to connect with resources, such as community and cultural connections or health and social services, that support the client to build their assets, ensure their rights are respected, and work towards their goals.

Cultural safety & humility

Indigenous people who seek mainstream health services – including those related to HIV and substance use – deserve to receive safe, respectful, and quality care (FNHA et al., 2013). Another aspect that Indigenous-led responses to HIV and substance use have in common is that they often integrate Indigenous healing practices with mainstream approaches to bring together the 'best of both worlds' (Brant Castellano, 2008, p. 389; Marsh, Cote-Meek, et al., 2016; Marshall et al., 2015; Rowan et al., 2014). This requires a specific orientation within mainstream health and social services referred to as 'cultural safety'. Cultural safety is different from cultural competency. With cultural safety, the spotlight is focused on the beliefs, biases, and behaviours of the provider/system, rather than on the cultural attributes of the Indigenous person seeking care (Pihama et al., 2017). Culturally-safe services are those that respect and honour Indigenous identities, perspectives, and approaches, and are free from racism and discrimination (FNHA, 2016a, 2016b). They are characterized by respectful engagement that can help people seeking care to find paths to well-being (Health Council of Canada, 2012). Explicit in this perspective is the recognition that healthcare services have not been safe spaces for Indigenous people, as we have explored previously in this chapter. Reaching cultural safety requires an ongoing process of cultural humility where both the system and individual health provider interrogate their own biases and power in relation to Indigenous peoples, and change both policies and practices that create harm or are barriers to health and wellbeing (Papps & Ramsden, 1996). Further, cultural safety and humility necessitates the system and provider also acknowledge the role of colonization and systemic violence in creating ill health and disparities among Indigenous peoples (Dell, Firestone, Smylie, & Vaillancourt, 2016).

1.2.8 mHealth for HIV

Simultaneously, use of mobile phones in healthcare settings (mHealth) has emerged as a tool to support healthy behaviours and engagement in health services for a variety of health concerns. The field of mHealth is broad, ranging from development of health-focused apps to innovations in diagnostic technologies (Jongbloed, Parmar, Kop, Spittal, & Lester, 2015). What I am interested in this dissertation, however, is a specific set of mHealth approaches using the text messaging or short message service (SMS) function of mobile phones to create a connection between clients and healthcare providers that may facilitate the healing-centered, strengths-based, culturally-safe approaches outlined in the previous section. Text messaging mHealth has been used primarily in two ways: unidirectional or bidirectional (Wald, Butt, &

Bestwick, 2015). Unidirectional or one-way text messaging mHealth usually involves the health system sending out reminders, information, or self-management prompts to a patient or client. In contrast, bi-directional or two-way text message mHealth involves some sort of back-and-forth interaction between the system and the client. For example, the WeITel mHealth model, which is the focus of this dissertation, is a two-way text message approach in which a weekly prompt query (e.g., How are you?) is sent to enrolled clients to initiate a client-led conversation about health concerns and issues important to them that week (Lester et al., 2010; van der Kop et al., 2012). A team of relevant health providers receives client responses and follows up with clients who have an issue to address, or with those who did not respond (Lester et al., 2010; van der Kop et al., 2012). The WeITel model has been tested in a variety of contexts, including in North America and Africa, and for a variety of health concerns, including HIV, tuberculosis, primary healthcare, and asthma (Tilahun et al., 2018). Specific literature on how mHealth has been used to address HIV and substance use is presented in more detail in the chapters that follow.

1.3 Rationale, overview, and objectives

To our knowledge, no previous studies have sought to integrate Indigenous responses to HIV with two-way supportive text message mHealth approaches. As a result, the purpose of this dissertation was to examine experiences of engagement with the HIV cascade of care, and evaluate The Cedar Project WeITel mHealth program for HIV-related health and wellness, among young Indigenous people who have used drugs living in British Columbia using qualitative and quantitative methods. It is guided by four objectives:

- O1: Examine experiences of engagement in the HIV cascade of care among Indigenous people, particularly young people who have used drugs.
- O2: Assess the feasibility and acceptability of mHealth for HIV-related health and wellness among young Indigenous people who have used drugs.
- O3: Evaluate the impact of mHealth on HIV-related health and wellness among young Indigenous people who have used drugs.
- O4: Understand engagement with mHealth for HIV-related health and wellness among young Indigenous people who have used drugs.

Chapters 1 (Introduction) and 2 (Methodology) answer the question, 'what is this dissertation all about?'. Chapters 3 and 4 address Objective 1 and seek to illustrate the 'status quo' of

engagement in the HIV cascade of care among Indigenous people. First, I present a broad perspective through a systematic review of the literature of experiences of the HIV cascade of care among Indigenous peoples in Australia, Canada, New Zealand and the United States (Chapter 3). Next, I provide a close and contextualized look at experiences of the HIV cascade of care among young Indigenous people who have used drugs living with HIV involved in the Cedar Project (Chapter 4). Chapter 5 examines acceptability and feasibility of mHealth among young Indigenous people who have used drugs to address Objective 2. Objective 3 is addressed in Chapters 6 and 7. Chapter 6 examines the effect of the mHealth program on HIV viral suppression among HIV-positive participants. Chapter 7 examines the effect of the mHealth program in terms of cultural connection, substance use, resilience, and psychological distress among both HIV-positive and HIV-negative participants. Chapters 8 and 9 seek to understand participants' engagement with, and perceptions of, the mHealth program from primarily quantitative (Chapter 8) and qualitative (Chapter 9) perspectives, addressing Objective 4. Finally, conclusions and recommendations are provided in Chapter 10. Please note that these chapters were written as manuscripts for publication in peer-reviewed journals. Therefore, there is some repetition in terms of context and study methods in each chapter.

Chapter 2 Methodology

The purpose of this dissertation was to examine experiences of engagement with the HIV cascade of care, and evaluate The Cedar Project WeITel mHealth program for HIV-related health and wellness, among young Indigenous people who have used drugs living in British Columbia. This chapter includes discussion of the Cedar Project methods more broadly, and how they shape and frame the dissertation project. The specific piece I was responsible for included leading the Cedar Project WeITel mHealth sub-study, as well as engaging with data from the Cedar Project Blanket Program for the first time.

This chapter begins by introducing the overarching research approach. Second, it presents The Cedar Project cohort study, as well as two relevant sub-studies (The Cedar Project Blanket Program and The Cedar Project WelTel mHealth Study), and discusses ethical considerations. Third, the dissertation sample, data sources, and measures are discussed with respect to its quantitative and qualitative components. Fourth, objectives, sample, instruments, study design, and analysis of each dissertation chapter are briefly outlined. Fifth, knowledge translation efforts are presented. Additional methodological details are further elaborated within each results chapter.

2.1 Overview of research approach

This study employed a transformative embedded mixed methods design (Creswell, 2014, pp. 227-228). It integrated qualitative components within a broader quantitative approach to develop an understanding about experiences of the HIV cascade of care among young Indigenous people who have used drugs living with HIV, as well as to better understand the role of mHealth in supporting health and wellbeing related to HIV treatment and prevention. The overarching mixed methods research question guiding this dissertation is,

To what extent and in what ways does the Cedar Project WelTel mHealth program support HIV-related health and wellness among Indigenous people who have used drugs living with or at risk of HIV infection?

The transformative paradigm guiding this dissertation was described in the previous chapter. Briefly, transformative research recognizes and seeks to illuminate contexts and structural inequities that result in asymmetric power relationships, as well as the strategies used to resist, challenge, and subvert these constraints (LeCompte & Schensul, 2010, p. 63). Transformative researchers acknowledge that power dynamics shape what is considered 'knowledge' and also whose 'reality' or 'truth' is privileged (LeCompte & Schensul, 2010, p. 63; Mertens, 2007; Mertens et al., 2010). Therefore, the impact of power must be addressed at every stage of the research process (Mertens, 2007). Further, the purpose of transformative research is to support positive social and structural change, in addition to simply creating new knowledge (Mertens, 2011). In the context of this dissertation, a transformative orientation leads to a methodological imperative to ensure that Indigenous people are involved as partners at all stages of the research and Indigenous worldviews are respected and privileged (LeCompte & Schensul, 2010, p. 65; Mertens, 2007; 2009, p. 3).

Mixed methods approaches have been identified as a methodological strategy that aligns with transformative ontology, epistemology, and axiology (Mertens, 2007). Its embedded change agenda requires multiple forms of data that resonate with different audiences, bridge different ways of knowing, and reveal different versions of reality (Mertens, 2011). Combining qualitative and quantitative approaches provides greater depth and complexity as a single type of data is not sufficient to answer the different questions that need to be answered (Creswell, 2014, p. 218; Creswell & Plano Clark, 2007, p. 67; Mertens, 2007). Using mixed methods also allows us to balance the strengths and weaknesses of both qualitative and quantitative approaches to draw strong conclusions and inferences about contested phenomena (Creswell, 2014, p. 218). Further, Indigenous scholars have argued that mixed methods is consistent with Indigenous approaches to research, as it constitutes a decolonizing and relational practice that facilitates collaboration between Indigenous and other paradigms (Botha, 2011; Chilisa & Tsheko, 2014).

Others have emphasized the value of mixed methods approaches within intervention research as it allows for a better understanding of the need for, and impact of, a program through collecting both quantitative and qualitative data over time (Creswell, 2014, p. 218). Use of mixed methods in intervention research may also make it possible to capture unintended impacts (positive or negative) not included in *a priori* measurements in the context of traditional trials (Bamberger, Tarsilla, & Hesse-Biber, 2016). Another benefit may be that this approach provides richer understanding of the dynamics of a program, which facilitates the transition from research into 'real world' application by capturing how it looks and functions in practice (Johnson & Schoonenboom, 2015). Song and colleagues have suggested that mixed methods are especially appropriate for studies involving 'socially complex interventions' characterized by interacting components, variable aims and outcomes, and higher degree of customization

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(Song, Sandelowski, & Happ, 2010). Building on their insight, it is possible to understand socially complex interventions as those seeking to engage people facing multiple and intersecting challenges affecting their health and wellbeing, such as those facing young Indigenous people who have used drugs (Song et al., 2010). Mixed methods in this context support the inclusion of participant voices and experiences in understanding the impact of the mHealth program, which in turn can inform its utility and acceptability in 'real world' settings (Song et al., 2010).

Therefore, this dissertation used an overarching transformative embedded mixed methods design in which qualitative components were embedded within, and used to elaborate on, a larger quantitative component (Creswell, 2014, p. 237). Within an overall mixed methods approach, some individual chapters used mixed methods to answer specific research questions. The qualitative data enriched the quantitative results, and provided a deeper understanding of the context of engagement in HIV cascade of care and our mHealth program. Further, they are used together to give a more powerful voice to participants' experiences. Integration of quantitative and qualitative components occurred at multiple points (Table 2.1) in an iterative, dynamic, non-linear way, so that a more complete understanding emerged than what was provided by either alone (Song et al., 2010).

Point of integration	Strategy
Theory	Viewed all study components through a similar theoretical lens (the dissertation conceptual framework presented in <i>Ch 1: Introduction</i>) (Creswell, 2014, pp. 51, 70; Creswell, Klassen, Plano Clark, & Clegg Smith, 2011, p. 4).
Research question	Guided by overarching mixed methods question with interconnected qualitative and quantitative components (Creswell, 2014, p. 151; Tashakkori & Creswell, 2007).
Embedded sample	Drew qualitative sample from within the larger quantitative sample (Creswell, 2014, p. 222).
Data collection	At multiple instances, collected qualitative and quantitative data simultaneously (Creswell et al., 2011, p. 7).
Data management	At multiple instances, combined qualitative and quantitative data within study datasets (Creswell et al., 2011, p. 7).
Analysis	Moved iteratively through multiple, cyclical analytical phases involving both qualitative and quantitative sources of data (Creswell et al., 2011, p. 5).
Presentation of findings	Merging, or use of side-by-side comparison of qualitative and quantitative data, was undertaken in four of seven results chapters (Creswell, 2014, p. 222; Creswell et al., 2011, p. 5).
Conclusion & recommendations	Sought to integrate results of the qualitative and quantitative study components into coherent conclusions and recommendations that are stronger than if they stood alone (Tashakkori & Creswell, 2007).

2.1.1 The Cedar Project

Initiated in 2003, the Cedar Project is a prospective cohort study of 782 young Indigenous people who have used illicit drugs in Vancouver and Prince George, BC. The methods used in the Cedar Project study have been previously published in detail (Spittal et al., 2007). Young people who self-identify as Indigenous were considered to be the descendants of the First Peoples of North America, including Indigenous Aboriginal, Métis, Indigenous, Inuit and First Nations, including those with or without status under the *Indian Act*. Participants were recruited through healthcare providers, street outreach and word-of-mouth. Eligible participants included those aged 14-30 who had used illicit drugs (other than marijuana) in the month prior to enrollment. Drug use was confirmed using saliva screens (Oral-screen, Avitar Onsite Diagnostics). Initial recruitment took place between 2003-2007, and was reopened in 2011. Indigenous and non-Indigenous study staff explained procedures, sought informed consent, and confirmed eligibility for each participant. Participants completed an intervieweradministered questionnaire to elicit socio-demographic characteristics, drug use patterns, sexual vulnerability, and use of services at baseline and every six months thereafter. Venous blood samples are taken and tested for antibodies to HIV and hepatitis c at each visit. Participants are offered pre- and post-test counselling with trained nurses. They are requested, but not required, to return for the results. Indigenous and non-Indigenous interviewers and nurses support both sites, and provide referrals to cultural supports, healthcare, substance use services, food programs, housing, and counseling for participants who seek them.

2.2 Research relationships & ethical considerations

2.2.1 Governance from the Cedar Project Partnership

Since its inception, the Cedar Project has been community-driven, interdisciplinary research responding to the continuing crisis of HIV infection and contributes to the health and healing of young Indigenous people who have used drugs. The Cedar Project Partnership, an independent body of Indigenous Elders, health and social service experts, scholars, and elected leaders, governs the entire research process. The Partnership provides protection, leadership, support, and ensures self-determining ethical principles and Indigenous knowledges are respected. It has been in place from the very beginning. Members of the Cedar Project Partnership during the period this dissertation took place included Elders Earl

Henderson (Métis & Cree) and Violet Bozoki (Lheidli T'enneh), Vancouver Native Health Society, Red Road HIV/AIDS Network, Canadian Aboriginal AIDS Network, Carrier Sekani Family Services, Positive Living North, Prince George Friendship Centre, and All Nations Hope, as well as Splatsin, Neskonlith, and Adams Lake Indian Bands. As a student, I was accountable to the Partnership by signing the Cedar Project Student Agreement and through mentorship from two Cedar partners: Ms. Sherri Pooyak (Cree) who is a Community Based Research Manager for the Aboriginal HIV & AIDS Community-Based Research Collaborative Centre (AHA Centre) and Mr. Lou Demerais (Cree and Métis) who has served as the founding Executive Director of Vancouver Native Health Society. This relationship involved multiple oneon-one visits with mentors and other partners to address matters relevant to the dissertation project. In addition, it involved participation in Partnership meetings to witness and learn from the work that took place, as well as share and receive feedback on the dissertation project specifically. The mentor-mentee relationship includes reciprocal accountabilities as the mentors support the student through cultural and experiential learning opportunities, and help the student to stay healthy and well as they engage in Cedar research. Alongside accountabilities related directly to the research project, students are also sometimes called upon to offer skills and knowledge in support of Partners' work when relevant.

With guidance from my Indigenous mentors and committee members, I undertook a program of learning related to Indigenous research standards from across Canada. These are discussed briefly here, and are incorporated with more detail in subsequent chapters. Governance from the Cedar Project Partnership reflects engagement with the principles of Ownership, Control, Access, and Possession in relation to research involving Indigenous people (Schnarch, 2004). The relationship between Cedar partners, investigators, and students further reflects what Willy Ermine (Sturgeon Lake First Nation) calls the "ethical space of engagement" – referring to the meeting point or space created when people who carry different worldviews come together with respect to dialogue, or in this case, to address a research question (Ermine, 2007). Cree scholar Shawn Wilson suggests viewing "research as ceremony" represents a commitment to hold up the moral authority, ethics, and worldviews of the people with whom we work (Wilson, 2008). Each of these perspectives center the importance of relationships in Indigenous axiology and methodology.

2.2.2 Cultural safety in the Cedar Project

As Cedar Project participants represent many of the diverse Indigenous communities and Nations across BC and Canada, the cedar tree was identified as a powerful metaphor for healing and wellness in all nations. The cedar tree – the tree of life – is traditional medicine used across many different nations in ceremonies, shelters, homes, and clothing. This meaning captures the goals of our study. The Cedar Project Partnership recognizes that conducting culturally-safe research with young Indigenous people requires creating safe spaces where their identities, voices, and stories are heard and respected (Papps & Ramsden, 1996). Overall, our paradigm is to acknowledge grief and historical trauma, while building on strengths among the young Indigenous people who have used drugs enrolled in our study. Cultural safety is built into the research process in a number of ways. Cedar staff are Indigenous and non-Indigenous people who are knowledgeable about the dynamics of colonial trauma and substance use; seek to build trusting, non-judgmental relationships with participants; and prioritize participants' needs and safety. Guided by the teachings of Elders, the staff builds a relationship with participants by beginning with reciprocal protocols of introduction, sharing who they are and where they are from (Jongbloed & The Cedar Project Partnership, 2018). Staff also work hard to ensure our site offices are safe, welcoming settings without judgment of drug use, where police are not allowed, and cultural identity is honoured. Cedar study coordinator Vicky Thomas (Wuikinuxv Nation) shares,

"To make Cedar a culturally-safe place for participants, I go on the teachings of my mom, my aunties, and other influential women in my life. You have to think of the office as a home, and think about what would you do to welcome someone into your home. We do things like have food, and its ok for people to sleep away a shift on the couch, take a sponge bath in the bathroom, or make calls to family." – Vicky Thomas, Wuikinuxv Nation (Jongbloed & The Cedar Project Partnership, 2018)

Another critical component is support from Cedar Partners who often provide access to traditional foods (e.g., salmon, elk, berries, moose), medicines (e.g., sage, cedar), and ceremonies (e.g., smudge, burning, feather) for Cedar participants. Cedar hosts annual feasts, memorials for participants who have passed away, and other ceremonies as part of our knowledge translation process (such as our 2013 learning potlatch). Further, research offices feature artwork, murals, and carvings, including some created by participants themselves. As a student member of the Cedar team, I played a role in supporting cultural safety throughout the research process, including staying accountable to participants and partners, helping out with

events, cooking for feasts, facilitating access to traditional foods and medicine, keeping an open heart and mind, and trying to stay humble when mistakes were made. Figure 2.1 provides some images representing cultural safety in our research process: (1) Relationships between Cedar partners, staff, investigators, and students; (2) artwork at research offices; (3) wall memorial for participants who have passed away; (4) traditional food and medicines provided by Cedar partners and cooked by students and staff; and, (5) events including the 2013 Cedar knowledge translation potlatch and annual feasts.



Figure 2.1: Examples of cultural safety in the research process

In addition to these ethical considerations, The Cedar Project follows the guidelines provided in the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans – Chapter Nine: Research involving the First Nations Inuit and Métis Peoples of Canada (CIHR, NSERC, & SSHRC, 2014). Both this dissertation and the Cedar Project WeITel mHealth Study were approved by the UBC Providence Health Care Research Ethics Board. All participants gave both verbal and written consent and it was emphasized that deciding not to participate in this sub-study would not affect continued involvement with Cedar or support from staff.

2.3 Methods

2.3.1 Study setting

The 2016 Canadian Census identified 270,585 Indigenous people living in BC, accounting for 5.9% of the total population (Statistics Canada, 2017). Cedar Project study storefront research offices are located in Vancouver's downtown eastside and in the downtown core of Prince

George (Table 2.2). Vancouver is a large city in southern BC located on the traditional territory of the Coast Salish peoples. Prince George is a forestry and mining town in the province's northern interior, located on the traditional territory of the Lheidli T'enneh people. In total approximately 11,155 (15.4%) Indigenous people live in Prince George and 13,900 (2.2%) live in Vancouver (Statistics Canada, 2018a, 2018b). Cedar participants represent many of the diverse First Nations, Inuit and Métis communities across Canada, and are often living far away from their home communities.

Characteristic	Vancouver	Prince George		
Traditional territory	Coast Salish peoples (Musqueam,	Lheidli T'enneh Nation		
	Squamish and Tsleil-Waututh Nations)			
Total population	618,210	72,550		
Indigenous population (%)	13,900 (2.2%)	11,155 (15.4%)		

Table 2.2: Study site characteristics

2.3.2 Cedar Project Blanket Program

Since 2011, Cedar Project participants living with HIV have been given the option of enrolling in 'The Cedar Project: Exploring HIV Case Management' study, also known as the Blanket Program. The Blanket Program is an individualized, culturally-safe case management approach connecting HIV-positive participants with a Cedar staff member at each study site who acts as the participant's Case Manager. Blankets hold a highly important place in many North American Indigenous cultures, as they continue to be used in giveaways and potlatches, honour children with names and celebrate young people coming-of-age. Blankets are used to symbolically wrap children in care, and represent inclusion of young people in the community. Through one-on-one conversations, Cedar Case Managers help participants identify barriers to accessing HIV services and help navigate access and sustained adherence to HIV treatment. In addition, Case Managers help participants deal with food insecurity, and organize gatherings open to all participants at the Cedar study offices where traditional foods, including wild game and fish, are offered in a family-style setting. A critical part of the Blanket Program is the use of regular blood work to monitor CD4 counts and HIV viral load. Case Managers and Cedar nursing staff support participants in interpreting these tests and counsel them about maintaining regular blood work as well as addressing any other health concerns. Of 98 Cedar Participants living with HIV in September 2014, 60 were enrolled in the Blanket Program. Reasons for not joining included: having died prior to initiation of the program (n=8), being lostto follow-up (n=17), not invited or not interested $(n=10)^5$, incarcerated (n=2), or joined later (n=1).

2.3.3 Cedar Project WelTel mHealth Study

The Cedar Project WelTel mHealth study was nested within the Cedar Project between September 2014 to January 2016 (Figure 2.2). The aim was to determine whether a bundle of mHealth supports was acceptable and effective to support health and wellbeing, including related to HIV and substance use, among young Indigenous people who have used drugs.



The Cedar Project WeITel mHealth program was a structured mobile phone initiative to connect young Indigenous people who have used drugs with Cedar Case Managers in a community-based setting, building on the Blanket Program approach. The mHealth program consisted of a bundle of supports, including a mobile phone and cellular plan, weekly two-way text messaging, and support from Cedar Case Managers (Figure 2.3). It took place over a 16-month period with continuous enrollment. Enrollment began in September 2014 and ended in August 2015. The program came to an end for all participants in January 2016. All participants received the program for a minimum of four months.



Figure 2.3: The Cedar Project WeITel mHealth program

⁵ Staff made concerted efforts to get in touch with all participants eligible for the Blanket Program. The 'not interested or not invited' category refers to those who were invited but did not return for an enrollment visit or who made the decision not to participate. It also includes eligible participants whom staff attempted to reach but were not successful. This group is not lost to follow-up as they continue to participate in other Cedar research.

Cedar Case Managers included Indigenous and non-Indigenous nurses and Cedar Project staff members who have extensive frontline outreach experience working with young Indigenous people who have used drugs. Cedar Case Managers followed a "culturally-safe" approach that acknowledges both trauma and strengths, and includes an explicit focus on the critical roles of cultural assets and safe relationships with care providers for successful HIV treatment and care (Papps & Ramsden, 1996).

Participants were provided with a cellular handset and plan at the beginning of the study. We are grateful for our partnership with TELUS, which provided free handsets and subsidized plans for the duration of the mHealth program. Initially, TELUS supplied us with Samsung Rugby smartphones. Once these were distributed, subsequent orders consisted of Alcatel A392a flip phones. Each phone was pre-programmed with phone numbers for emergency and health-related services relevant to the study site. Over the study period, participants received a monthly cellular plan, which included unlimited calling and texting within Canada, but no data. Including long-distance calling and texting was an explicit decision to provide the opportunity for participants to connect with family and loved ones living in home communities and elsewhere in Canada. If phones were lost or stolen, participants were eligible to receive one replacement. If two phones were lost, the participant could bring in their own SIM⁶ card-enabled cellular handset to use with the study monthly cellular plan.

Each Monday at noon, a text message saying, "how's it going?" was automatically sent to participants through the WelTel mHealth platform. Cedar Case Managers logged in within 24 to 48 hours to triage the incoming text messages. Cedar Case Managers responded to all participants and followed up with participants who replied with a specific problem or need. On Wednesday, participants who had not replied received an additional text saying, "Haven't heard from you, are you ok?" On Thursday or Friday staff attempted to call all remaining participants who had not responded by text message, by phone, or in-person.

Experienced Cedar Case Managers and nurses from the Vancouver and Prince George offices received training in the mHealth program and study protocols over three days in June 2014.

⁶ A subscriber identification module (SIM) card is an integrated circuit that stores mobile subscriber information (such as mobile phone number, network, and plan) that can be removed from a phone to allow the user to switch between mobile devices.

Training consisted of reviewing study protocols (day 1), orientation to the WelTel platform by representatives from WelTel (day 2, morning), a site visit to the Oak Tree Clinic to see how they used the WelTel platform (day 2, afternoon), orientation to the study phones by a representative from TELUS (day 3, morning), and hands-on practice of the WelTel platform and study protocols (day 3, afternoon). The in-person training was followed by a three-week internal pilot test of the WelTel platform and weekly text messages involving 20 Cedar staff, trainees, investigators, partners, and family members.

2.3.4 Sample

In total, 131 Cedar participants were involved in the mHealth program (Figure 2.4), including 52 participants living with HIV, which constitutes the study sample for this dissertation. Eligible participants were contacted, either by me or a Cedar staff member, to invite them to learn more about the mHealth program and consider participating. If they were interested, staff scheduled an appointment to review study procedures and informed consent. Participants could enroll at that point, or take time to consider. Consent to participate in the mHealth program was renewed when it became possible to extend the program for additional time. In addition, I sought specific informed consent for in-depth qualitative interviews with a subset of participants described in more detail below.





HIV mHealth sample. All participants enrolled in the Blanket Program were eligible for enrolment the Cedar Project WeITel mHealth study. In total, 52 Blanket Program participants living with HIV participated in the Cedar Project WeITel mHealth study and contributed data to this analysis. Reasons for not joining mHealth included: died (n=1), lost to follow-up (n=4), or

not interested (n=3). Compared to other participants living with HIV, those in Prince George and those without a history of homelessness were significantly more likely to be among the 52 participants who joined the mHealth program (Table 2.3). Differences by city may reflect the long-term relationships Cedar staff have developed with participants in Prince George, the greater variety of HIV-related services in Vancouver, and that living in Vancouver may be a proxy indicator for periods of greater instability preventing people from engaging in HIV-related programs. Differences related to housing status may reflect that people with housing instability are more likely to have been lost to follow-up or died prior to the beginning of mHealth. No other differences were observed between the two groups.

			HIV+			
Characteristic	Obs	Total (n=101)	Not in mHealth (n = 49)	In mHealth (n = 52)	p- value	Missing (%)
Demographics & Social Determinants						
Age (median, IQR)	101	25 (22–28)	25	25	0.965	0 (0.0%)
Sex (Female)	101	63 (62.4%)	31 (63.3%)	32 (61.5%)	1.000	0 (0.0%)
Location (Prince George)	101	33 (32.7%)	8 (16.3%)	25 (48.1%)	0.001	0 (0.0%)
In a relationship	100	30 (30.0%)	11 (22.4%)	19 (36.5%)	0.205	1 (<1%)
Sexual identity (LGBT)	101	18 (17.8%)	7 (14.3%)	11 (21.1%)	0.521	0 (0.0%)
Ever homelessness	101	76 (75.2%)	42 (85.7%)	34 (65.4%)	0.033	0 (0.0%)
Colonial Violence & Trauma						
Either parent at residential school	100				0.813	1 (<1%)
Yes		44 (44.0%)	20 40.8%)	24 (47.1%)		
Unsure		41 (41.0%)	21 (42.9%)	20 (39.2%)		
Apprehended from biological parents	101	73 (72.3%)	32 (65.3%)	41 (78.8%)	0.195	0 (0.0%)
Childhood sexual abuse (≤13)	98	52 (53.1%)	24 (50.0%)	28 (56.0%)	0.695	3 (3.0%)
Ever incarcerated	100	77 (77.0%)	39 (79.6%)	38 (74.5%)	0.714	1 (<1%)
Sexual Vulnerability						
Ever sex work	101	61 (60.4%)	30 (61.2%)	31 (59.6%)	1.000	0 (0.0%)
Substance Use						
Ever used injection drugs	101	77 (76.2%)	37 (75.5%)	40 (76.9%)	1.000	0 (0.0%)
Ever overdosed	101	40 (39.6%)	19 (38.8%)	21 (40.4%)	1.000	0 (0.0%)
Mental & Physical Health						
HCV co-infection	101	82 (81.2%)	37 (75.5%)	45 (86.5%)	1.000	0 (0.0%)
Ever attempted suicide	99	34 (34.3%)	15 (31.9%)	19 (36.5%)		2 (2.0%)

 Table 2.3: Baseline characteristics of Cedar participants living with HIV (n=101), by

 enrolment in mHealth

Note: Bolded results indicate statistical significance

HIV negative sample. In addition, with an aim to recruit 94 HIV-negative Cedar participants, 131 were randomly selected to be invited, of whom 79 (78.7%) agreed to join. Stratification was used to achieve a balance of key factors, including study site (Prince George and Vancouver) and reporting injection drug use at the last visit (yes/no). A sampling frame of eligible participants was created based on the following eligibility criteria: (1) currently enrolled in the

Cedar Project; (2) had completed main Cedar Project baseline questionnaire and attended at least one follow-up visit since 2009; (3) had not tested positive for HIV; (4) joined study in Vancouver or Prince George; and (5) was alive at initiation of the Cedar Project WeITel mHealth study. Those who were invited but did not enroll were more likely to have experienced an overdose and were slightly older (Table 2.4). No other significant differences were observed between the two groups.

			HIV negative			
Characteristic	Obs	Total (n=131)	Invited, not enrolled (n = 52)	Invited, enrolled (n = 79)	p- value	Missing (%)
Demographics & Social Determinants						
Age (median, IQR)	130	24 (21-27)	25	23	0.027	1 (0.7%)
Sex (Female)	131	76 (58.0%)	27 (51.9%)	49 (62.0%)	0.334	0 (0.0%)
Location (Prince George)	131	61 (46.6%)	21 (40.4%)	40 (50.6%)	0.331	0 (0.0%)
In a relationship	128	26 (20.3%)	12 (23.5%)	14 (18.2%)	0.609	3 (2.2%)
Sexual identity (LGBT)	131	17 (13.0%)	5 (9.6%)	12 (15.2%)	0.432	0 (0.0%)
Ever homelessness	131	93 (71.0%)	35 (67.3%)	58 (73.4%)	0.577	0 (0.0%)
Colonial Violence & Trauma						
Either parent at residential school	130				0.271	1 (0.7%)
Yes		57 (43.8%)	18 (35.3%)	39 (49.4%)		
Unsure		36 (27.7%)	17 (33.3%)	19 (24.1%)		
Apprehended from biological parents	131	90 (68.7%)	31 (59.6%)	59 (74.7%)	0.104	0 (0.0%)
Childhood sexual abuse (≤13)	119	60 (50.4%)	42 (57.5%)	18 (39.1%)	0.077	12 (9.2%)
Ever attempted suicide	123	54 (43.9%)	21 (42.9%)	33 (44.6%)	0.996	8 (6.1%)
Sexual Vulnerability						
Ever sex work	131	69 (52.7%)	23 (44.2%)	46 (58.2%)	0.164	0 (0.0%)
Substance Use						
Ever used injection drugs	131	73 (55.7%)	31 (59.6%)	42 (53.2%)	0.584	0 (0.0%)
Ever overdose	126	38 (30.2%)	20 (41.7%)	18 (20.1%)	0.044	5 (3.8%)
Mental & Physical Health						
HCV co-infection	131	61 (46.6%)	27 (51.9%)	34 (43.0%)	0.413	0 (0.0%)
Ever incarcerated	129	83 (64.3%)	35 (68.6%)	48 (61.5%)	0.526	2 (1.5%)

 Table 2.4: Baseline characteristics of HIV-negative Cedar participants invited vs.

 enrolled in mHealth (n=131)

Note: Bolded results indicate statistical significance

2.3.5 Data sources

Dissertation analyses involved use of primary and secondary data collected as part of the Cedar Project, the Blanket Program, and the Cedar Project WelTel mHealth study. Each source is described below (Figure 2.5).



Primary data

In-depth interviews. In-depth interviews were carried out with 19 mHealth participants (12 HIV-positive, 7 HIV-negative) after the end of the mHealth program in March/April 2016. Interview sampling and procedures are described in depth in *Chapters 4 and 9*. Briefly, interviews were semi-structured with a topic guide, developed with input from Mr. Lou Demerais and Ms. Sherri Pooyak (Cedar Project Partners and Indigenous Mentors). Three themes informed the question groups: (1) Experiences of the cascade of care; (2) Using mobile phones to connect to care and support; (3) Experiences of the Cedar Project WeITel mHealth program. Interviews were open-ended to allow participants to share stories they felt were important. The topic guide was piloted with Cedar participants who have many years of experience of involvement in research. I conducted the interviews alone, or with a Cedar staff member in Prince George where I had spent less time and was less familiar to participants. In total, they took between 33 to 100 minutes. Interviews were audiotaped, and following data collection, I transcribed them verbatim using f5 transcription software.

Secondary data

Main Cedar Project cohort data. Interviewer-administered questionnaires collected at enrollment into the Cedar Project and every six months thereafter as part of the main Cedar Project cohort captured socio-demographics, strengths, intergenerational and lifetime trauma, sexual vulnerability, substance use patterns, and health outcomes. At these six-month visits, participants provide blood samples which are tested for HIV and hepatitis C. Since 2011, two additional psychometric scales have been collected to assess resilience (Connor-Davidson Resilience Scale, or CD-RISC) and psychological distress (Symptom Checklist-90-R, or SCL-90-R).

Blanket Program data. In addition to the above, since 2011 Blanket Program participants have attended quarterly visits with a Cedar Case Manager that include HIV-specific questionnaires and bloodwork to measure CD4 counts and viral load.

mHealth baseline and end-of-study surveys. Two brief questionnaires were used to capture data related to mobile phone use and the mHealth program specifically. The baseline survey asked about ownership and use of mobile phones, frequency of text messages, and perceived helpfulness or concerns about receiving text messages related to health. It was collected between September 2014 to August 2015 at participants' mHealth enrollment visit. At the end of the mHealth program, participants completed an administered mHealth follow-up questionnaire to assess satisfaction with the mHealth program. This short survey also asked questions about how participants engaged with phones and text messaging in relation to health. It was collected between October 2015 to April 2016. Both the baseline and follow-up surveys included some open-ended questions which informed embedded qualitative analyses. Both mHealth questionnaires were collected primarily by me in Vancouver and by Cedar staff in Prince George.

WeITel platform data. The WeITel platform was used to manage text messaging between Cedar participants and Case Managers, as well as notes written by Case Managers regarding offline interactions with participants. The platform also included meta data such as time, date, study site, and mHealth status (active/inactive). Content of text message interaction between participants and study staff collected throughout the Cedar Project WeITel mHealth study was downloaded from the WeITel mHealth platform, along with additional meta data and notes. This included both quantitative and qualitative data.

Field notes & procedural documents. This analysis was also informed by my in-person and text message engagement with Cedar participants and staff while the WelTel mHealth program was underway. Field notes involved regularly writing detailed observational and analytical

memos about the mHealth program during and immediately following over 400 hours spent in the Vancouver Cedar site office, with additional time in the Prince George office. Documents, including program procedures and protocols, team memos, and meeting minutes contributed secondary data to support understanding how a community-based mHealth program looks and functions in practice.

2.3.6 Measures

Quantitative measures used in the analyses that follow seek to reflect the conceptual framework presented in *Chapter 1: Introduction*. They fall into a number of related categories: (1) demographics and social determinants of health; (2) cultural connection and resilience; (3) colonial violence and trauma; (4) substance use and sexual vulnerability; (5) mental and physical health; (6) HIV cascade of care; and (7) mobile phone patterns and mHealth.

Demographics & social determinants of health. Socio demographic variables included age (years), sex (male/female), city (Prince George/Vancouver), relationship status (single/in a relationship), LGBT sexual identity (yes/no), educational attainment (high school diploma/did not graduate), and recent homelessness (yes/no). Participants were also asked what type of place they currently lived in. Jail, no fixed address, street, room in hotel, shelter, hostel, and treatment/recovery house were classified as unstable housing.

Cultural connection & resilience. Cultural connection was assessed using a series of measures defined by Earl Henderson (Cree & Métis) and Violet Bozoki (Lheidli T'enneh Nation) who are Indigenous Elders, traditional knowledge keepers, and members of the Cedar Project Partnership. Variables included: having a traditional language spoke often at home growing up (often/always vs. never/rarely); ever having participated in traditional ceremonies (including: potlatch, feast, fast, burning ceremony, washing ceremony, naming ceremony, big/smoke house, rites of passage, smudge, dances, or any other traditional Indigenous ceremony) (yes/no); living by traditional culture (often/always vs. never/rarely); knowing how to speak traditional language (yes or a bit vs. no); speaking traditional language today (often/always vs. never/rarely); and recent access to traditional food (yes/no). Resilience, or the ability to cope with adversity, was characterized using the Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003). The CD-RISC scale measures resilience via 25 items on a 5-point scale with scores ranging between 0-100, with higher scores indicating greater resilience. Use of the CD-RISC scale has been previously been validated for use with Cedar participants

(Pearce, 2014; Pearce, Jongbloed, et al., 2015). Resilience was assessed either semi-annually or quarterly over the study period.

Colonial violence & trauma. Variables were included that sought to capture experiences of the colonial institutions and related historical and lifetime colonial traumas outlined in *Chapter 1: Introduction.* Three measures were asked once, at baseline. Participants were asked if either/both of their parents had attended residential school (yes/no/unsure) and if they had ever been removed from their biological parents (yes/no). If participants said 'yes' to having been forced to have sex against their will and/or been molested prior to age 14, they were considered to have experienced childhood sexual abuse (yes/no). Additional variables were measured at each six-month follow-up, including recent incarceration (yes/no). As well, we created a 'ever had a child apprehended' (yes/no) variable based on if participants responded 'yes' to having recently had a child apprehended at any follow-up during the study period.

Substance use & sexual vulnerability. Sexual vulnerability and substance use variables were assessed at baseline and every six months over the study period. We asked participants if they had recently been involved in sex work (yes/no) or recently experienced sexual assault (yes/no). The following self-reported binary measures were used to assess substance use and related treatment experiences: recent injection drug use (yes/no), ever experienced a non-fatal overdose (yes/no), recent alcohol/drug treatment (yes/no), recently unable to access drug treatment (yes/no), ever on methadone (yes/no), current methadone treatment (yes/no), and ever having tried to quit drugs or alcohol.

Mental & physical health. Mental and physical health outcomes assessed at each follow-up visit included HIV infection (yes/no), hepatitis C infection (yes/no), recent hospitalization (yes/no), and ever attempting suicide (yes/no). Psychological distress was measured using the Symptom Checklist-90-R (SCL-90-R). The SCL-90-R is a 90-item self-reported symptom inventory measuring the severity of nine dimensions of psychological distress in the past three months scored on a five-point Likert scale (from not at all to extremely). SCL-90-R scores were transformed into an average Global Severity Index ranging between 0-1.5, providing a single average measure profiling the overall degree of psychological distress (Derogatis, 1996). The SCL-90-R has previously been validated for use with Cedar participants (Pearce et al., 2018; Pearce, 2014). Psychological distress was assessed either semi-annually or quarterly over the study period.

HIV cascade of care. We assessed engagement in the HIV cascade of care as follows. Retention in care was measured using the question, "do you have a doctor you see regularly for HIV?" (yes/no). At each visit, participants were asked if they had ever been offered ART (yes/no) and if they were currently on ART (yes/no). HIV viral suppression was measured using HIV Nucleic Acid Amplification Tests that determined the number of copies of the HIV virus present in the blood. This was expressed as a continuous (\log_{10} viral load) or dichotomous (\leq vs. >40 copies/mL, referred to as suppressed vs. unsuppressed) variable, where appropriate.

Mobile phone patterns & mHealth. Participants responded to questions about their mobile phone ownership and use at the beginning and end of the mHealth program. At the beginning of the mHealth program, the following variables were collected: owned phone at enrollment into mHealth (yes/no); type of phone (basic/smart); texting plan (yes/no); type of texting plan (pay-as-you-text/unlimited/limited/unsure); access internet on phone (yes/no); share a phone (yes/no); frequency of texting (never/rarely/occasionally/frequently/very frequently). Participants were asked, "do you think using a cell phone would help with your healthcare and be helpful to you?" and "do you have any concerns about using text messaging for your healthcare"; they could answer yes, no, or unsure.

At the end of the mHealth program, we asked participants if they: currently have a phone that works for calling and texting (yes/no); lost a phone during the study (yes/no); faced any challenges using the phone in the past three months (yes/no); used the pre-programmed phone numbers (yes/no); was anything they did not like about the program (yes/no); would recommend the program to a friend (yes/no); and would like the program to continue (yes/no). Further, participants responded to a number of questions about program satisfaction that used a Likert scale (1-5; "not at all" to "very much so"), as well as a few short answer and multiple response questions detailed in the latter chapters of this dissertation.

In addition, we sought to capture mHealth engagement over the mHealth program period (Table 2.5). Throughout the mHealth period, participants were either active (currently have phone connectivity) or inactive (no phone connectivity, for example lost or stolen) in the WeITel platform each week. Each Monday at noon, an automatic system-generated "how's it going?" text was sent to all active participants. If participants did not reply by Wednesday at noon, a second automatic message went out that said, "haven't heard from you, just checking in" (or a

similar variation). If participants did not respond by Thursday or Friday, Cedar Case Managers followed up by phone. After the program came to an end, I reviewed interactions manually and categorized them as "not responding" if participants did not respond at any point to our texts or phone call during the week. Those who responded by text, phone, or in person were categorized as "active and responding" that week. A dichotomous "level of mHealth engagement" variable was created (active and responding/inactive or active, not responding). Level of mHealth engagement was therefore measured each week; however, in some of the chapters that follow, this variable is collapsed into proportion of active and responding weeks (denominator) divided by the total number of weeks (numerator) to align better with the timeframe of data collection of other variables.

Not yet enrolled	Inactive	Active, not responding	Active and responding
Not yet enrolled	 Participant's phone is lost or stolen. No current active number. Marked as "inactive" in the WeITel software. WeITel software is not sending them any messages. 	 Participant is "active" in the WeITel software. On Monday, they were sent the 'how's it going' text message by the system. However, they did not respond (by text or otherwise) to the message that week. 	 Participant is "active" in the WelTel software. On Monday, they were sent the 'how's it going' text message by the system. They responded either by text or otherwise at some point during the week.
			Engaged

Table 2.5 · I	evel of	^r mHealth	enaaaement
1 abie 2.3. L		IIIIICaittii	engagement

2.4 Overview of dissertation methods by chapter

Table 2.6 provides a general overview of the research approach undertaken in each results chapter in this dissertation, including the aim, strategy, sample, and analysis. Each chapter includes additional details about the specific methods used. For each chapter, emphasis (capital letters) is used to indicate if weight is placed on the qualitative or quantitative component of the study, or if there is balance between the two approaches.

Chapter	Aim	Strategy	Sample	Analysis						
Objective 1: E	xamine experiences of er	ngagement in the HI	/ cascade of care am	ong Indigenous people,						
particularly young people who have used drugs.										
Ch 3	Assess current evidence related to experiences of HIV cascade of care among Indigenous	Mixed methods systematic review	93 articles published between 1996-2017	 Quant: textual narrative synthesis Qual: Qualitative Assessment and Review Instrument 						
.	peoples			(QARI) process						
Ch 4	Explore experiences of HIV cascade of care among young Indigenous people who have used drugs	Exploratory sequential mixed methods	Qual: 12 HIV+ Cedar participants Quant: 52 HIV+ Cedar participants	 Qual: Interpretive Description Quant: Longitudinal generalized linear mixed effects logistic regression models 						
Objective 2: A	Assess the feasibility and ac ople who have used drugs.	ceptability of mHealth	for HIV-related health	and wellness among young						
Ch 5	Assess acceptability and feasibility of mHealth	Embedded mixed methods	131 mHealth participants	 QUANT: Comparative statistics Qual: Rapid thematic analysis 						
Objective 3: E have used dru	Evaluate the impact of mHea gs.	alth on HIV-related hea	alth and wellness amo	ong young Indigenous people who						
Ch 6	Evaluate effect of Cedar Project WelTel mHealth for viral suppression	Repeated measures pre-post design	52 HIV+ mHealth participants	QUANT: Comparisons followed by longitudinal generalized linear mixed effects logistic regression models						
Ch 7	Evaluate effect of Cedar Project WelTel mHealth program for other health and wellness indicators	Repeated measures pre-post design	131 mHealth participants	QUANT: Comparisons followed by longitudinal generalized linear mixed effects logistic regression models						
Objective 4: U	Inderstand engagement wit	h mHealth for HIV-rela	ated health and wellne	ess among young Indigenous						
people who ha	ve used drugs.	ſ	ſ	1						
Ch 8	Characterize engagement with the Cedar Project WelTel mHealth program	Embedded mixed methods	131 mHealth participants	 QUANT: Descriptive statistics and longitudinal generalized linear mixed effects logistic regression models Qual: Rapid thematic analysis 						
Ch 9	Explore engagement with the Cedar Project WeITel mHealth program	Interpretive description	131 mHealth participants	QUAL: Interpretive Description						

Table 2.6: Overview of dissertation chapters

2.5 Knowledge translation

Bringing forward the voices of young Indigenous people who have used drugs to advocate for structural and health system changes is a central purpose of this dissertation. The findings contained within the chapters that follow affirm what Indigenous peoples and communities already know, but are likely new to Canadians, including policy makers and health professionals. The Cedar Project overall takes an integrated knowledge translation (iKT)

approach, in contrast to one where knowledge translation occurs at the end of the study (CIHR, 2012). Similarly, this dissertation involved multiple iKT engagements throughout the entire process. First and foremost, I took part in an iterative iKT process through frequent one-on-one engagement with Indigenous mentors, as well as attendance and presentations during Cedar Project Partnership meetings. Further, there were opportunities to engage with other academic, health system, and frontline stakeholders, such as through blogs, oral and poster presentations, and one-on-one conversations. Future iKT will include creation of lay summaries (including visual summaries) for circulation to Cedar partners and other stakeholders, as well as direct engagement with relevant health system stakeholders to share findings and support integration into policy and programs.

Chapter 3 Results – Experiences of the HIV cascade of care among Indigenous peoples: a systematic review

3.1 Background

The HIV cascade of care has emerged as a key framework to understand "success" with respect to HIV prevention and treatment around the globe (UNAIDS, 2014a). According to the HIV cascade of care framework, the ultimate clinical goal of HIV treatment is achievement of viral suppression, which in turn reduces HIV transmission, morbidity, and mortality (Cohen et al., 2011; Lima et al., 2007). To reach viral suppression, people living with HIV must achieve and sustain the steps of the HIV care cascade: they must know they are positive, be linked and retained in care, initiate antiretroviral therapy (ART), and adhere to medications (Gardner et al., 2011). The HIV cascade framework has been widely accepted and is the basis of the global HIV treatment agenda outlined in the UNAIDS 90-90-90 treatment targets (UNAIDS, 2014a). These targets seek to ensure that 90% of people living with HIV globally are diagnosed; 90% of those diagnosed are on treatment; and 90% of those on treatment are virally suppressed by 2020. If these global targets are met, it is hypothesized that an end to the HIV epidemic is possible by 2030. Recent figures indicate that 66% of people living with HIV globally know their status (UNAIDS, 2017). Among these, 77% are accessing ART and 82% of those on treatment are virally suppressed (UNAIDS, 2017). Addressing substantial gaps in HIV care that persist among populations facing significant barriers to treatment remains imperative (UNAIDS, 2014b, 2017).

Indigenous leaders and scholars continue to voice concerns that systemic oppression and lack of culturally-safe prevention and care services impede Indigenous people living with HIV from accessing health services that make up the HIV care cascade. Culturally-safe care is that which is free from racism and discrimination, where Indigenous perspectives of health and wellbeing are respected, impacts of ongoing colonization are acknowledged, and health providers adopt a humble, self-reflective clinical practice to walk beside Indigenous people on their health and wellness journeys (FNHA, 2016b; Health Council of Canada, 2012; Papps & Ramsden, 1996). HIV among Indigenous peoples must be considered in the context of ongoing colonization and systemic violence. Indigenous peoples in Australia, Canada, New Zealand, and the United States in particular share similar experiences of legislated dispossession and dislocation as a result of British colonial rule (Chansonneuve, 2005; McKenzie et al., 2016; Smith, 1999). Colonization in these countries included legislated restriction of movement, criminalization of peoples seeking to maintain ceremonies and traditions, and forcible removal of Indigenous children from families and communities. The result of these colonial onslaughts has been termed a "soul wound" passed through generations (Duran et al., 1998). The impacts of these policies are a powerful determinant of health, manifesting in preventable health inequities (Adelson, 2005; Loppie Reading & Wien, 2013; Reading, 2015). According to a recent review, HIV rates among Indigenous peoples in four countries are: Australia (31.2 per 100,000; Rate Ratio: 1.19), Canada (179.2 per 100,000; RR: 6.14), New Zealand (18.9 per 100,000; RR: 1.02) and United States (9.3 per 100,000; RR: 1.33) (Negin et al., 2015). In all cases, these rates are higher than among non-Indigenous people (Negin et al., 2015; Shea et al., 2011). Given the disproportionate burden of HIV among Indigenous peoples, it is a serious concern that Indigenous people living with HIV may become the '10-10-10' of the UNAIDS targets – those who are not engaged in care (Pala, 2015).

As the HIV cascade of care framework is increasingly the focus of global, national, and local HIV agendas, it is imperative that existing evidence is taken into account (Xiao & Watson, 2017). Two previous systematic reviews have focused on HIV incidence (Duncan et al., 2011) and risk/prevention (Negin et al., 2015) among Indigenous peoples in Canada and elsewhere. An additional literature review by Nowgesic (2015) focused on Indigenous people's experiences of ART therapy, but did not include the additional cascade stages of HIV testing, linkage to care, and retention in care. Thus, this systematic review assesses the evidence related to epidemiology and experiences of the HIV cascade of care among Indigenous peoples in Australia, Canada, New Zealand, and United States. Further, it draws on included studies to support understanding of whether the HIV cascade of care framework is meeting the needs of Indigenous peoples and identify gaps in existing literature.

3.2 Methods

3.2.1 HIV cascade of care framework

The HIV cascade of care is the guiding framework for this review and includes the following steps towards engagement in HIV care: (1) Testing and diagnosis; (2) Linkage to care; (3) Retention in care; (4) ART initiation; (5) ART Adherence; and (6) Viral Suppression (Figure 3.1) (Gardner et al., 2011).



3.2.2 Search strategy

We followed the PRISMA guidelines for reporting systematic reviews (Liberati et al., 2009). Search terms (Table 3.1) combined keywords from each of three conceptual categories: (1) HIV/AIDS; (2) Indigenous peoples in Australia, Canada, New Zealand and the United States; and (3) HIV cascade of care. Medline, Embase, CINAHL, and Web of Science searches were conducted in March 2016 and again in January 2018, prompted by the publication of several valuable articles related to the cascade of care among Indigenous people living with HIV in 2016 and 2017. Three relevant journals (*Pimatisiwin: Journal of Aboriginal and Indigenous Community Health; Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*; and *International Journal of Indigenous Health/Journal of Aboriginal Health*) were hand searched as they are not indexed. Finally, we reviewed references from eligible articles to identify additional relevant publications.

CATEGORY	CONCEPT	SEARCH TERMS
Condition	HIV/AIDS	HIV OR AIDS
		AND
Population	Indigenous peoples (in Australia, Canada, New Zealand, United States)	Indigeno\$ OR Aborigin\$ OR "First Nations" OR "First Nation" OR Inuit OR Metis OR "Native" OR "Native American" OR "American Indian" OR Maori OR Torres strait\$ OR Native Hawai\$ OR Alaska\$ Native\$
		AND
Intervention	Experiences of the HIV care cascade	Continuum OR cascade OR engagement or
		Treatment OR antiretroviral OR HAART OR ART or
		Test\$ OR prevent\$ OR diagnos\$ OR link\$ OR
		Viral\$ suppress\$ OR viremia OR viral load OR undetect\$ OR suppress\$

Table 3.1: Search terms

Note: Truncation and Boolean operators were modified for each database, as required.

3.2.3 Assessment for inclusion

Articles were included if they met the following criteria: (1) Presented findings related to one or more of the stages of the HIV cascade of care: testing and diagnosis, linkage or retention in care, ART initiation or adherence, and viral suppression; (2) Geographic: Australia, Canada, New Zealand, United States; (3) Dates: January 1, 1996-January 11, 2018 (year HAART came out to present); (4) Study design: qualitative, quantitative, mixed methods, observational studies, intervention studies; (5) Types of articles: peer-reviewed and presenting primary data (exclude: reviews, commentaries, reports, conference abstracts, theses); (6) Language: published in English; (7) Population: Studies among Indigenous people living with HIV, and those with Indigenous participants living with HIV as part of a larger sample that included analysis by Indigenous identity; did not report a cascade of care outcome; did not report primary data; or the quantitative study sample included <10 Indigenous people.

First, two authors independently reviewed each title and abstract. An inclusive approach was taken at this stage to ensure that no relevant studies were missed. If reviewers disagreed on eligibility of an article, it was discussed until consensus was reached. Full-text was accessed for further clarification if necessary. Second, we retrieved full-text publications to further assess compliance with eligibility criteria. Those deemed not to meet the inclusion criteria after full-text review were discussed in person with at least one other author.

3.2.4 Data extraction and synthesis

We extracted data into a structured Google Forms database in three areas: study characteristics, HIV cascade of care outcomes, and quality assessment (detailed below). Study characteristics included author, year, title, study approach, study design, study name, country, Indigenous group, key population, sample size, total number of Indigenous participants, and level of Indigenous focus. To extract HIV cascade of care data, we used a checklist to identify the stage of the cascade dealt with in the article (testing & diagnosis; linkage to care; retention in care; ART initiation; ART adherence; or viral suppression). We also recorded the findings related to that cascade stage in as much detail as possible. Findings included frequencies, proportions, summary statistics, confidence intervals, and p-values, as well as qualitative themes. We prioritized understanding and describing cascade experiences among Indigenous peoples in absolute rather than relative terms (e.g., comparisons to other ethnicities). Due to variability in cascade stage definitions, we also extracted the definition provided in the article.

The data extraction form was pilot-tested on five randomly selected included studies and refined accordingly (Green & Higgins, 2011). Data from included studies were extracted by the lead author, and verified through independent extractions by co-authors on a selection (n=21; 22.6%) of articles.

3.2.5 Analytical approach

For quantitative studies, diversity of measures and heterogeneity of statistics prevented metasummary or development of pooled estimates by cascade stage (Xiao & Watson, 2017). Instead, we used a textual narrative synthesis to highlight insights related to common measures of each cascade stage; volume and quality of available evidence; regional patterns; and trends over time. Bubble plots representing a rough overview of the most frequently occurring measure for each cascade stage are presented.

For qualitative studies, we meta-aggregated data within an existing theoretical framework (HIV cascade of care) using a modified Qualitative Assessment and Review Instrument (QARI) process (Noyes & Lewin, 2011; Pearson, 2004). Each article that included qualitative findings was coded using the stages of the HIV cascade of care defined by Gardner et al. (Gardner et al., 2011). We extracted key findings and related illustrations (quotes) overall and for each cascade stage, grouped findings into categories, and then created a synthesized summary for each category (Pearson, 2004).

3.2.6 Quality assessment

Study quality was assessed in two stages. Given that this review engages with health research involving Indigenous peoples, it was important to assess the quality of the included studies through both Indigenous and mainstream lenses. Recent literature has called for efforts to strengthen and decolonize reviews to better meet the needs of Indigenous peoples (Chambers et al., 2017; McDonald et al., 2010). Yet, to our knowledge, no tool currently exists to evaluate the quality of evidence included in a systematic review from an Indigenous perspective. As a result, we (a team of Indigenous and non-Indigenous scholars) developed a brief checklist (Figure 3.2) that would indicate whether included studies had taken steps to conduct their research with consideration of Indigenous communities to describe an action that is done in accordance with Indigenous values and protocols (Flicker et al., 2015). We use it here to reflect an approach to research that embeds ethics, protocols, and cultural safety according to

Indigenous paradigms and methodologies (Absolon, 2011; Kovach, 2009; Smith, 1999; Wilson, 2008). Research continues to be a tool of colonization, used as a way of pathologizing and surveilling Indigenous peoples (Castellano, 2004; Smith, 1999). However, others have identified the power of research, when done in a good way, to be empowering, healing, and self-determining (Castellano, 2004). Checklist items were identified from literature on Indigenous methodologies and research ethics, as well as the expertise of team members involved with this review (Chambers et al., 2017; Ermine, 2007; Ermine, Sinclair, & Jeffery, 2004; Flicker et al., 2015; Kovach, 2009; Loppie, 2007; Loppie Reading & Wien, 2013; Reading, 2015; Schnarch, 2004; Wilson, 2008). As Indigenous research standards are growing and developing, an 'other' category was included to capture actions not included on the existing list. Articles that incorporated some or several approaches listed are indicated with a * in the table.

Figure 3.2: Tool developed and used to roughly assess whether research was conducted 'in a good way' according to common Indigenous research standards

ʻln a g	ood way': Brief Indigenous research standards checklist
	It was not - study shows no evidence of community input or ownership
	Community Advisory Council
	Reviewed by Indigenous research ethics board
	Involvement of Elders
	Indigenous authors / investigators
	Reference to OCAP / Tri Council / other guidelines for research with Indigenous people
	Reported that findings were disseminated to community
	Data owned by community
	Participatory research (participants were involved in research process)
	Situated in context of colonization & historical trauma
	Privileged Indigenous knowledeges
	Researchers completed Indigenous Cultural Safety training
	Unclear
	Other:

In addition, we used a condensed *Newcastle-Ottawa Quality Assessment Scale - Cohort Studies* to assess quality of included quantitative observational studies, which make up the bulk of those identified in this review (Wells et al., 2015). The condensed scale assesses external and internal validity using four items with four possible responses that represent the highest level of validity to lowest. For each item, a star is awarded if the highest or second highest level of validity is achieved (Wells et al., 2015).

3.3 Results

Two areas of evidence emerged over the course of this review. One focused on narratives, contexts, and experiences of engagement in the HIV cascade of care among Indigenous

peoples using qualitative data. The other focused on the epidemiology of the HIV cascade of care among Indigenous peoples including rates, comparisons, and predictors. We begin with an overview of the included studies. Next, overarching determinants of engagement in the HIV cascade of care among Indigenous peoples are discussed (McDonald et al., 2010). Then, we present detailed results by each stage of the HIV cascade of care, starting with experiences (qualitative evidence) followed by epidemiology (quantitative evidence).

3.3.1 Overview of included articles

Database searches yielded a total of 5668 articles (Medline=1649, Embase=1740, CINAHL=645, and Web of Science=1634) (Figure 3.3). We identified an additional 19 articles through hand-searches of un-indexed journals. After duplicates were eliminated, 3255 records were screened and 179 full-text articles that met the eligibility criteria were further assessed for eligibility. Of these, 91 articles were excluded for the following reasons: data on cascade outcomes were not disaggregated by Indigenous identity (n=34); did not report a cascade of care outcome (n=40); did not report primary data (n=14); or quantitative study sample included <10 Indigenous people (n=3). Reviewing reference lists identified an additional 5 articles. In total, 93 articles fulfilled the inclusion criteria and were included in this review (Figure 3.4).

Figure 3.3: Selection of articles for systematic review of experiences of the HIV cascade of care among Indigenous peoples (PRISMA diagram)



Author	Year	Loca	ation	Key Population	Good Way	Quality	Testing	Linkage	Retention	Initiation	Adherence	Suppressi
Mill	2000	CAN	I: Northern Alberta	Women		-						
Prentice	2011	CAN	l: National	Young people	*	-						
Sozogor	2011	CAN	l Vancouver	roung people		-						
Sazeyai	2013	CAN	. vancouver			-						
Nwangwu-Ike	2015	USA	: National	Women								
Thompson	2009	AUS	: Western Australia		*	-						
Mill (a)	2008	CAN	I: National	Young people	*							
Mill (c)	2008	CAN	I: Alberta		*	-						
Plitt	2009	CAN	I: Northern Alberta			****						
Origener	2003	NIZ.	National		•							
Grierson	2004	NZ:	National									
Reading	2013	CAN	I: 5 regions			-						
Mill (b)	2008	CAN	I: Alberta		*	-						
Cain	2013	CAN	I: National	Co-morbid (depression)	*	- 1						
Kalonua	2001	LISA	Hawaii		*							
Dedeuu	2001	CAN	L F angiero			-						
Barlow	2006	CAN	i: 5 regions			-					-	
DuBois	1996	CAN	I: Montreal									
Connor	1997	NZ:	Auckland/Christchurch			***						
Miller	1998	AUS	: Anangu Pitiantiatiara		*	****						
Krause	1999	LISA	Western Mtn Region	Co-morbid (SCI) men		**						
Martin	2002	CAN		Substance use		***						
Marun	2002	CAN		Substance use								
Denny	2003	USA	: National			-						
Mak	2003	AUS	: Western Australia	Perinatal		**						
Folev	2005	USA	Southwest	Substance use		*						
Mong	2005	CAN	l: Alborta	Poripotal		****						
wang	2005	CAN		Fermatai								
wardman	2006	CAN	I: BC		-	-						
Sanchez	2006	USA	: National	MSM		***						
Bucharski	2006	CAN	I: Edmonton	Women	*							
Lapidus	2006	USA	: Portland		*							
Barnes	2010	1194	National									
Comportit	2010	UCA	Notional			**						
Campsmith	2010	USA	. Induonal			***						
Hodge	2010	USA	: California									
Orchard	2010	CAN	I: National		*	***						
Long	2010	CAN	I: Alberta	Co-morbid (TB)								
Worthington	2010	CAN	I National	Young people	*							
Sonder	2014	LICA	Montana	. surig poople								
Sondag	2011	USA	. wontana		•							
Sawleshwarkar	2011	AUS	: National			**						
Burks	2011	USA	: Oklahoma City	MSM	*							
Mill	2011	CAN	I: National	Young people	*	-						
Takahachi	2011	LISA	S California		*							
Dawar	2011	000	l. O. California	Terreto		**						
Bauer	2012	CAN		Trans people	-							
Kwan	2012	AUS	: Western Australia	Perinatal		**						
Paquette	2013	AUS	: Sydney	Substance use	*							
Ward	2013	AUS	: NSW	Young people	*							
Pearson	2013	LISA	7 cities	MSM	*							
	2014	CAN	L Alberte	Compatibil (TD)		**						
Long	2014	CAN	Alberta									
Sionean	2014	USA	: National	Heterosexual		***						
Ford	2015	USA	: National	Older adults		**						
Williams	2015	AUS	: Western Australia	Young people	*							
Ward	2016	ALIS	65 remote communities	Young people		***						
vvalu	2010	100	. 05 remote communities									
Anastario	2017	USA	: Fort Peck Reservation	Substance use		-						
Cahn	2017	USA	.: National	Men		**						
McCall	2009	CAN	I: Western Canada	Women	•							
Diamond	2001	USA	: Seattle / Denver / LA			**						
Mitech	2017	LISA	28 jurisdictions			***						
WILSON	2017	034		147								
Krontii	2017	CAN	I: BC / Ontario / Quebec	vvomen		-					1	
Connel	2014	USA	.: Oklahoma			***						
Dickson	2012	NZ:	National			**						
Newman	2007	AUS	Western Australia		*	-						
Templeton	2015	ALIC	National									
rempleton	2015	AUS	. reduoridi	141							-	
McCall	2014	CAN	I: Vancouver	Women	•	1-1						
Chongo	2011	CAN	I: Vancouver	Men	•	-						
Martin	2010	CAN	I: Northern Alberta			*						
Erickson	2015	CAN	I: Winnipeg	Substance use		**						
Duran	2000	IIC A	Western	Rural	*	**						
Duran	2000	USA	. western	nulai								
masching	2014	CAN	i: National		-	-						
Rachlis	2017	CAN	I: Ontario		*	**						
Milloy	2016	CAN	I: Vancouver	Substance use	*	**						
Wood	2003	CAN	I: BC	PLWHA who died		****						
Nowgesic	2015	CAN	I Saskatchewan	Substance uno	*	-						
nowyealc Oaldatas	2013	CAN		DUMUA when "		-						
Goldstone	2000	CAN	: vancouver	PLWHA who died								
Miller	2006	CAN	I: BC			***						
Jaworsky	2016	CAN	I: Toronto		*	**						
Klakowicz	2016	CAN	I: Vancouver			***						
Wood	2006	CAN	l: Vancouver	Substance use		**				-		
	2000	UN	Dessiv	Gabalance dae		***						
Jurgos	2006	USA	. Phoenix		-							
Monette	2009	CAN	I: Ontario		•	•						
Beswick	2013	CAN	I: Ontario		*	*						
ima	2006	CAN	I: BC			***						
rolu	2010	LICA	Southwoot	Pural	•	***						
raiu	2010	USA	. Southwest	Rufal		*						
	2004	USA	: Hawaii		*							
Ka'opua	2010	USA	: Navajo Nation		*	-						
Ka'opua Duran	2014	CAN	I: Edmonton									
Ka'opua D <i>uran</i> Gunther	A 14 1 1 1 1	CAN				**						
Ka'opua D <i>uran</i> Gunther Samii	2044	CAN										
Ka'opua Duran Gunther Samji	2014		I: BC / Ontario / Quebec			**						
Ka'opua Duran Gunther Samji Samji	2014 2015	CAN			•	**						
Ka'opua Duran Gunther Samji Samji Puskas	2014 2015 2017	CAN	BC			**						
Ka'opua Duran Gunther Samji Samji Puskas Vang	2014 2015 2017 2017	CAN	I: BC									
Ka'opua Duran Gunther Samji Samji Puskas Wang Dillag	2014 2015 2017 2017	CAN	I: BC I: BC	Derivetal		**						-
Ka'opua Duran Gunther Samji Samji Puskas Wang Gilles	2014 2015 2017 2017 2007	CAN CAN AUS	I: BC I: BC I: Western Australia	Perinatal		**						
Ka'opua Duran Gunther Samji Samji Puskas Wang Gilles Gilles	2014 2015 2017 2017 2007 2001	CAN CAN AUS CAN	I: BC I: BC I: Western Australia I: Northern Alberta	Perinatal		**						
Ka'opua Duran Gunther Samji Puskas Wang Gilles Martin ART-CC	2014 2015 2017 2017 2007 2011 2013	CAN CAN AUS CAN CAN	I: BC I: BC I: Western Australia I: Northern Alberta I: BC	Perinatal		** * **						
Ka'opua Duran Gunther Samji Samji Puskas Vang Gilles Martin ART-CC Martin	2014 2015 2017 2017 2007 2011 2013 2013	CAN CAN AUS CAN CAN	I: BC I: BC I: Western Australia I: Northern Alberta I: Northern Alberta	Perinatal		** * ** **						
Ka'opua Duran Gunther Samji Samji Puskas Wang Gilles Martin ART-CC Martin Cancon	2014 2015 2017 2017 2007 2011 2013 2013 2014	CAN CAN AUS CAN CAN CAN	I: BC I: BC I: Western Australia I: Northern Alberta I: Northern Alberta	Perinatal		** * ** **						
Ka'opua Duran Gunther Samji Samji Puskas Wang Gilles Martin ART-CC Martin Cescon	2014 2015 2017 2017 2007 2011 2013 2013 2014	CAN CAN AUS CAN CAN CAN CAN	I: BC I: Western Australia I: Northern Alberta I: BC I: Northern Alberta I: BC	Perinatal		** * ** ** **						
Ka'opua Duran Gunther Samji Samji Puskas Marg Silles Martin ART-CC Vartin Lescon .efebvre	2014 2015 2017 2017 2017 2017 2017 2011 2013 2013 2014 2014	CAN CAN AUS CAN CAN CAN CAN CAN	: BC : Western Australia : Northern Alberta : BC : Northern Alberta : BC : Northern Alberta	Perinatal		** * ** ** **						
Ka'opua Duran Gunther Samji Puskas Wang Gilles Martin ART-CC Martin Cescon Lefebvre Benoit (a)	2014 2015 2017 2017 2017 2017 2011 2013 2013 2014 2014 2014 2017	CAN CAN AUS CAN CAN CAN CAN CAN CAN	I: BC I: BC I: Western Australia I: Northern Alberta I: Northern Alberta I: Northern Alberta I: Northern Alberta	Perinatal	*	** * * ** ** ** ** ** **						

Figure 3.4: Overview of available evidence of Indigenous peoples' experiences along the HIV cascade of care

 10 ML
 35
 10 ML
 20 ML
 21 ML
 21

Overall, the 93 included articles involved approximately⁷ 52,000 Indigenous participants in 70 studies (Table 3.2). In total, 14 (15.1%) were qualitative, 72 (77.4%) quantitative, and 7 (7.5%) mixed methods. By country, 12 (12.9%) involved data from Australia, 52 (55.9%) from Canada, 3 (3.2%) from New Zealand, and 26 (28.0%) from the United States. Additional characteristics of included studies can be found in Table 3.2.

Characteristic	N (%) of articles
Overview	
Total articles	93
Total studies	70
Indigenous people represented	Approx. 52,000 ⁷
Country	
Australia	12 (12.9%)
Canada	52 (55.9%)
New Zealand	3 (3.2%)
United States	26 (28.0%)
Study approach	
Qualitative	14 (15.1%)
Quantitative	72 (77.4%)
Mixed methods	7 (7.5%)
HIV cascade of care stage	
Testing & diagnosis	50 (53.8%)
Linkage to care	14 (15.1%)
Retention in care	20 (21.5%)
ART initiation	21 (22.6%)
ART adherence	23 (24.7%)
Viral suppression	24 (25.8%)
Key populations*	
Women	10 (10.8%)
Perinatal women	4 (4.3%)
Men	5 (5.4%)
Men who have sex with men	3 (3.3%)
Trans people	1 (1.1%)
People involved in substance use	8 (8.6%)
Young people	7 (7.5%)
Rural	2 (2.2%)
People with co-morbidities	4 (4.3%)
Quality assessment	
Research done in a 'good way'	48 (51.6%)

Table 3.2: Summary of characteristics of all included studies

*Note: Most articles included general samples of Indigenous people. Some (n=37) focused on a key sub-population of Indigenous people

3.3.2 Overarching determinants of engagement in the HIV care cascade

Several overarching determinants of engagement in the HIV care cascade among Indigenous peoples emerged from the 21 studies presenting qualitative data, each of which applies to the

⁷ We have attempted to avoid counting participants twice by adjusting for multiple articles published by the same study. However, it may be that some participants are represented in more than one study.

cascade of care as a whole or to multiple stages (Figure 3.5). The determinants identified were interconnected. Some helped promote engagement in care, while others hindered it.

Figure 3.5: Overarching determinants of engagement in the HIV care cascade identified in articles involving qualitative data (n=21)

 Hinder engagement 4. Historical, intergenerational, and lifetime trauma 5. Stigma and discrimination 	Promo 1. 2. 3.	ote engagement Indigenous culture, identity, and ceremony Strength, resilience and determination Social support systems – a circle of care
6. Intersecting health concerns	Hinde 4. 5. 6.	r engagement Historical, intergenerational, and lifetime trauma Stigma and discrimination Intersecting health concerns

Indigenous culture, identity, and ceremony. Indigenous identity was a source of strength and wellbeing identified by participants in the gualitative studies (Cain et al., 2013; McCall, Browne, & Reimer-Kirkham, 2009). Participation in the ceremonies and cultural activities of their nation was an important way to maintain health and wellness in the context of HIV for some Indigenous people living with HIV (IPHAs) (Ka'opua, 2001; Mill, 2000). For others, HIV diagnosis prompted learning more about Indigenous spirituality and traditional healing (Mill, Keenan, Lambert, Larkin, & Ward, 2008). Culture and ceremony were identified as especially helpful for the spiritual and emotional aspects of living with HIV, including coming to terms with diagnosis (Barlow et al., 2008; Ka'opua, 2001; Mill (c), Lambert, Larkin, Ward, & Harrowing, 2008). For example, a participant in Ka'opua's study among Native Hawaiian people living with HIV described participating in *ho'oponopono*, a relational wellness ceremony convened by her family to ease her stress and depression related to living with HIV (Ka'opua, 2001). Many IPHAs sought to integrate traditional wellness practices alongside mainstream services. Care providers who supported this approach were valued (Bucharski, Reutter, & Ogilvie, 2006; Chongo, Lavoie, Hoffman, & Shubair, 2011; Reading, Brennan, & Masching, 2013). However, the enduring legacy of spiritual abuse stemming from colonization, such as that which took place in Canada's residential school system, could be a barrier to engagement with Indigenous cultural practices and ceremonies (Cain et al., 2013; Ka'opua, 2001; TRC, 2015a, p. 278). In addition, some IPHAs reported that they felt cultural wellness practices were sidelined in relation to the dominance of the mainstream biomedical model in care settings (Reading et al., 2013).

Strength, resilience, and determination. Resilience and determination despite adversities emerged as important contributors to engagement in HIV care, as well as health and wellbeing overall. Choosing to fight HIV was a deliberate decision made by a number of IPHAs involved in these qualitative studies (Cain et al., 2013; McCall et al., 2009). Responsibility for caring for their children and families was also a powerful motivator to seek care, as well as a source of strength and self-worth (Ka'opua, 2001; Mill, 2000; Reading et al., 2013; Thompson et al., 2009). For example, Ka'opua et al.'s interviews with six Native Hawaiians living with HIV revealed that being well enough to fulfil *kuleana* (responsibilities), such as taking care of an extended family member, was a major reason to manage health (Ka'opua, 2001; McCall et al., 2009). Other studies revealed that involvement in the HIV community, such as through volunteering, activism, or peer support, contributed to an individual's own wellbeing and sense of self, which in turn contributed to their participation in HIV care (McCall et al., 2009; Mill (c) et al., 2008; Reading et al., 2013). Taken together, this suggests that engagement in HIV care is likely to be enhanced if it includes assessing and building from IPHAs strengths, rather than areas of weakness.

Social support systems - a circle of care. Another overarching theme was the critical importance of having other people in life to help navigate the challenges and complexities of living with HIV and the demands of sustained engagement in care. As one of Mill et al.'s participants explained, "I can't deal with this alone" (Mill et al., 2008). Included articles identified and described different types of social support systems. Family members (especially partners) were identified as providing tangible (e.g., cooking, medication reminders), affirmational (e.g., reason to keep going, love and affection), and spiritual (e.g., facilitating access to traditional healing) support (Reading et al., 2013). Friends and peers (with HIV) often played an important role in IPHA support systems (Barlow et al., 2008; McCall et al., 2009; Mill (c) et al., 2008; Mill et al., 2008; Reading et al., 2013; Sazegar, Tu, Littlejohn, & Myran, 2013). Professionals, including healthcare providers, social workers, and the organizations they work for, were also within IPHA support systems. Support systems were often reciprocal, with IPHAs having valued and meaningful responsibilities to fill within these relationships (Mill et al., 2008). Further, human connectedness and sense of belonging had intrinsic value that contributed to health and wellbeing (Reading et al., 2013). In this way, participation in these relationships was an important part of self-worth and identity for IPHAs. The current iteration of the cascade of care framework focuses on the individual; however, given the importance of support systems to sustained engagement in care, clinicians must recognize and support strong circles of care.
Historical, intergenerational, and lifetime trauma. Included studies highlighted the ways Indigenous life in Australia, Canada, New Zealand, and the United States were forcibly disrupted by the arrival of settlers and establishment of colonial states. Trauma experiences continue to be fundamental determinants of HIV infection among Indigenous peoples (Barlow, 2003; Negin et al., 2015). Historical, intergenerational, and lifetime trauma experiences may also be a barrier to engagement in HIV care and treatment through a number of pathways. Experiences included: grief and loss (Cain et al., 2013; Reading et al., 2013); childhood sexual abuse (Barlow et al., 2008; Bucharski et al., 2006; McCall & Lauridsen-Hoegh, 2014b; Mill (c) et al., 2008; Mill et al., 2011; Thompson et al., 2009); domestic violence (Bucharski et al., 2006; McCall et al., 2009); spiritual, cultural, and community disconnection (Ka'opua, 2001; Reading et al., 2013); forced removal from parents into residential schools or the child welfare system (Bucharski et al., 2006; McCall & Lauridsen-Hoegh, 2014b; Nowgesic, Meili, Stack, & Myers, 2015; Reading et al., 2013); and poverty (Duran et al., 2010; McCall et al., 2009). Acknowledging historical trauma and ongoing systemic oppression has been recognized as a critical element of successful health services for Indigenous peoples (Barlow et al., 2008; Bucharski et al., 2006; Reading et al., 2013). Further, supporting IPHAs to heal from trauma may be an important way to facilitate sustained engagement in the HIV cascade of care.

Articles identified several possible pathways through which trauma may affect engagement in care. First, experiences of trauma may contribute to a lack of self-worth and increased hopelessness, which may affect IPHAs interest or ability to consistently engage in care (Bucharski et al., 2006; Chongo et al., 2011). Disconnection and dislocation from community and identity has a powerful impact on self-worth (Ka'opua, 2001). Grief and witnessing the death of loved ones and others may further contribute to hopelessness (Cain et al., 2013). Second, some IPHAs cope with the pain and stress of these traumas through substance use, which emerged as a major proximal barrier to HIV care and treatment in the included studies (Bucharski et al., 2006; Cain et al., 2013; Chongo et al., 2011; Nowgesic et al., 2015; Thompson et al., 2009). For example, Ka'opua reported that one participant in her study described feeling *kaumaha*, a "profound heaviness associated with dislocation from family," and desire to numb this feeling contributed to continued substance use (Ka'opua, 2001). Third, several IPHAs reported feeling distrustful of healthcare and/or healthcare providers which may reflect having experienced or witnessed harms perpetrated within the context of healthcare (e.g. medical experimentation, isolation, racism) (Allan & Smylie, 2015; Bucharski et al., 2006;

90

Geddes, 2017; Lux, 2016; Mosby, 2013). Finally, trauma experiences may also exacerbate negative social determinants of health, resulting in further marginalization from engagement in HIV care and services (McCall et al., 2009).

Stigma and discrimination. Participants reported both fear and experiences of discrimination by healthcare providers, family, friends, and community (McCall et al., 2009; Nowgesic et al., 2015). These experiences reflected multiple layers and intersections related to race, substance use, sexual or gender identity, and spirituality, as well as HIV (Barlow et al., 2008; Cain et al., 2013; Masching et al., 2014; Nowgesic et al., 2015; Reading et al., 2013). Fear of discrimination led some IPHAs to avoid accessing services (Bucharski et al., 2006). Other IPHAs undertook strategies to avoid these negative feelings, including seeking Indigenousspecific, gender-specific, or HIV-specific services (Bucharski et al., 2006; Burks, Robbins, & Durtschi, 2011; McCall et al., 2009). However, these were not always available, especially for those living in small communities and remote areas. Internalized stigma also played a role in determining engagement in care (McCall et al., 2009).

Intersecting health concerns. A diverse set of wellness priorities – including but not limited to HIV health and wellbeing – were identified. Intersections of trauma, substance use, mental health, and HIV were important reoccurring themes. Substance use (e.g., alcohol, illicit drugs) and mental health issues (e.g., depression, post-traumatic stress) were understood simultaneously as risk factors for HIV acquisition, consequences of HIV diagnosis, and barriers to engagement in HIV care (Cain et al., 2013; Chongo et al., 2011; Masching et al., 2014; McCall et al., 2009; Mill (a) et al., 2008; Nowgesic et al., 2015). As a result, supporting IPHAs to engage in care requires a wholistic⁸ approach that addresses intersecting health needs and wellness priorities. IPHAs continue to demand care and services that address the many factors impacting their lives in addition to HIV infection (Newman et al., 2007; Prentice et al., 2011; Sazegar et al., 2013). Of note, HIV was described as both a physical and emotional disease by participants in several studies (Cain et al., 2013; Ka'opua, 2001; McCall et al., 2009; Mill (c) et al., 2008; Sazegar et al., 2013). Yet, the cascade of care framework focuses only on the physical aspects of HIV and does not explicitly address these emotional consequences which have tremendous implications for linkage, retention, and adherence.

⁸ This spelling is explicit as it implies "whole" instead of "hole" (deficit focused), as recommended by Mi'kmaq Elder Murdena Marshall (Marshall et al., 2015).

3.3.3 Testing & diagnosis

Screening is essential for early detection, treatment, and prevention of HIV infection (Ha et al., 2014). Testing and diagnosis was the most well studied step in the HIV care cascade, involving 50 articles.

Experiences of testing & diagnosis

Fourteen articles provided qualitative insight into Indigenous people's experiences of HIV testing, with the majority coming from Canada (n=11). Unlike the quantitative literature which focused only on the testing event, these articles also focused on experiences of diagnosis. Fear of testing positive was a reoccurring theme and was a reason some Indigenous people chose to avoid or delay testing (Bucharski et al., 2006; Mill (a) et al., 2008; Mill et al., 2011). This was linked to the ongoing perception that HIV is a "death sentence", as well as fear of being discriminated against by family, friends, and community (Cain et al., 2013; Mill (c) et al., 2008; Reading et al., 2013).

Articles identified reasons Indigenous people choose to seek testing, including: having participated in behaviours that could result in HIV transmission (Bucharski et al., 2006; Mill (a) et al., 2008; Mill (c) et al., 2008; Mill et al., 2011); having HIV symptoms (Mill (c) et al., 2008; Prentice et al., 2011); part of regular screening (Mill et al., 2011); or at the beginning of a new relationship (Mill et al., 2011). Testing or diagnosis in the context of care for other health concerns was also common, including perinatal care (Bucharski et al., 2006; Mill (a) et al., 2008; Mill (c) et al., 2008; Mill et al., 2011) and substance use treatment (Thompson et al., 2009). Testing took place in a number of settings, including with a physician, in a hospital, in a community or public health centre, or in an STI clinic (Bucharski et al., 2006; Mill (a) et al., 2008). However, inconvenient hours and/or location of testing sites remained an obstacle to testing (Burks et al., 2011; Mill (a) et al., 2008).

Distrust of healthcare providers and institutional discrimination in healthcare were identified as formidable barriers to testing (Bucharski et al., 2006). These barriers were rooted in the ongoing impact of colonization. For example, among women in Northern Alberta, fear that testing positive would result in their children being apprehended was a powerful impediment to testing (Bucharski et al., 2006). Indigenous youth living with HIV from across Canada reported delaying testing until they began to have symptoms, which suggests a reluctance to engage with the healthcare system (Mill (c) et al., 2008; Prentice et al., 2011). Confidentiality concerns,

including fear of disclosure and lack of anonymity in small communities, were a barrier to testing in a number of studies (Bucharski et al., 2006; Mill (c) et al., 2008; Mill et al., 2011). In response, some participants chose to be tested outside of their community (Mill (a) et al., 2008). Linked to confidentiality concerns was fear of discrimination and judgement by healthcare providers in the context of testing (Bucharski et al., 2006; Mill et al., 2011). In two studies, IPHAs shared that being asked personal questions about behaviours that could result in HIV transmission during testing was perceived as shaming and judgmental (Bucharski et al., 2006; Mill (c) et al., 2008). Focusing on behaviour was seen to reflect a lack of understanding of life experiences, and participants preferred to focus on the present and future, rather than digging into past actions (Bucharski et al., 2006). Healthcare providers in Reading et al.'s 2013 study reported that Indigenous women in particular were more likely to be asked personal questions, for example about sexual activity, compared to non-Indigenous women, and this reflected racist attitudes (Reading et al., 2013). In contrast, testers who were nurturing, supportive, and took their time were valued (Mill (c) et al., 2008). Additional barriers to testing were low perceived risk (Mill (a) et al., 2008; Mill et al., 2011) and feeling invulnerable (Mill et al., 2011).

While testing may appear to be a discrete, highly defined step on the HIV care cascade, qualitative research suggests that coming to terms with diagnosis is a process that may affect both health and healthcare engagement. Participants described an emotional response to diagnosis, including shock, anger, fear, denial, and shame (Cain et al., 2013; Mill (c) et al., 2008; Mill, 2000; Thompson et al., 2009). Four studies proposed frameworks for understanding the process of coming to terms with diagnosis. Thompson et al.'s study involving 20 Indigenous people living with HIV in Western Australia suggested that immediately after diagnosis there may be a spike in behaviours like substance use as IPHAs try to avoid and escape this new reality; however, this was often followed by a "slowing down" of substance use as participants came to terms with their diagnosis and focused on their health (Thompson et al., 2009). Sazegar et al. developed a similar understanding in their interviews with IPHAs in Vancouver. Canada, describing three stages of post-diagnosis coping: shock and loss; scared and alone; and acceptance and healing (Sazegar et al., 2013). Mill et al.'s study among 8 Indigenous women living with HIV in Northern Alberta, Canada portrayed a "downward spiral" in reaction to diagnosis that lasted from six months to three years, before participants came to a "turning point" towards positive living (Mill, 2000). Again, in a study among 31 IPHAs in Alberta, Mill et al. described a cycle which may take several years: receiving the diagnosis; adapting to the diagnosis; accepting the diagnosis; and ongoing challenges (Mill (c) et al., 2008). For many

participants across studies and countries, the coping phase included escalation of substance use for numbing and a temporary escape (Cain et al., 2013; Ka'opua, 2001; Mill (c) et al., 2008; Thompson et al., 2009); self-imposed isolation from others (Cain et al., 2013; Mill (c) et al., 2008); as well as hopelessness and suicidal ideation (Cain et al., 2013; Mill (a) et al., 2008; Mill (c) et al., 2008). Despite the difficulty of the diagnosis, HIV could be a turning point for IPHAs during which they actively made a decision "to live" and stay healthy (Cain et al., 2013; Mill (c) et al., 2008; Mill, 2000). This transition could involve seeking out alternate coping strategies such as support from others (Mill et al., 2008; Sazegar et al., 2013; Thompson et al., 2009) and participation in Indigenous cultural practices and spirituality (Barlow et al., 2008; Mill (c) et al., 2008; Mill, 2000).

Epidemiology of testing

Thirty-eight articles provided quantitative data on HIV testing among Indigenous peoples. They included diverse measures of testing, including proportion of people: ever tested (n=15), tested in the past year (n=10), tested in the context of care for another health concern (n=7), with late diagnosis (n=3), and others.

Thirteen studies with complete data reporting the proportion of Indigenous people who had ever received testing are summarized in Figure 3.6. The proportion of those ever tested for HIV appears relatively steady over time in general and in youth populations, at approximately 50%. Studies with trans people, men who have sex with men, and people who use drugs, report higher proportions of those ever having been tested for HIV in recent years.



Figure 3.6: Studies reporting proportion of Indigenous people who had ever received

Note: Plots are not comprehensive but represent an overview of the most frequently occurring measure for this stage. Each bubble represents one study. Bubble size represents sample size. Color indicates study country. Key populations are indicated with tags. If none is identified, the study involved a more general population.

We identified varied results across studies that compared likelihood of HIV testing among Indigenous and non-Indigenous people. Six studies suggested that Indigenous people are more likely to be tested for HIV, compared to non-Indigenous people (Barnes, Adams, & Powell-Griner, 2010; Bauer, Travers, Scanlon, & Coleman, 2012; Denny, Holtzman, & Cobb. 2003; Ford, Godette, Mulatu, & Gaines, 2015; Kwan, Giele, Combs, & Mak, 2012; Sawleshwarkar, Harrison, Britt, & Mindel, 2011). Three others observed no differences in likelihood of testing between Indigenous and non-Indigenous participants (Mak, Murray, & Bulsara, 2003; Paquette, McEwan, & Bryant, 2013; Plitt et al., 2009), including two that were in specific settings: remote antenatal care (Mak et al., 2003) and a pharmacy-based needle exchange program (Paquette et al., 2013). Just one - a New Zealand study from the early 1990s – observed lower odds of testing among Maori participants compared to others (Connor, Paul, Sharples, & Dickson, 1997).

Testing & diagnosis summary

High proportions and odds of testing among Indigenous people identified in this review may reflect the perception that Indigenous people are 'at risk' and are therefore tested more often than non-Indigenous people.

Reviewing both qualitative and quantitative approaches to understanding testing and diagnosis among Indigenous people reveals that, from a clinical perspective, testing and diagnosis may

be important but circumscribed events. In contrast, from the perspective of IPHAs, testing and diagnosis, especially in the case of a positive diagnosis, is a process that does not begin or end with the testing or diagnosis event. Appropriate supports are required to ensure that the healthcare system does not fail to keep IPHAs engaged during this transition period. For example, it is paramount that HIV diagnosis is followed up with access to culturally-safe HIV care.

3.3.4 Linkage to care

Delays in accessing care after an HIV diagnosis may increase the risk of disease progression and transmission (Cohen et al., 2011). Current guidelines recommend that those who test positive be immediately linked to care (International Advisory Panel on HIV Care Continuum Optimization, 2015). Yet, just 11 articles examined linkage to HIV care among Indigenous people.

Experiences of linkage to care

Very limited qualitative data are available on linkage to care. We identified just four qualitative articles (all Canadian) that addressed this cascade stage. The emerging theme across these studies was that the challenges of post-diagnosis coping delay linkage to care (Mill (c) et al., 2008; Mill, 2000; Sazegar et al., 2013; Thompson et al., 2009). For example, Indigenous youth living with HIV in Canada reported that time to care after diagnosis ranged from a few months to seven years, with some waiting until they were very sick to access care (Mill (a) et al., 2008; Prentice et al., 2011). Fear, hopelessness, avoidance, misperceptions of care, substance use, and challenges accessing care in smaller communities underpinned delays accessing care across studies (McCall et al., 2009; Mill (a) et al., 2008; Prentice et al., 2011; Sazegar et al., 2013). Clinical recommendations for immediate linkage to care coincide with a stressful period in IPHAs lives which may include approaches to coping (e.g., substance use, isolation, hopelessness, denial) that are in opposition to care seeking. Sazegar et al. suggested that, until IPHAs reach a stage of acceptance and healing post-diagnosis, they may not be ready to engage in care (including self-care) (Sazegar et al., 2013).

Epidemiology of linkage to care

Eight quantitative studies reported on linkage to care. Indicators of linkage to care included: proportion of IPHAs presenting late to care (n=3); receiving a blood test within a specified time period post diagnosis (n=2); median time to care (n=1); and self-reported access to HIV care

(n=1). While the diversity of measures limits comparisons across studies, evidence suggests that high proportions of Indigenous people have never accessed care (Kronfli et al., 2017; Prentice et al., 2011) or have delayed access (Connel, Stroup, Stephens, & Martin, 2014; Diamond, Davidson, Sorvillo, & Buskin, 2001; Dickson, McAllister, Sharples, & Paul, 2012; Kronfli et al., 2017; Plitt et al., 2009). Three studies that examined the proportion of IPHAs presenting late to care reported that between 24-46% of IPHAs enter care when they are already seriously ill (Connel et al., 2014; Diamond et al., 2001; Dickson et al., 2012). Studies that compared Indigenous and non-Indigenous participants observed mixed results. However, more studies found increased risk of delays among Indigenous people (Dickson et al., 2012; Kronfli et al., 2017; Plitt et al., 2009) than found decreased risk of delays (Diamond et al., 2001).

Linkage to care summary

A paucity of evidence, inconsistency of measures, and mixed results overall suggest that linkage to care is an important area for future study to ensure that Indigenous people living with HIV are receiving timely care after diagnosis. Overall, findings suggest that supporting IPHAs to move through the difficult process of coming to terms with HIV diagnosis is an important aspect of enhancing engagement in the cascade of care. Recommended by Sazegar et al., a "first response strategy" involving physicians, counsellors, and peer support in the period immediately after diagnosis may help mitigate coping responses that can be an obstacle to linking to care (Sazegar et al., 2013). Further, among youth, encouragement and support from family, friends, and professionals may be critical to initiating care and traditional healing practices post-diagnosis (Prentice et al., 2011). Clinical care must take into account the power of social support, as well as challenges of coming to terms with a positive HIV diagnosis, when developing strategies and programs to enhance linkage to care among IPHAs.

3.3.5 Retention in care

Until a cure for HIV is available, staying well and reducing transmission while living with HIV demands lifelong engagement with health services (Gardner et al., 2011). We identified 16 studies that provided insight into retention in HIV care among Indigenous peoples.

Experiences of retention in care

Attending clinic appointments and participating in laboratory monitoring for CD4 counts and viral load (indicators of retention in care) were just two of many actions IPHAs took to stay healthy; other care strategies include reducing substance use, accessing traditional healing,

and maintaining health through diet, sleep, and exercise (Prentice et al., 2011; Sazegar et al., 2013). Some participants were keen to know the results of laboratory monitoring, but emphasized the need for clinicians to occasionally revisit the meaning and implications of these counts (Sazegar et al., 2013). Others avoided appointments and lab testing for fear of what they would reveal: "I know I was supposed to take another blood test six months ago but I didn't. I've been holding back and holding it off because I am scared...I don't want to find out more than I know" (Mill, 2000).

How HIV care services were delivered played an important role in retention in care. Overall, being able to trust the care provider was essential (Reading et al., 2013). Fear of discrimination from healthcare providers was a powerful deterrent, especially for IPHAs who had previous experience of discrimination in institutional settings (Chongo et al., 2011; McCall et al., 2009). IPHAs reported that specialized services for people with HIV could be higher quality and participants could feel less judgement in these settings (McCall et al., 2009). Some described positive experiences with a team approach to care which involved accessible support from a doctor, nurse, and social worker (Mill et al., 2008). In contrast, lack of specialized services in non-urban areas could contribute to experiences with healthcare providers who were misinformed, judgmental, or unfamiliar with providing HIV care (McCall et al., 2009; Mill et al., 2008). Accessibility of care was also an important factor, as concerns were identified about limited hours, long wait times, and distance of care from home (McCall et al., 2009). Some IPHAs, especially in small communities, reported that attending HIV health services had resulted in unwanted disclosure of their HIV status; others were concerned about the potential for disclosure if they were seen accessing care (McCall et al., 2009; Newman et al., 2007). One study briefly mentioned continuity as beneficial in relationships with healthcare providers; this warrants more attention in future research related to the HIV cascade of care among Indigenous people (Mill et al., 2008).

Other aspects of life also influenced retention in care. As mentioned previously, IPHAs often face a diverse set of health challenges and wellness priorities, which may enhance or diminish retention in care. Sazegar et al.'s study among people living with HIV (50% of whom were Indigenous) in Vancouver, Canada, included asking participants to identify and rank HIV-related health priorities. Drug addiction, mental illness, and unresolved trauma topped the list, with access to doctors and nurses ranking 28th of 29 priorities (Sazegar et al., 2013). Five studies reported that periods of active substance use made regularly attending care a

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challenge (Masching et al., 2014; McCall et al., 2009; McCall & Lauridsen-Hoegh, 2014b; Mill et al., 2008; Sazegar et al., 2013). McCall et al. found that among eight female IPHAs, those experiencing addiction reported that attention to substance use was their primary concern and HIV care was a lower priority (McCall et al., 2009). Navigating domestic violence and meeting basic needs (e.g., housing, food) in the face of poverty were two other competing priorities next to HIV care (McCall et al., 2009). Being pregnant was a motivator for women to attend clinic appointments and participate in regular laboratory monitoring to ensure the health of their child (Prentice et al., 2011).

Epidemiology of retention in care

Ten quantitative studies were related to retention in care. However, lack of consistency in measurement made it difficult to compare across studies. Laboratory monitoring (n=6), clinic visits (n=2), self-reported retention (n=1), and missed appointments (n=1) were all used to measure retention in care. Three recent studies measuring proportion of IPHAs who had at least two lab tests at least three months apart within a one-year period identified that 34.9-58.9% of IPHA were retained in care, according to this definition (Mitsch, Babu, Seneca, Whiteside, & Warne, 2017; Nwangwu-Ike, Hernandez, An, Huang, & Hall, 2015; Rachlis et al., 2017). Several studies included comparisons between Indigenous and non-Indigenous people. All but one (Kronfli et al., 2017) observed worse retention in care outcomes for IPHAs, compared to those of other ethnicities (Diamond et al., 2001; Martin, Houston, Yasui, Wild, & Saunders, 2010; Nwangwu-Ike et al., 2015; Rachlis et al., 2017; Templeton et al., 2015).

Retention in care summary

These findings highlight the need for wholistic approaches to retention in care. The qualitative articles in this review demonstrate that retention in care is about a sustained relationship or partnership between an IPHA and a team of care providers over a lifetime. In contrast, the quantitative articles suggest that retention in care is primarily about laboratory monitoring, a key clinical priority. To strengthen care partnerships as a way of improving retention in care, the pressing health and wellness priorities of IPHAs must not be sidelined.

Further, there is a lack of consensus on the best way to understand and measure retention in care. Existing data are insufficient to determine whether Indigenous people living with HIV are adequately retained in care. The qualitative literature demonstrates that trusting, respectful, culturally-safe relationships with care providers are imperative to sustained engagement in HIV

care. We must improve measures and data collection related to retention in care to understand the extent to which IPHAs remain engaged in HIV care over the long term.

3.3.6 ART initiation

Mounting evidence supports early or immediate initiation of ART for all people living with HIV, regardless of CD4+ count (Grinsztejn et al., 2014; INSIGHT START Study Group, 2015). However, supporting all people living with HIV to begin treatment remains a challenge globally (UNAIDS, 2014b). Twenty-two studies examined ART initiation among Indigenous peoples.

Experiences of ART initiation

Participants who initiated ART noticed positive changes in their lives, including increased energy, better appetite, and affirming improvements in CD4 and viral load levels (Sazegar et al., 2013). Incentives to initiate treatment included pregnancy (Mill, 2000; Newman et al., 2007; Prentice et al., 2011); feeling sick (Mill, 2000); or clinical indications/advice (Prentice et al., 2011). However, others decided not to initiate medication despite experiencing HIV-related symptoms and illnesses (McCall et al., 2009).

Seven studies reported on experiences of ART initiation and identified a number of reasons that IPHAs choose not to begin medication, including feeling healthy or not having been told by a physician to begin ART (Prentice et al., 2011). Some IPHAs did not have confidence in the efficacy of ART, were concerned about side effects, believed that ART was not good for them, or did not perceive HIV as a treatable illness (Grierson et al., 2004; McCall et al., 2009; Mill, 2000; Prentice et al., 2011). For others, taking ART was a constant unwanted reminder of their HIV status (McCall et al., 2009) or a trigger related to a history of substance use (Mill, 2000). Another concern was the potential for disclosure of HIV status to family, friends, or colleagues if medications were noticed (Newman et al., 2007). In addition, two studies shared that some female IPHAs articulated a sense of hopelessness or internalized shame that prevented treatment initiation (McCall et al., 2009; Mill, 2000). Of note, no articles reported lack of access to ART, including financial barriers, as a reason for not initiating ART (Newman et al., 2007).

Epidemiology of ART initiation

Sixteen studies described the epidemiology of ART initiation. Main quantitative measures of ART initiation included ever having been on ART (n=7) or currently being on ART (n=11). Seven studies reported proportions of Indigenous people <u>ever</u> receiving ART, with the lowest

proportion (54.4%) among IPHAs who died in BC, Canada between 1995-2001 (Wood et al., 2003), and the highest (72.0%) among Maori people living with HIV in 2001-2002 (Grierson et al., 2004). In addition, 11 studies reported proportions of IPHAs <u>currently</u> on ART, with the lowest proportion (29.2%) reported among IPHAs who use drugs between 1996-2003 in Vancouver, Canada (Wood et al., 2006), and the highest proportion (94%) among IPHAs who use drugs in Vancouver in 2014 (Milloy et al., 2016). Those with complete data are presented in Figure 3.7, which suggests improvements in ART initiation over time.



Figure 3.7: Studies reporting proportion of Indigenous people on ART (n=8)

Note: Plots are not comprehensive but represent an overview of the most frequently occurring measure for this stage. Each bubble represents one study. Bubble size represents sample size. Color indicates study country. Key populations are indicated with tags. If none is identified, the study involved a more general population.

In terms of comparisons with other cultural groups, two older Canadian studies demonstrated differences between Indigenous and non-Indigenous people in terms of ART initiation (Wood et al., 2006; Wood et al., 2003); however two more recent studies in Toronto (Jaworsky et al., 2016) and Vancouver (Milloy et al., 2016) indicated no differences. These findings hint that that the gap between Indigenous and non-Indigenous people on ART may have declined in recent years.

ART initiation summary

Clinical guidelines for treatment initiation center around CD4 count thresholds; however, evidence from the qualitative studies in this review suggest that IPHAs arrive at "readiness" for medication only when they have reached a point of acceptance of their HIV diagnosis (Sazegar et al., 2013). "Readiness" may involve a transition from hopelessness in the period immediately after diagnosis, to a desire "to stay healthy and alive" (Prentice et al., 2011). This process is challenging and may take several months or even several years. Again, the clinical underpinnings of the cascade of care framework do not reflect the lived realities of IPHAs. Clearly, there is an opportunity to bridge these two understandings of ART "readiness" so IPHAs and providers can work in tandem towards timely ART initiation.

Measurement of ART initiation is relatively homogenous compared to other cascade stages. However, as in other stages, the available data is fragmented. Australia is the only country for which recent population-level national estimates of ART initiation among IPHAs are available (Templeton et al., 2015). Lack of this vital data limits our ability to draw conclusions and measure progress in meeting treatment targets among Indigenous people living with HIV.

3.3.7 ART adherence

Once initiated on ART, people living with HIV must continue treatment for life without interruption in order to achieve sustained viral suppression, prevent illness, and avoid resistance (Nachega et al., 2007). Overall, 23 of the studies focused on ART adherence.

Experiences of ART adherence

Qualitative studies illustrated that adherence to ART is not simply a matter of taking or not taking medications each day, but rather about balancing management of health and wellbeing with other responsibilities and challenges. Staying healthy and surviving for themselves, as well as for their children and loved ones, were reasons IPHAs chose to keep taking ART (Ka'opua, 2001; McCall et al., 2009; Prentice et al., 2011). However, substance use (Chongo et al., 2011; Ka'opua, 2001; McCall & Lauridsen-Hoegh, 2014b; Newman et al., 2007; Nowgesic et al., 2015; Prentice et al., 2011; Thompson et al., 2009); homelessness (McCall et al., 2009); food insecurity (Chongo et al., 2011; McCall et al., 2009); mental health issues (Chongo et al., 2011); and lack of self-worth (Chongo et al., 2011; Ka'opua, 2001), all contributed to making adherence more difficult. IPHAs also reported that ART adherence was easier when they also received support with other challenges in their lives, such as trauma, mental health, substance use, and poverty (Chongo et al., 2011; Duran et al., 2010; Newman et al., 2007). Some chose to stop or reduce drug use, sometimes with the support of opioid substitution therapies, to enhance their adherence (Chongo et al., 2011; Thompson et al., 2009). For others, attention to their spiritual health, including participation in cultural practices and ceremonies, contributed to better adherence (Barlow et al., 2008; Chongo et al., 2011; Ka'opua, 2001; Reading et al., 2013).

Together, these barriers and facilitators to adherence can result in IPHAs having "good days and bad days" (Ka'opua, 2001). For most, adherence was not an all or nothing situation, but rather some IPHAs experienced intermittent treatment interruptions as a result of illness or, for some, periods of high intensity substance use (Ka'opua, 2001). Feeling sick, whether it was a result of side effects or HIV symptoms, sometimes resulted in treatment interruptions (Ka'opua, 2001; Mill, 2000) or a decision to stop treatment altogether (Chongo et al., 2011; Ka'opua, 2001; Thompson et al., 2009). In one study, women reported discontinuing treatment after giving birth as their counts were good, or because they had found the treatment regimens frustrating or difficult (Newman et al., 2007).

Social support was identified as being vital to ART adherence, including resuming treatment after an interruption (Chongo et al., 2011; Ka'opua, 2001). Ka'opua reported that among six Native Hawaiians living with HIV, intimate partners provided a variety of supports that enhanced adherence, especially on "bad days" (Ka'opua, 2001). These supportive actions included ensuring IPHAs took their medications, preparing meals, and taking care of other family responsibilities so that IPHAs could focus on their health (Ka'opua, 2001). Partners provided affection, helped reduce feelings of isolation, and provided or supported access to traditional healing (Ka'opua, 2001). These actions served to re-inforce participants' commitment to medication adherence. As one participant explained, when her partner provided this support, "I feel like someone's really there on my side and it encourages me to be good" (Ka'opua, 2001). Other IPHAs noted that support from outreach workers who helped participants take their medications were also important for maintaining adherence (Chongo et al., 2011).

Epidemiology of ART adherence

Thirteen quantitative studies addressed ART adherence. Again, inconsistency in how adherence is measured prevented comparisons across studies. Measurements included pharmacy refill (n=4); treatment interruption (n=3); doses taken (n=4); or other (n=2). Three Canadian studies reported large proportions of treatment interruptions among IPHAs, ranging from 21.8% to 60.4% (Samji, Chen, Salters, Montaner, & Hogg, 2014; Samji et al., 2015; Wang et al., 2017). Another three Canadian studies reported greater than 95% adherence through linkage to pharmacy refill data, ranging from 32.8% among IPHAs who used drugs (Milloy et al., 2016) to 77.1% among male IPHAs with a history of injection drug use (Puskas et al., 2017). Among studies that compared IPHAs with non-Indigenous people, six reported no differences (Gunther, Foisy, Houston, Guirguis, & Hughes, 2014; Ka'opua & Mueller, 2004; Lima et al.,

2006; Milloy et al., 2016; Samji et al., 2014; Wood et al., 2003) and four reported higher nonadherence among IPHAs (Miller, Spittal, et al., 2006; Puskas et al., 2017; Samji et al., 2015; Wang et al., 2017). Interestingly, seven of these studies showing varied results involved cohorts of people living with HIV in BC, Canada. One large recent study capturing populationlevel data for all people living with HIV in BC between 1995 to 2015, involving 1022 IPHAs, observed higher treatment interruptions among Indigenous people compared to non-Indigenous people (Wang et al., 2017).

ART adherence summary

Adherence was measured in a variety of ways, including use of scales, self-reported adherence, treatment interruptions, and prescription refills. Even within measurements, significant variation in the data prevents us from reaching a conclusion about ART adherence among IPHAs. Researchers must bring measurement into alignment to improve consistency across studies.

Treatment interruptions emerged as a concern in both the quantitative and qualitative literature. One qualitative study identified a lack of understanding about how to deal with missed doses; for example, whether it was possible to "catch up" (Thompson et al., 2009). This may be an important area for discussion during clinic visits.

3.3.8 Viral suppression

Suppression of HIV viral replication to undetectable levels in the blood through sustained use of ART has been demonstrated to significantly reduce morbidity, mortality, and HIV transmission (Cohen et al., 2011; Lima et al., 2007; Montaner, Guillemi, & Harris, 2013). In total, 24 articles provided evidence related to viral suppression among IPHAs.

Experiences of viral suppression

Despite being a focus of many quantitative studies related to HIV care among Indigenous people, considerations of viral suppression appear in just two of the qualitative studies. A case study of one female IPHA in Vancouver indicated that the participant's viral load was detectable (McCall & Lauridsen-Hoegh, 2014b). Among 26 people living with HIV in inner-city Vancouver, 50% of whom were Indigenous, viral load was a low priority, ranking 23rd out of 29 HIV-related health priorities (Sazegar et al., 2013). Compared to non-Indigenous participants in this study, viral load was ranked significantly lower on IPHAs list of priorities (Sazegar et al., 2013).

Notably, apart from these two studies, the other 11 qualitative studies involving IPHAs included no discussion of viral suppression in the context of HIV health and wellbeing at all.

Epidemiology of viral suppression

Twenty-two articles presented findings related to viral suppression among Indigenous participants. Despite attention to viral suppression in the epidemiological literature, there is still no consistent measurement of this outcome. Articles included median (n=11), mean (n=2), and proportion suppressed (n=14). The latter, presented in Figure 3.8, included a variety of thresholds (i.e., <400, <200, and <50 copies/mL), which likely represents changes in testing and guidelines over the past 20 years. Proportion suppressed varied widely, from 17.9 to 86.0%. Two recent population-level studies among IPHAs living in the US which reported that 33.6% (Nwangwu-lke et al., 2015) of female IPHAs and 45.1% of all IPHAs (Mitsch et al., 2017) were suppressed are especially concerning.



Figure 3.8: Studies reporting proportion of IPHAs whose viral load was suppressed

Note: Plots are not comprehensive but represent an overview of the most frequently occurring measure for this stage. Each bubble represents one study. Bubble size represents sample size. Color indicates study country. Key populations are indicated with tags. If none is identified, the study involved a more general population.

Comparisons of viral suppression between Indigenous and non-Indigenous people yielded mixed results. Two studies observed lower median viral load among IPHAs compared to others (Antiretroviral Therapy Cohort Collaboration, 2013; Lima et al., 2006). Six studies indicated no differences in viral suppression related to Indigenous identity (Gilles et al., 2007; Jaworsky et al., 2016; Martin et al., 2011; Miller, Spittal, et al., 2006; Milloy et al., 2016; Templeton et al., 2015). Six studies identified worse viral suppression outcomes among IPHAs compared to non-Indigenous people living with HIV (Benoit (a) et al., 2017; Cescon et al., 2014; Erickson, Becker, Shaw, Kasper, & Keynan, 2015; Lefebvre, Hughes, Yasui, Saunders, & Houston, 2014; Martin

et al., 2010; Nwangwu-Ike et al., 2015). Notably, the three studies with the most Indigenous participants (\geq 497 each), two of which involved longitudinal data collected over more than 10 years, identified worse viral suppression outcomes among IPHA (Benoit (a) et al., 2017; Cescon et al., 2014; Nwangwu-Ike et al., 2015).

Viral suppression summary

Taken together, the strongest evidence available suggests that viral suppression targets have not yet been reached and that IPHAs may be experiencing disparities in this area compared to non-Indigenous people. This may reflect the apparent disconnect between clinical priorities as articulated within the HIV cascade of care, and the health and wellness priorities identified by IPHAs in the qualitative literature. It is important that clinical care is patient-led to ensure that all concerns of IPHAs are addressed, including those related to mental, physical, spiritual, and emotional health, and are not limited to viral suppression.

3.3.9 Quality assessment

Included studies were of varying quality. Of 93 studies, 48 (51.6%) took steps to incorporate Indigenous research standards outlined in the methods section above. The proportion of studies that used these approaches differed by type, including all of the mixed methods studies, 92.3% of the qualitative studies, and 38.9% of the quantitative studies. Ways study teams sought to do research in a good way included: (1) involvement of Indigenous scholars on study teams; (2) engagement of a community advisory board; (3) inclusion of ceremony and involvement of Elders in the research process; and (4) contextualization of both health and risk in terms of the underlying determinants of Indigenous health, including self-determination, Indigenous wellness practices, colonization, trauma, and discrimination. A few studies were reviewed by Indigenous research ethics boards (Duran et al., 2010; Gorgos, Avery, Bletzer, & Wilson, 2006; Paquette et al., 2013; Thompson et al., 2009; Williams et al., 2015)

One star was awarded if the study incorporated Indigenous research standards, and a possible four stars could be awarded related to epidemiological quality (Figure 3.4). One quantitative study achieved the highest level of quality both in terms epidemiological and Indigenous research standards with five stars (Miller & Torzillo, 1998) and five others were of very high quality with a total of four stars (Benoit (a) et al., 2017; Benoit (b) et al., 2017; Gorgos et al., 2006; Iralu et al., 2010; Orchard et al., 2010). Emerging examples of epidemiological studies that seek to meet both standards for quality provide a model for the work ahead.

3.4 Discussion

This review provides a comprehensive summation of peer-reviewed evidence related to epidemiology and experiences of the HIV care cascade among Indigenous peoples in Australia, Canada, New Zealand and the United States. Taken together, the findings affirm that significant gaps remain in achieving universal engagement in HIV care among Indigenous peoples. Evidence suggests that improving IPHAs linkage and retention in care must include policies to improve cultural safety in client-provider relationships and support healthy coping after an HIV diagnosis. Supporting ART initiation and adherence requires that clinicians provide culturally-safe, non-judgmental care that builds on IPHAs existing support systems and addresses other health and wellness concerns alongside HIV. Further, it is essential that social and structural barriers that continue to impede Indigenous peoples from engaging all along the HIV cascade of care, including stigma and racism, trauma experiences, and intersecting health concerns, are taken into account in healthcare settings.

Both qualitative and quantitative studies highlight a disconnect between the clinical priorities embedded in the HIV cascade of care framework, and experiences of IPHAs' HIV journey. For example, the framework conceptualizes HIV-related health within a biomedical paradigm, focused on achieving specific therapeutic outcomes. Although IPHAs may seek cascade-related services as a way of maintaining good health and prolonging life, these actions may not capture the full extent of their health-seeking behaviours (Paparini & Rhodes, 2016; Pawluch, Cain, & Gillett, 2000). Inclusion of social, spiritual, emotional, cognitive, and daily life outcomes would create a more culturally-inclusive framework within which to understand and support the engagement of Indigenous peoples in HIV-related care. Further, a critical consideration in moving forward includes recognition that the inherent willingness of the 90-90-90 approach to leave a tenth of the population living with HIV behind is incompatible with Indigenous worldviews that emphasize a wholistic and inclusive approach to health and wellness (Poitras, 2016). Finally, the model would benefit from a reshaping of its very linear process, to one that reflects prolonged or re-engagement in one or more phases of the cascade. This could be presented as a series of loops within and between each phase of the model.

Almost 100 articles that address HIV cascade of care outcomes among Indigenous peoples were identified over the course of this review. Yet, many of these studies lack sufficient Indigenous-specific context to support culturally relevant interpretation of the data. Given the distinct social drivers of HIV among Indigenous peoples globally (e.g. historical and intergenerational trauma as well as stigma and racism) care must be taken in interpreting data related to Indigenous people's prioritization of testing and treatment as well as their engagement in the cascade of care. Despite the volume of available data, results are mixed and do not paint a clear picture. Tremendous diversity within measures of cascade of care outcomes was observed across included studies. Standardizing measures for each phase of the cascade will create relevant benchmarks and improve our capacity to assess trends over time and place, vital for program and policy planning.

Many studies were excluded, as key findings were not disaggregated by Indigenous identity, meaning that disparities and unique experiences of Indigenous peoples may not be adequately captured. This might reflect attempts to avoid research that has been criticized for pathologizing Indigenous peoples by focusing on health disparities without adequate context. Indigenous-led analyses of population-level data, disaggregated by Indigenous identity are required to understand what proportion of Indigenous peoples are disengaging at each stage of the HIV care cascade.

3.4.1 Limitations

Indigenous peoples, identities, experiences, and cultures in Australia, Canada, New Zealand and the United States are diverse. As there is no single Indigenous culture or experience, it is important to avoid generalizations. This paper is one step towards conceptualizing an Indigenized cascade of care framework. It has omitted an essential area of evidence related to Indigenous people's experiences of the HIV cascade, specifically, oral knowledge and wisdom held by Elders and traditional knowledge keepers. Additional work must be done to incorporate these voices in conceptualizing the HIV care cascade through an Indigenous lens. We have deliberately sought out evidence representing diverse research approaches and paradigms. As a result, the heterogeneity of the studies included here prevented us from conducting a metaanalysis. Caution is required when comparing the results of various studies. Differences between countries may reflect different healthcare models that affect access to healthcare and medications. They may also reflect changes in treatment guidelines within countries and over time. We cannot discount that this review may be biased by selection of studies. It is probable that informative data related to Indigenous people's engagement in the HIV care cascade remain unpublished. As the authors are based in Canada, it is possible that this review is biased as a result of greater familiarity with Canadian research landscape, including related to

Indigenous research ethics and methodologies. Included data likely underestimate the total number of IPHAs, as some studies excluded those who identify with multiple categories or grouped Indigenous with non-Indigenous peoples into a single category (e.g., Asian/Pacific Islander).

3.4.2 Conclusion

In sum, with the HIV cascade of care framework increasingly becoming the focus of global, national, and local HIV agendas, it is critical that the contexts of Indigenous peoples' experiences of HIV are understood and accounted for. At present, considerable research exists related to HIV testing and diagnosis; however, much less is known about post-diagnosis experiences, particularly linkage to and retention in care. More work is required to ensure that the perspectives of Indigenous people living with HIV are reflected within the clinically-focused HIV cascade of care framework. What remains essential is that Indigenous peoples have access to culturally-safe services at all stages of the HIV cascade of care.

Chapter 4 Results – Exploring intergenerational child apprehension and HIV among young Indigenous people who have used drugs

4.1 Background

Indigenous peoples have long histories of health and wellness rooted in cultural practices that sustained families, communities, and nations for thousands of years. A common thread through BC's diverse Indigenous peoples is a wholistic perspective of health and wellness, which includes mental, physical, emotional, and spiritual health (FNHA, n.d.; King et al., 2009; Loppie Reading & Wien, 2013). Musqueam Elder Larry Grant has shared his perspective of wellness saying, "The first thing about wellness is to know who you are. Who you come from. Your history. Your ceremonies. Your language. Your community" (Grant, 2017). This teaching highlights the vital role of family and identity in health and wellbeing, which has been articulated by many Indigenous scholars, leaders, and knowledge keepers across Canada and globally (Christian, 2010; Clark et al., 2011; Marshall et al., 2015; Pooyak, 2009; Van Uchelen et al., 1997). In this view, children are sacred gifts from the creator who play a critical role in cultural continuity and a community's hope for the future (Haight, Waubanascum, Glesener, & Marsalis, 2018; Monture, 1989; RCAP et al., 1996a, p. 3:22; Zubrick et al., 2004, p. xii). Traditional child safety laws and practices existed to keep children safe, and raising children using traditional parenting approaches ensured that their cultural birthright remained intact (Blackstock et al., 2006, p. 6; Christian, 2010; Sandy, 2011).

In contrast, wellbeing is eroded and undermined when Indigenous children are forcefully removed from their territories, families, and communities as they have been through the colonial reserve, residential school, and child apprehension systems. The *Indian Act* created a legal infrastructure to abduct Indigenous children which has been described as "genocide by legislation" and a tool of assimilation (Christian, 2010; Monture, 1989; Sinclair, 2016; UN General Assembly, 2007). Indigenous scholars suggest that the legacy of the residential school system, alongside misguided changes in legislation, created conditions for the Sixties Scoop era (1960-1990) during which Indigenous children were removed into the child apprehension system en masse (Christian, 2010; Sinclair, 2007, 2016; TRC, 2015c, p. 15). Amendments to Section 88 of the *Indian Act* in 1951 effectively shifted responsibility for child welfare to the provinces (Bennett et al., 2005, p. 45; Sinha et al., 2011, p. 7). Federal funding was provided

per capita, which incentivized the removal of Indigenous children, with no funding for prevention to keep families intact (Sinclair, 2016; TRC, 2015c, p. 14). Thousands of children experienced permanent out-of-province and international transcultural adoptions, and many of these children – now adults – remain missing from their communities (Sinclair, 2007). Some families and communities lost nearly an entire generation of children (Christian, 2010). Once the bureaucratic infrastructure of the system grew, sustaining it required that the apprehensions continue to ensure that funds would remain flowing (Sinclair, 2016). Despite these forces working against them, Indigenous peoples have long resisted the removal of their children and fought for their rights to grow up within their nation of origin, such as through upholding traditional child safety laws and practices (Blackstock, 2007; Christian, 2010; Monture, 1989; Sandy, 2011; Simard, 2009); protests and demonstrations (Christian, 2010); legal action against the state ("Brown v. Canada," 2017; "First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada, CHRT 2," 2016); and finding / welcoming home lost children (CBC News, 2019; Landers, Danes, & Hawk, 2015).

Cycles of government apprehension of Indigenous children continue to this day as intergenerational residential school survivors and former foster children face significant risk of their own children being apprehended, contributing to losses that reverberate through families across generations (Special Advisor on Indigenous Children in Care, 2016, p. 34). Half of the nearly 30,000 foster children under 15 years old identified in the 2016 Canadian Census are Indigenous, despite making up less than 8% of children in the country (Statistics Canada, 2018c). In BC, although only 10% of children are Indigenous, they comprise 60% of children in custody of the BC Ministry of Children and Family Development (MCFD) (Special Advisor on Indigenous Children in Care, 2016, p. 11). Indigenous children are 15 times more likely to be in care than non-Indigenous children in BC (Special Advisor on Indigenous Children in Care, 2016, p. 11). Further, it has been suggested that there are approximately three times as many Indigenous children in foster care today than there were enrolled in residential schools at their peak (Blackstock & Trocmé, 2005; Picard, 2018). Concerns about significant overrepresentation of Indigenous children in care have been recognized Internationally, by the United Nations Committee on the Rights of the Child (UN Committee on the Rights of the Child, 2012). These disproportionate figures have been termed the 'Millennial' or 'Millennium' Scoop and are understood as a continuation of child apprehensions that took place during the residential school and sixties scoop eras (Foster, 2018; Sinclair, 2007). As in previous eras, present disproportionate apprehensions are based in government policy and legislation.

Through the funding formula known as Directive 20-1 introduced in 1991, Indigenous and Northern Affairs Canada is responsible for funding for delegated agencies which are child welfare organizations established, managed, and controlled by First Nations, but which must administer provincial legislation (Special Advisor on Indigenous Children in Care, 2016, p. 31). Directive 20-1 has led to profound funding disparities between First Nations children on reserve and other Canadian children (Blackstock, 2016; Special Advisor on Indigenous Children in Care, 2016, p. 31). Shortfalls have led to denials, disruptions, and delays in services, especially lack of funding for prevention services aimed at stabilizing families and keeping them intact (Blackstock, 2016). At present, funding is insufficient to create culturally-safe services to address the context of intergenerational trauma stemming from the residential school system (Blackstock, 2016). Further, like legislation that incentivized apprehensions during the Sixties Scoop, Directive 20-1 triggers federal funding payments only when the court orders that a child be removed and placed in care (Special Advisor on Indigenous Children in Care, 2016, p. 31; TRC, 2015c, p. 21). In 2016, the Canadian Human Rights Tribunal ruled that the Canadian federal government had systematically underfunded the on-reserve system and led to perverse incentives contributing to apprehensions (Blackstock, 2016; "First Nations Child and Family Caring Society of Canada et al. v. Attorney General of Canada, CHRT 2," 2016; Grammond, 2018). After receiving four non-compliance orders, Canada finally agreed to respect the ruling in 2018 (Picard, 2018). In addition to funding disparities, jurisdictional disputes between federal and provincial service delivery impact the health and wellbeing of Indigenous children in care (Monture, 1989). While the federal government is responsible for funding on-reserve health and social services, provincial governments are responsible for delivery of health and social services to both Indigenous and non-Indigenous people off reserve. In 2007, Parliament formally supported Jordan's Principle, intended to ensure that federal/provincial jurisdictional disputes do not cause delays or disruptions to services for Indigenous children in care (Sinha & Kozlowski, 2013). The principle emerged in honour of Jordan River Anderson of Norway House Cree Nation who died in 2005 following a two-year stay in hospital, despite not needing hospital care, while Canada and Manitoba argued over payment for his at-home care (Blackstock, 2012).

Disrupting connections between children and families creates obstacles to transmission of culture, language, and identity, which are fundamental to health and wellbeing (Mosher & Hewitt, 2018). Foster care and adoption isolated Indigenous children through placement with non-Indigenous families, secluding them from cultural identity and heritage, and contributing to

lasting spiritual and cultural losses, as well as issues related to self-identity and self-worth (Monture, 1989; Sinclair, 2007; TRC, 2015c, p. 15). Sixties Scoop survivors testify that the toll on identity was exacerbated by experiences of racism and cultural denigration, as well as sexual, physical, and emotional abuse or neglect, while government wards and at the hands of some foster or adoptive parents and siblings (Fournier & Crey, 1997, pp. 32, 37-39, 42-43, 85; Monture, 1989; TRC, 2015c, p. 17). Child apprehension experiences have also been linked to concerning mental and physical health outcomes among former foster children later in life (Zubrick et al., 2004). Among Cedar participants, having been apprehended from parents was independently associated with suicide ideation (aOR: 1.8; 95%CI: 1.3–2.6) and attempt (aOR: 1.4; 95%CI: 1.0–2.1), as well as mental health diagnosis (aOR: 1.6; 95%CI: 1.1–2.3) and hospitalization (aOR: 1.7; 95%CI: 1.1-2.7) (Clarkson et al., 2015). Among only those who used injection drugs at baseline, being apprehended from parents was associated with non-fatal overdose (aOR: 2.7; 95%CI: 1.6–4.5) (Clarkson et al., 2015). On average, Cedar participants who had been apprehended during childhood scored 10 points lower on the resilience scale, compared to those who had not been apprehended (p=0.044) (Pearce, Jongbloed, et al., 2015). Consequences of apprehensions for parental health and wellbeing are also profound. After the Splatsin (formerly Spallumcheen) community lost nearly an entire generation of children to the Sixties Scoop, drinking and despair intensified among the parents left behind (Bennett et al., 2005, p. 20; Christian, 2010). Nearly 50 years later, mothers in Cedar who reported having recently had a child apprehended were twice as likely to attempt suicide (aHR: 2.0; 95%CI: 1.0-4.1) (Ritland et al., 2019).

Despite high prevalence of intergenerational child apprehension experiences among Indigenous people involved in substance use, there is a paucity of research related to child apprehension (as a child or parent) among Indigenous people in the context of HIV health and wellbeing. Among young Indigenous people who have used drugs enrolled in Cedar, those who had been involved with the child apprehension system were more than two times as likely to be living with HIV at enrollment (Clarkson et al., 2015). In a small sharing circle study focused on housing and HIV experiences involving nine HIV-positive Indigenous mothers and grandmothers living in Ontario, narratives related to child apprehension emerged as a critical area of concern (Greene, O'Brien-Teengs, Whitebird, & Ion, 2014). Indigenous women living with HIV in the study shared that fear of potential child apprehension formed a barrier to support, and that they continued to fight for HIV health, to keep their children, and for place in their communities (Greene et al., 2014). Alarming links between intergenerational child

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apprehension and HIV-related health concerns indicated in the limited available literature suggests that additional exploratory and epidemiological research is urgently required. This study uses qualitative and quantitative data from the Cedar Project to explore how intergenerational child apprehension experiences shape HIV health and wellness among young Indigenous people who have used drugs living with HIV.

4.1.1 Overview of research approach

This chapter presents an exploratory sequential mixed methods sub-study embedded within the Cedar Project Blanket Program. Since Cedar's inception, governance has been provided by the Cedar Project Partnership and Indigenous mentors who were involved in every step of the research process. Ethics approval was sought and obtained from the University of British Columbia Providence Health Care Research Ethics Board.

A detailed description of Cedar Project cohort methods was provided in *Chapter 2: Methodology*. Briefly, Cedar Project is an ongoing cohort study involving 782 young Indigenous people who use injection and non-injection drugs in Vancouver and Prince George, BC, on the traditional territories of the Coast Salish and Lheidli T'enneh peoples. Participants were eligible if they self-identified as Indigenous; were 14-30 years old; had smoked or injected drugs in the 30 days prior to enrolment; and provided written informed consent. At enrolment and every sixmonth follow-up visit, participants complete a detailed interviewer-administered questionnaire on socio-demographic characteristics, trauma experiences, drug use, and sexual vulnerability. Venous blood samples were drawn and tested for HIV and hepatitis C. Trained nurses provide pre- and post-test counseling. Participants are invited to return for their test results and referrals to care. Cedar staff work with participants to access physical, mental, spiritual, and emotional support if requested, including traditional healing, drug treatment, and housing. In gratitude for participant contributions, honoraria are provided at each follow-up visit.

Since 2011, Cedar participants living with HIV have been given the option of enrolling in '*The Cedar Project: Exploring HIV Case Management*' study, also known as the Blanket Program. The Blanket Program is an individualized, culturally-safe approach connecting HIV-positive participants with a Cedar Case Manager. Blankets hold a highly important place in many North American Indigenous cultures, as they continue to be used in giveaways and potlatches, honour children with names, and celebrate young people coming-of-age. Blankets are used to symbolically wrap children in care, and represent inclusion of young people in the community.

Through one-on-one conversations, Cedar Case Managers help participants identify barriers to accessing HIV services, as well as navigate and sustain engagement with the HIV cascade of care. In addition, Case Managers help participants with cultural supports and referrals to ancillary services. An example is hosting annual gatherings open to all participants where traditional foods, including wild game and fish, are offered in a family-style setting. Case Managers and Cedar nursing staff support participants to maintain regular HIV-related blood work, interpret results, and address any other health concerns.

4.1.2 Rationale

Emerging from the systematic review presented in *Chapter 3*, there was an obvious disconnect between the qualitative (IPHA perspective) and quantitative (health system perspective) literature in terms of emphasis and value placed on viral suppression. While viral suppression received a tremendous amount of attention in the quantitative literature, it was barely mentioned in the qualitative. This reaffirmed the importance of speaking to young Indigenous people who have used drugs living with HIV about their experiences of this stage of the HIV cascade of care in particular, and how historical and social contexts shape these experiences. What emerged from in-depth interviews with Blanket Program participants living with HIV (n=12) affirmed findings from the systematic review, particularly around the overarching determinants of engagement in the HIV care cascade (Jongbloed et al., 2019). However, where participant's narratives diverged from the established literature was the way in which intergenerational involvement with the child apprehension system affected their HIV-related health and wellness. Specifically, participants spoke about the profound impacts of having been apprehended from their parents during childhood and having had their own children apprehended. This prompted us to use longitudinal guantitative data collected since 2011 through the main Cedar cohort and Blanket Program to test for possible associations between two indicators of intergenerational child apprehension and viral suppression.

Embedding this work within the larger Cedar cohort and Blanket Program provided a unique opportunity to explore intersections of HIV and intergenerational child apprehension using an exploratory sequential mixed methods approach (Figure 4.1). Use of mixed methods is consistent with a transformative paradigm, which underpins this dissertation, as it supports contextualizing findings within historical and present day structures of discrimination and oppression, as well as an integrated and iterative process of community engagement within the research (Mertens et al., 2010). Further, Indigenous scholars have argued that using mixed

methods is consistent with Indigenous approaches to research, as it constitutes a decolonizing and relational practice that facilitates collaboration between Indigenous and mainstream paradigms (Botha, 2011; Chilisa & Tsheko, 2014). The mixed methods design enabled us to bring together different strengths and non-overlapping weaknesses of gualitative and quantitative methods to help best understand what was observed as we sought to arrive at valid and well-substantiated conclusions (Creswell & Plano Clark, 2007, pp. 62-65). We followed the process described by Creswell and Plano Clark to explore a phenomenon with qualitative data in phase one, and then build to a second, quantitative phase in order to triangulate, validate, and generalize what was observed in the gualitative phase (Creswell & Plano Clark, 2007, p. 77; 2011, p. 9). Integration included embedding data (embedding qualitative data into our primary quantitative data set), connecting data (using qualitative data to inform development of quantitative analysis), and merging data (reporting qualitative and quantitative results together) (Creswell et al., 2011, p. 5; Creswell & Plano Clark, 2007, pp. 83-84). In other words, findings from the gualitative inductive phase shaped the research guestion and analytical strategy for the quantitative deductive phase (QUAL \rightarrow quan) (Morse, 2010, pp. 6-8). The qualitative phase was guided by two objectives: (O1) explore experiences of the HIV cascade of care from the perspective of young Indigenous people who have used drugs; and (O2) understand how historical and social contexts shape experiences of the HIV care cascade. Results from the qualitative phase led us to develop a third quantitative objective: (O3) determine if the link between intergenerational child apprehension experiences and HIV health observed in the qualitative interviews was present in the available quantitative data. In this chapter, methods and findings from the gualitative phase are followed by the methods and findings of the quantitative phase. Then, findings from both phases are interpreted and presented together in the discussion.



Figure 4.1: Overview of exploratory sequential mixed methods study design

4.1.3 Theoretical framework

This study was informed by the conceptual framework laid out in *Chapter 1: Introduction*. Briefly, it takes a perspective of health and wellbeing that includes the physical, mental, spiritual, and emotional health of the individual, as well as whole families, communities, and nations (FNHA, n.d.; King et al., 2009; Loppie Reading & Wien, 2013) and recognizes that ongoing colonization is a negative structural determinant of health and wellbeing (Reading, 2015). Within this context, young Indigenous people who use drugs may turn to substance use to cope with stress of intergenerational and lifetime traumas stemming from colonization; however, access and connection to family, cultural strengths, identity, and traditional practices, can serve as buffers to support health and resilience (Pearce, Jongbloed, et al., 2015; Walters et al., 2002; Walters & Simoni, 1999, 2002; Walters et al., 2000).

4.2 Qualitative phase

4.2.1 Qualitative methods

Interpretive description was the method of inquiry for the qualitative phase of this analysis (Thorne, 2016). It was selected as it explicitly seeks to inform applied practice, in contrast to other approaches which may emphasize theory generation (Thorne, 2016). This approach allowed us to engage as witnesses to participants' stories related to intergenerational child apprehension experiences and HIV health and wellbeing, with the explicit goal of informing HIV care and services (Starks & Trinidad, 2007).

Recruitment and sample

Twelve Cedar participants involved in the Blanket Program took part in the qualitative component of this study. Purposive sampling was used to enroll participants who had received the Cedar Project WelTel mHealth program and who were open to having a conversation about their experiences of the HIV cascade of care with me. This approach was chosen as the exploratory nature of our inquiry aimed to understand patterns and variability in experiences of the HIV care cascade among young Indigenous people who have used drugs from their own perspective (Schensul, Schensul, & LeCompte, 1999). Eligible participants were invited into the study by a trusted Cedar Project staff member known to the participant and were told about the study's purpose. Those who expressed interest were booked for an appointment at a time and place that worked best for them.

Of the 12 in-depth interview participants, five (41.7%) originally entered the Cedar Project in Prince George and seven (58.3%) in Vancouver. Their average age at enrollment into the Blanket Program was 31.25 years. Nine were women (75.0%) and three (25.0%) were men. Eleven (91.6%) had been apprehended as children (Table 4.1). In addition, eight (66.7%) spoke about being parents, all of whom reported that the MCFD was/had been involved with their own children. Some had custody of their children at the time of the interview, while others did not.

Sex	Apprehended as a child?	Parent?	MCFD involved?	Current custody?
Female	Yes	Yes	Yes	No
Female	Yes	Yes	Yes	Yes
Female	Yes	Yes	Yes	Yes
Female	Yes	Yes	Yes	Complicated
Male	No	No	-	-
Female	Yes	Yes	Yes	Yes
Female	Yes	Yes	Yes	No
Male	Yes	No	-	-
Female	Yes	Not discussed	-	-
Female	Yes	Yes	Yes	No
Female	Yes	Yes	Yes	Yes
Male	Yes	Not discussed	-	-

Table 4.1: Intergenerational child apprehension experiences (n=12)

Data collection

In-depth open-ended interviews were carried out in March/April 2016 to understand experiences along the HIV cascade of care from the perspective of young Indigenous people who have used drugs (Schensul et al., 1999). A loosely structured topic guide was developed with input from Mr. Lou Demerais and Ms. Sherri Pooyak (Cedar Project Partners and Indigenous Mentors). Four themes informed the question groups: (1) personal experiences along each step of the cascade of care; (2) historical and social contexts that shape experiences of the HIV care cascade; (3) participants' own conceptualizations of "success" in terms of HIV; (4) participants' strategies for health, safety, healing, and resilience. In addition, participants were asked to reflect on involvement in the Cedar Project WeITel mHealth program, which is analyzed and presented in a subsequent chapter *(Chapter 9)*. Interviews were openended to allow participants' experiences to direct the interview process and enable them to share stories they felt were important. The topic guide was piloted with three experienced Cedar participants with many years of involvement in research and revised slightly to be more open ended and conversational. In addition to formal interviews, this analysis was informed by my in-person and text message engagement with the 12 participants and others during the 16 months while the mHealth program was underway.

Interviews took place in private offices in the Cedar study sites (10), which are familiar to and convenient for participants, or participants' homes (2). I conducted all interviews. In Prince George, where I had spent less time, most interviews were conducted jointly with one or two Cedar staff. Steps were taken to establish a safe interview environment in which the interviewer/interviewe relationship was central and participants' voices were respected and honoured (Kornelsen, Kotaska, Waterfall, Willie, & Wilson, 2010; Wilson, 2008). Each interview visit began with an offer of food (e.g., fruit and cookies) or a hot drink. The interview topic was outlined again and participants were asked if they were still interested. If yes, the interviewer reviewed the consent form and answered any questions that arose. Each participant was offered tobacco (a pack of cigarettes) in gratitude for the knowledge they would share (CIHR et al., 2014; Kovach, 2009; Nowgesic, 2015; Pooyak, 2009). Participants were assured of confidentiality and reminded that they could refuse to answer any question or decide to stop the interview at any time. Once the consent form was signed, the interviewer asked for permission to turn on the audio recorder.

Interviews lasted from 33 to 100 minutes. Interviewers and participants sat side by side at a small table; the interviewer positioned themselves in a physically non-threatening manner. Participants were also offered the most comfortable chair. If the participant appeared to be uncomfortable or upset related to a line of questioning, the interviewer asked if it was okay to continue with that topic before proceeding. If not, the interviewer asked if the participant wanted to continue with the interview before moving to another topic. At the end of the interview, a small pouch of sage smudge, picked by Cedar Partner Ms. Margaret Poitras (Cree, Muskowekwan First Nation; Executive Director, All Nations Hope Network), was made available to those who wanted it (Wilson, 2008). In gratitude for participants' time, a \$20 honorarium was also provided. Participants were asked if they would like a referral to a counsellor or other support service to talk more about any issues that may have come up over the course of the interview.

All interviews were audio recorded and transcribed verbatim by me using f5 transcription software. Transcribed data was checked against the audio recordings at least one additional time to ensure accuracy. Pauses, 'ums', and 'ahs' were edited out of quotes provided below unless they contributed useful meaning or context. Each participant was given a pseudonym to protect their confidentiality. Names were selected from nature as a way to honour the strength and resilience of the participants. Extensive field notes were kept to supplement audio recordings with observational, contextual, theoretical, analytical, methodological, and personal reflections.

Analysis

Consistent with interpretive description, the aim of the analysis was to move beyond pure description and into identification of higher level patterns and interpretation in order to help 'make sense' of what participants shared (Paterson, Hirsch, & Andres, 2013; Thorne, 2016, p. 192). I moved iteratively through a series of cognitive operations outlined by Morse: comprehending, synthesizing, theorizing, and re-contextualizing (Morse, 1994; Morse & Field, 1996; Thorne, 2016, pp. 184-185). Strategies taken at each stage are presented in Table 4.2. Strategies used to enhance validity and rigour are presented in Table 4.3.

Operation	Aim	Strategies used
Comprehending	Learning everything possible about setting and experiences of study participants. Making sense of the data (Morse & Field, 1996, p. 104).	 Immersion in the data through interviewing, transcribing, listening, and reading Use sticky notes to capture themes and label ideas Revisit field notes from all stages Reflexive journaling
Synthesizing	Exploring patterns and relationships, looking for both typical and disconfirming cases. Decontextualizing from the individual and sifting off the insignificant noise (Morse, 1994, p. 31).	 Arrange and re-arrange sticky notes Mind mapping Move back and forth between data and scaffolding Develop or apply conceptual labels to key themes and sub-themes Reflexive journaling
Theorizing	Building towards a structured conceptual whole which explains a 'best guess' about what I am seeing and why. Sorting phase where different models are tested (Morse & Field, 1996).	 Active, continuous process of assembling "data puzzle" into best fit model Mind mapping Compile themes into a hierarchical coding framework with operational definitions and examples Review themes with Cedar Project staff, investigators, and partners Arrive at a 'final' coding framework Reflexive journaling
Re-contextualizing	Integrating the interpretive description	 Once coding framework was finalized, used nVivo to code the data Narrative, conversational approach to report findings Verbatim quotes Work with partners to develop applied recommendations Reflexive journaling

Table 4.2: Morse's Taxonomy of Cognitive Operations

Comprehending. Immersion in the data occurred through the process of interviewing, transcribing, re-listening to check for accuracy, and then reading/re-reading all transcripts. Early in this process, I first re-listened to the interviews while simultaneously reviewing the transcripts for accuracy, using sticky notes and reflexive journaling to capture emerging themes and label ideas. Then, transcripts were printed and read multiple times, during which sticky notes and reflexive journaling were used to identify additional themes. The next step was to return to memos written during the interviewing and transcribing stages to ensure that themes identified during this stage were also represented. Extensive field notes were taken during each of these phases. When listening to participants' stories, I took the perspective that all participants were telling the truth, and that their long-term involvement with HIV care made them experts on this topic (Halldorsdottir 2000, Ricoeur 1990).





Synthesizing. Following this initial immersion in the data, time was spent time arranging and re-arranging the sticky notes into clusters of shared experiences and meaning, returning repeatedly to the transcripts themselves. At this point, I also returned to theoretical scaffolding, drawing in *a priori* themes identified from previous Cedar studies, the systematic review of HIV cascade of care experiences among Indigenous peoples (*Chapter 3*), and discussions with Cedar Partners. To explore relationships between emerging themes and begin to move into higher levels of abstraction, the next step was to move between sticky notes and mind mapping to make sense of what was observed in the data (Thorne, 2016). A process of constant comparison was used to identify similarities and differences among participants' experiences (LeCompte & Schensul, 1999). Special attention was given to negative or disconfirming cases to avoid generalizing and to refine understanding (LeCompte & Schensul, 1999).



Theorizing. Next, themes were compiled into a hierarchical coding framework with operational definitions and examples. The initial framework was reviewed by members of the Cedar investigative team, including Indigenous Mentors Mr. Demerais and Ms. Pooyak, and revised. Transcripts were then imported into the computer software application NVivo where they were coded (QSR International Pty Ltd, 2014). Analysis was completed when themes were clearly defined and saturated, and all interview text was attached to a code. In consultation with the investigative team and study partners, a decision was made to focus on the area where participants' narratives diverged from the established literature related to Indigenous experiences of HIV care and treatment (explained in greater detail below).

Re-contextualizing. Themes were reintegrated into an explanatory narrative, including verbatim quotes. Personal narratives were presented in a way that attempted to avoid fragmentation and honour participants' experiences, their cultures and their lives (Kovach, 2009; Pooyak, 2009). Finally, I worked with the Cedar Project Partnership to further interpret and present the findings within a culturally-safe framework and identify meaningful recommendations (CIHR et al., 2014). During this process findings were discussed in detail with three Indigenous child welfare experts who sit on the Cedar Project Partnership for validation, feedback and interpretation through an Indigenous lens: Kukpi7 *Wunu'xtsin* Wayne Christian (Chief of Splatsin First Nation and Tribal Chief of Secwepemc Nation); *Maaxswxw*

Gibuu Mary Teegee (Gitk'san and Carrier from Takla Lake First Nation, member of the Luxgaboo Wolf Clan, Executive Director of Child & Family Services at Carrier Sekani Family Services and President of the BC Aboriginal Child Care Society Board of Directors); and Sherri Pooyak (Cree, MSW, Instructor at University of Victoria School of Social Work and First Nations University of Canada, Department of Indigenous Education Health and Social Work).

Table 4.3: Strategies	used to	enhance	validity	and	rigour
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Validity concerns	Strategies used		
Doing research in a	Study governance and oversight by the Cedar Project Partnership, which included		
'good way'	involvement of Elders (Flicker et al., 2015; Schnarch, 2004)		
	Creating safe environment for participants to tell their story, including by sharing of		
	food and traditional medicines (CIHR et al., 2014; Kornelsen et al., 2010; Kovach,		
	2009; Nowgesic, 2015; Pooyak, 2009; Schensul et al., 1999; Wilson, 2008)		
	 Privileging Indigenous voices, knowledges, and perspectives through refining the 		
	coding framework and interpreting findings in collaboration with Cedar Project		
	Partners (LeCompte & Schensul, 2010, p. 63; Mertens, 2007; Mertens et al., 2010)		
	 Self-locating / critical reflexivity (Kovach, 2009, pp. 110-113) 		
	 Relational accountability to participants and partners (Wilson, 2008, p. 6) 		
Credibility	Peer debriefing with Dr. Patricia Spittal (Cedar Project Principal Investigator), Vicky		
	Thomas (Wuikinuxv Nation, Cedar Project Coordinator), Sherri Pooyak (Cree,		
	Indigenous Mentor), and Dr. Margo Pearce (Co-investigator), added multiple		
	perspectives throughout the process (Creswell, 2014, p. 202; Maxwell, 2012, pp.		
	127-128; Schensul et al., 1999, p. 283; Starks & Trinidad, 2007).		
	 Audio recorded interviews, verbatim transcripts and quotes (Maxwell, 2012, p. 126; 		
	Schensul et al., 1999, p. 283).		
	• Attention to negative or disconfirming cases (Creswell, 2014, p. 202; Maxwell, 2012,		
	pp. 127-128)		
	Refining coding framework and interpreting study findings in collaboration with		
	Cedar Project partners (Schensul et al., 1999, p. 283; Thorne, 2016, p. 235)		
	• Prolonged engagement (Creswell, 2014, p. 202; Maxwell, 2012, p. 126). I have		
	been involved with the Cedar Project for over eight years, and over the course of		
	this dissertation spent over 400 hours visiting with participants in the Vancouver		
	Cedar site office, with additional time in the Prince George office. As well, I have		
	had the opportunity to learn from study Elders and Partners through participation in		
Transforability	ceremonies, feasts, potiatch, pow wow, and other cultural events.		
Transferability	Provided thick contextual background (Creswell, 2014, p. 202)		
	Detailed participant characteristics and situated within historical context (Schensul stel 1000 m 000)		
	el al., 1999, p. 286)		
Dependebility	Ose of topic guide to semi structure interviews (Schensul et al., 1999, p. 286)		
Dependability	Audit trail (visual and written records of process) to make visible now study process americad eventime (Creavell, 0014, p. 000)		
	emerged over time (Creswell, 2014, p. 203)		
	Feel review and debrening (see above) Triangulation using quantitative data and provides Coder studies (Creavell, 0014, p		
	• Triangulation using quantitative data and previous Cedar studies (Creswell, 2014, p. 2014,		
	201, Maxwell, 2012, p. 128, Schensul et al., 1999, p. 283)		
	 Origonaly relievable journaling (Wall, 2007) Datailed description of study methods (Schensul et al. 1000, p. 288) 		
Confirmability	 Detailed description of study methods (Schensul et al., 1999, p. 288) Took stops to oppute the applysic was grounded in the data by to opplying the final 		
Commanity	 rook steps to ensure the analysis was grounded in the data by re-applying the final opting framework until all text data was linked to option nVivo aeftware (OSD) 		
	International Ptv I to 2014)		
	 Ongoing reflexive journaling (Watt 2007) 		
	 International Pty Ltd, 2014) Ongoing reflexive journaling (Watt, 2007) 		

4.2.2 Qualitative findings

The twelve young Indigenous men and women who participated in qualitative interviews shared stories of strength, courage, resistance, and resilience. They also spoke about significant trauma and adversity they had faced over the course of their lives. It is important to note that participants' decision to share their stories is an act of resistance and a deliberate way in which they are working to break cycles of trauma for their own families.

What emerged from in-depth interviews affirmed findings from the qualitative literature included in the systematic review (*Chapter 3*), particularly around the overarching determinants of engagement in the HIV care cascade (Jongbloed et al., 2019). Promoting determinants included: (1) Indigenous culture, identity, and ceremony; (2) strength, resilience, and determination; and (3) social support systems (a strong circle of care). Hindering determinants included: (4) historical, intergenerational, and lifetime trauma; (5) stigma and discrimination; and (6) intersecting health concerns.

Where participant's narratives diverged from the established literature was the way in which intergenerational involvement with MCFD affected their HIV-related health and wellness. Specifically, participants spoke about the profound impacts of having been apprehended from their parents during childhood and having their own children apprehended. Themes highlighting intersections of child apprehension experiences and HIV included: (1) impact of participants' removal from their families on long-term health and wellbeing; (2) re/connecting with parents, children, and other family; (3) stress and demands of maintaining/regaining custody of children; (4) intersections of substance use, child apprehension experiences, and HIV; and (5) traditional wellness practices were both valued and complicated.

Theme 1: Impact of intergenerational removals from families on long-term health and wellbeing

Intergenerational family disconnections resulting from government legislation were prevalent in the narratives shared by participants. A few spoke of experiences where their parents and grandparents had been taken to residential schools:

"Yeah my grandma...my great grandmother was raised in ahhh...nun place...what do you call that? ...A residential school and was raised by nuns and had a pretty rough go, so" (Willow, Female, Prince George)

"We know nothing of my mother's side. She moved us out thank goodness because of all the....my grandparents were in residential school. My oldest aunt was in residential school and my mother went through hell. My mother went through a lot of abuse. Even more so than I ever have." (Petal, Female, Vancouver).

All but one participant had been involved in the child apprehension system as a child, and many shared painful memories of these disconnections. Participants described multiple transitions in childhood, including periods of time spent with their biological parents, extended family, foster families, adoptive families, and in group homes. For example, Aspen explained that he and his siblings had experienced a cycle of being apprehended and returning to live with their mom throughout childhood. He shared,

"[Mom] would constantly be harassed and bugged by child services and basically we'd be taken away kind of like a revolving door effect kinda thing. She'd get us back and then the same thing would happen again, come take us away again, get us back." (Aspen, Male, Vancouver)

Participant experiences reflected the transcultural adoptions prevalent during the Sixties Scoop. Some described being placed far from their home communities and families, which prevented them from regular contact with their kinship connections and traditional territories. Some also described experiencing abuse while wards of the state. Linden shared,

"When I was two, put into a foster home and then when I was 8...my sister came later, couple years later and we were both adopted to [US state] and I was in [US state] for about four years. We were both adopted [by] the same family in [US state] and things didn't work out. It was very, very abusive...they took me out of there and put me in a foster home in [US state], so I was in foster homes here and there, and then they repat-ed me to Canada when I was about 12 years old and then from there I kinda jumped from foster home to foster home. And then the same people that took care for me from when I was two and a half until I was 8, they found me and I went back to their home until I was 18." (Linden, Male, Vancouver)

Participants connected these childhood experiences to substance use later in life, as well as MCFD's involvement with their own children. Willow concisely described the cascade of consequences of a difficult adoption from her own perspective:
"I was adopted at two and a half. Ummm...had a rough go...my adopted parents...well, we were kind of in and out. I was put in a, a group home at 16 until I was 18 and then I was set out on my own. So, then became an addict and had a daughter and I lost her to the Ministry" (Willow, Female, Prince George)

These intergenerational disconnections had taken a profound toll that contributed to instability, substance use, and struggles with self-worth and identity, which had consequences for participants' engagement in HIV care.

Theme 2: Re/connecting with parents, children, and other family

Participants talked about the work they were doing to break the cycles of disconnection by actively trying to reconnect with their parents and children, as well as other family members. As this quote suggests, some tried to reconnect with parents and siblings immediately after aging out of foster care:

"One of my brothers had found me...and he told me that my father was here, lived here. So, we got connected and I met my dad...I would recommend anybody that hasn't found their parents to find their parents, you know. I mean that. There are a lot of people that say don't do it but it was definitely...because I often wondered what they looked like and who they were. It filled in a lot of holes in my, in my reality I guess." (Linden, Male, Vancouver)

Others had come to the point of connecting and learning about their family and Indigenous identity more recently, like Willow:

"Right now, I'm trying to get my Métis card. I've just recent...well not recent, in the last year, got a great big binder with all my family tree and history from my birth mom's cousin...I guess it would be my great grandmother's daughter and my great grandma raised me until I was two and a half...and then so it would be her daughter [name] which would be my aunt? Yeah...great aunt? So yeah, my great aunt sent it to me. She came on onto Messenger and, yeah, printed me off a bunch of pictures of me and my family when I was a baby. Pictures of my cousin, my grandma. Yeah, it was so cool to get lots of baby pictures of me!" (Willow, Female, Prince George)

Connecting with family was one component of staying healthy in the context of HIV for a number of participants. For Ivy, despite experiences of apprehension, time spent with family and loved ones helped her to deal with the mental and emotional aspects of the disease:

"Yea. I don't want to think about [HIV], I don't really. But there's nothing I can do, and I have to accept what I have, and take it. And you know...I have to keep my mind busy, keep myself busy with my friends and my family or whatever." (Ivy, Female, Vancouver)

Others spoke about the importance of connecting with their parents but recognized that it was not that simple, as their parents were sometimes still struggling with substance use and other challenges themselves. For Fern, taking care of and feeling forgiveness towards her mom who continued to deal with substance use issues was a critical part of taking care of her own health and wellness:

Interviewer: Can you tell me about the kinds of things you do to take care of yourself?

Fern: "Well...first off, I pay the rent (laughing) and then I always try to like buy groceries and stuff. And no matter what I always like, you know, try to look out for my mom, you know what I mean. And like, not like disown her or whatever or put like blame on her for the way I grew up, right." (Fern, Female, Prince George)

Eight participants spoke about being parents themselves, and all reported that MCFD was or had been involved with their own children. At the time of the interview, some of these parents currently had custody of their kids while others did not. Parents spoke about the importance of reconnecting with their own children for their own health and wellbeing. Like reconnecting with parents, the process was not always easy or straight forward. For example, Willow and Petal shared:

I want to spend more time with [older daughter], really trying to....to get a more open relationship with her. She's a little shy still. When she's here and it's just us and she's not around her foster mom, she seems pretty good but when I talk to her on the phone it's kinda...seems you can tell the foster mum's sitting right there listening and so...yeah it's a little...it's a touchy subject." (Willow, Female, Prince George)

"The oldest two, so when they came home it was really, really different. You know, we all didn't know how to talk to each other, we all didn't know who each other was, how they like their eggs. We all went from...the family of three [partner], myself, and the baby, then to a family of five." (Petal, Female, Vancouver)

Theme 3: Intersections of substance use, child apprehension experiences, and engagement in HIV care

Participants' stories reflected that child apprehension experiences, substance use, and engagement in HIV care were deeply entwined. They presented a way of thinking about substance use that was complex, dynamic, and non-linear. At the time of the interviews, participants were at diverse stages in their substance use journeys with some participants using daily, some using infrequently, some accessing opioid substitution therapies, and some having quit entirely.

Many participants had grown up affected by their own parents' involvement in substance use which was interconnected with their own child apprehension experiences. For example, Dawn who is the oldest child in her family, described having to go to a treatment centre with her family in her early teens during a period when she was running away a lot. The words Dawn used to describe this experience suggests that substance use treatment was required by her family as a condition for keeping their family intact, rather than a decision they had made themselves. This reflected the coercive contexts in which engagement with substance use services sometimes took place. She explained,

"[My mom]'s like, 'You need to come back otherwise they're going to take away all your brothers and sisters,' she said. 'We're fucking going to family treatment. If you don't come then all the kids are getting taken away.'" (Dawn, Female, Prince George)

Participants expressed concerns about the harms they experienced through prolonged drug use. Some used the term 'wired' to describe their experience of addiction, depicting a sense of becoming so dependent that stopping ceased to be a choice. Many expressed regrets that they had become 'wired' as it prevented them from quitting even though they wanted to. For example, Fern said,

"I've already destroyed like years and years of freaking blowing it up in smoke or just trying to numb myself and didn't get anywhere, just damaging myself, right? So, I'm just putting my life back together and myself back together." (Fern, Female, Prince George)

No matter where they were on their journey, most participants articulated a deep desire to reduce drug-related harms for themselves and their families. All participants reported engaging

with a variety of substance use related services, including needle exchanges, opioid substitution therapy, detox, residential treatment, 12-step programs, and services designed specifically for moms and babies. Despite a desire to quit, for some this aim remained out of reach, and resulted in apprehension of their own children, as the following quote from Dawn highlights:

"I was clean and sober for the last...two months of my pregnancy and I even had my own apartment...I had a crib in the room and I had all his clothes and diapers like I was ready to have baby any time and......and then I went and did drugs and went into labour after that and that's when it all got fucked up and they never gave me a chance to keep him so I lost him." (Dawn, Female, Prince George)

Others explained that having a child apprehended prompted relapse, rather than the other way around, as was the case with Poppy who has now regained custody of two of her children:

"When I lost the kids, I lost the [housing] subsidy and then I lost the house and then I lost my sobriety and so yeah...yeah [big sigh]...yeah. It was a big long struggle. I...I was depressed the entire time." (Poppy, Female, Vancouver)

Engagement with substance use and recovery services sometimes connected participants with HIV care or support adherence, for example if ART was dispensed daily with methadone. For some, deciding to 'get clean' and engaging in HIV care happened simultaneously. Having custody or seeking custody of their kids was a reason for many participants to seek or maintain sobriety and focus on HIV health. For example, Poppy powerfully summarized the life force of her connection to her children:

"I can't live without them." (Poppy, Female, Vancouver)

Similarly, as we spoke about the value of understanding CD4 counts and viral load, Dawn shared that they took on meaning for her over time in the context of being a mom. She explained,

"It's important to me now. Like, as years progress with me having HIV and me having my children...before I didn't give two shits about myself." She added, "I just want to be a better role model for my children and...I want to be able to watch them grow up and live their life and I want to be there instead of being selfish. Like, it's not just me to think about it's also my children and I don't ever want to leave them until I have to." (Dawn, Female, Prince George) Many women spoke about a transition moment during pregnancy that turned them towards a healthier life. For some, this was after having one or multiple children apprehended that they resolved to get clean and focus on their HIV-related health to avoid experiencing another child being taken away. For example,

"I cleaned up. I've been clean and sober for five years. Almost the same age as [daughter]...I've only had one relapse...I just said I wasn't going to give another one of my kids away. Fuck that." (Dawn, Female, Prince George)

"I was finally getting sick of the life, sick of hanging out downtown and working and ...getting beat up by my ex. So, I found myself spending more and more time with [current partner] and yea lo and behold little [daughter], little [daughter] became and I went on the methadone program." (Willow, Female, Prince George)

On the other hand, participants spoke about the hopelessness they felt when their children were not in their care, and how this contributed to relapse or a sense of "what's the point" when it came to taking care of their own health related to HIV and substance use. This illustrates that both experienced and internalized shame can contribute to worthlessness, making it even harder to focus on caring for oneself. For example, Azalea shared:

"The only thing that will make me probably get clean is my daughter, if I ever met her. I don't think I ever will so doesn't matter. It's the only fucking thing that would've made me change if I ever got a chance to meet her, you know." (Azalea, Female, Vancouver)

What is clear from participants' narratives is that HIV cannot be viewed narrowly as a chronic, treatable health concern with clear, discrete stages along a cascade of care, but rather as something bound tightly to past and current experiences related to substance use (including quitting, recovery, relapse, and access to services) and child apprehension (both as a child or as a parent).

Theme 4: Fear, stress, and demands of maintaining/regaining custody of children

Parents in the study emphasized how stressful and demanding it was to maintain or regain custody of their children. They spoke a lot about the fear, stress, complexity, and sheer amount of time and energy it took to try to navigate conditions of custody, as well as being required to prove and re-prove their ability to parent. Stories reflected feelings of lack of control or agency within a system that determined access to their own kin.

Many spoke about feeling judged and scrutinized for issues such as where they lived and who they knew, rather than substantiated cases of abuse or their ability to parent their children. Sometimes participants shared that they felt apprehensions were the result of incorrect perceptions or technicalities, rather than legitimate concerns for child welfare.

"They didn't want me to leave the hospital with my baby. They were like, 'well you had no prenatal' so I...we were there for a month because they were trying to fight me." (Poppy, Female, Vancouver)

"They came and took him when he was three months old because of my acquaintances and my friends were known drug dealers and I was seen going to fucking drug houses – but I didn't use! So, that was their reasoning for taking [son] when he was three months old. So, I finally just had ummm agreed to open adoption. He's been with the same foster parents since he was three months old, so. But yeah...yeah they just brought up my past history and......dug freaking dirt and like basically didn't have any legit reasons to take [son], I didn't think anyways." (Fern, Female, Prince George)

Participants' stories reflected feelings of powerlessness in the face of the system that tightly controlled the circumstances in which they could interact with their own children. For example, Petal, who now has custody of her children, recalls a time when she tried to advocate for more access to her children who were in her mother's custody:

"My mom ended up with pneumonia and the social worker phoned me and said, 'Ok, well, we're gonna need you to go to your mom's, look after your kids, clean up her house, get their breakfast lunch dinner, get them to school. I need you to go and do that.' And I said, 'I'm not going to do that unless you talk to me about overnight visits.'...And then he says to me, 'No, you're not ever gonna be, you're not ever gonna get those children into your care...never." (Petal, Female, Vancouver)

Petal could not reconcile being asked to fulfill parenting responsibilities, while simultaneously being told that she could not ever expect to regain custody of her children. Similarly, Fern understood that access to her children was conditional:

"I'm trying to get stability so I can see my son more often because as we stand right now they're only going to let me see him once a year and freaking... But [Cedar staff] said we could go over the open adoption agreement and change that but I have to make sure my stability and everything like that is freaking on par." (Fern, Female, Prince George)

A few shared strategies they used to demonstrate their strengths with social workers. For example, Poppy invited her child's social worker to join her at a community service project she was involved with. She felt this action had resulted in a 180-degree shift in the social workers' perception of her and her family:

"I invited the social workers to come to do, to sit in one of the film sessions with the women and they went from hating us to...is it three sixty or one eighty...(laughing) after that, they were like our new best friends." (Poppy, Female, Vancouver)

Conditions of custody sometimes made daily life logistics such as putting food on the table, making the school run, and maintaining a stable home more complicated for participants. This was interconnected with staying with partners they did not want to continue a relationship with, as being in this relationship was a condition of remaining in contact with their child. For example, Iris shared that making ends meet related to food and housing was both difficult and stressful, and it was made more complicated by the fact that her partner and not she herself had custody of their son. Her partner's anger issues contributed to bad relationships with service providers who may have helped them during this period of food and income insecurity:

"If I had him in my care, I'd get a crisis grant but [partner] can't do that because they won't allow him any because he's yelled at them and everything before. He's blacklisted from everywhere. Why he has that kid in his name...I just...I wish he didn't 'cause then I'd be able to do everything and get everything for him. But he won't let me have him back." (Iris, Female, Prince George)

Similarly, Poppy spoke about how her partner's struggles with depression made daily life difficult and caused her to worry about her children being apprehended again. However, them staying together as a couple was a condition of custody, and she was told if they separated that MCFD would take permanent guardianship through a continual custody order (CCO):

"He left and I actually wanted him to stay gone. But then they told me, 'Well if he stays gone then it's going to take longer for you to get the kids back. So, like if it takes longer then...you're going to get your fucking CCO...!' So, he came back and everything got worked out and sometimes I think maybe it would have been better if we had just fought that way than having him stay." (Poppy, Female, Vancouver) In sum, participants were actively fighting to hold on to their children. In the face of these challenges, they communicated a sense that managing HIV was made more complex and was sometimes sidelined by these more pressing issues.

Theme 5: Traditional wellness practices were both valued and complicated

A number of participants talked about participating in ceremony and cultural practices, including potlatch, smudging, feasting, and protocols related to honouring family members who had passed away. Participants shared that connecting to culture was often highly valued but could be complicated. Some held teachings that engaging in ceremony during periods of substance use was disrespectful. They felt cultural practices could not be part of their life unless they were drug free, which for some felt out of reach. Narratives like this quote from Azalea reflected that if participants could find some respite from the feelings of shame they carried, they may welcome engagement with cultural supports:

Interviewer: Do you ever do any cultural stuff? Azalea: "I used to. I don't do that when I'm using drugs. Because it's not healthy. It's not very, I can't, it's disrespectful...yep. Disrespecting, disrespecting them, mother earth and the higher power. It's like, I can powwow sing, I can powwow dance, everything. I can do everything but I won't do it because I just don't want to disrespect it. I just respect the songs and stuff that I was taught, so." (Azalea, Female, Vancouver)

A few participants spoke about not having been raised with culture, and therefore were hesitant to connect. Others, like Fawn, had good memories of being raised with culture, but a major shift or disconnection such as the death of a grandparent who represented their connection to culture, resulted in a loss of that connection to this day. Often, these moments of disconnection coincided with a time where their involvement in the child apprehension system escalated, and represented a negative turning point in their lives.

Fawn: Ahh, I'm not into anything cultural.
Interviewer: No? On purpose? Like you don't want to?
Fawn: Umm, I choose not to.
Interviewer: Yea, it's not so meaningful for you?
Fawn: No, since my grandmother passed away, I just stopped with everything.
Interviewer: So, she was for you the connection.
Fawn: Yeah. (Fawn, Female, Vancouver)

4.2.3 Summary

Intergenerational child apprehension experiences were a central concern that participants returned to often within the context of conversations focused on HIV health and wellbeing, as well as engagement with the HIV cascade of care. Conversations highlighted that intergenerational child apprehension experiences were a part of participants' pasts and presents, and contributed to feelings of imbalance, stress, fear, disconnection, and harm. Participants expressed profound desire to break cycles of disconnection in their families and have the opportunity to parent their children. What we heard is that engagement in HIV care is shaped and influenced by these experiences in a big way.

4.3 Quantitative phase

4.3.1 Quantitative methods

The qualitative findings above informed the second quantitative phase of our mixed methods approach. It was clear from the qualitative phase that from participants' perspectives, intergenerational child apprehension experiences are of paramount importance for HIV health and wellbeing. Given the small sample involved in the qualitative phase, we wanted to examine whether this finding held in the quantitative data. The quantitative component of this mixed methods analysis involved longitudinal observational data collected from Blanket Program participants in the larger Cedar Project cohort.

Sample

In total, 52 Blanket Program participants living with HIV contributed data to this analysis. We chose to limit the sample to Blanket Program participants who had also agreed to participate in the Cedar Project WeITel mHealth Study to keep the sample consistent across this dissertation.

Data collection & measures

Longitudinal data collected between 2011-2014 were included in the analyses presented here. This study combined three Cedar Project datasets: (1) main Cedar Project baseline data (collected at enrollment into the cohort); (2) main Cedar Project follow-up data (collected every six months); and (3) Cedar Project Blanket Program laboratory and questionnaire data (collected every three months). For this analysis "baseline" refers to: (1) time invariant variables collected at enrolment into the main Cedar Project cohort, such as sex or having a parent who attended residential school; (2) time variant variables collected during the follow-up questionnaire closest in time to enrollment into the Blanket Program, such as injection drug use in the past six months or sex work in the past six months; and (3) any variable collected as part of intake into the Blanket Program, such as HIV viral load or ART adherence.

The primary outcome was HIV viral suppression (yes/no). HIV Nucleic Acid Amplification Tests were collected quarterly over the study period and used to determine copies of the HIV virus present in the blood. Viral load was dichotomized into suppressed (<40 copies/mL) versus unsuppressed (>40 copies/mL). The main study variables were two indicators of intergenerational child apprehension experiences. When the Cedar Project was initiated, study partners and Elders emphasized the need to include survey questions addressing the impact of colonial systems in participants' lives. The first variable we used identified whether participants had been apprehended from their parents during childhood (yes/no). This was measured at enrollment into the Cedar Project cohort when participants were asked if they had ever been taken from their biological parents. The second variable assessed whether participants had ever had a child apprehended by the time they joined the Blanket Program (yes/no). At each follow-up, participants were asked whether they had a child apprehended by MCFD since their last visit. Participants who responded "yes" to this question during any follow-up prior to enrollment in the Blanket Program were considered to have ever had a child apprehended. Potential confounders included age (years), sex (male/female), and recent injection drug use at Blanket Program baseline (yes/no).

Analysis

Baseline characteristics were compared between those who were suppressed versus unsuppressed using Pearson's chi-squared tests or Fisher's exact (dichotomous variables), and t-tests or Wilcoxon rank sum (continuous variables), where appropriate. Generalized linear mixed effects logistic regression models (GLMM) were used to assess the effect of intergenerational child apprehension experiences on viral suppression (Breslow & Clayton, 1993). All participants were included in the models exploring effect of having been apprehended, while only those who reported being a parent were included in models exploring the effect of having had a child apprehended. As within-participant primary and secondary measures are highly correlated over time, GLMMs were used to account for repeated measures of individual participants. All analyses were conducted using R statistical software (version 3.5.0) with Ime4 and sjPlot packages (Bates, Mächler, Bolker, & Walker, 2014; Lüdecke, 2016; R Development Core Team, 2019). P-values of 0.05 were considered statistically significant and 95% confidence intervals are reported.

4.3.2 Quantitative findings

Participant characteristics

Baseline participant characteristics are presented in Table 4.4. Median age at enrollment into the Blanket Program was 31.5 years (IQR: 29.0-34.0). More than half were women (n=32; 61.5%) and slightly less than half lived in Prince George (n=25; 48.1%). Cultural connection was reported by less than half of participants, including having a traditional language spoken at home growing up (n=23; 46.0%); knowing how to speak a traditional language (n=23; 45.1%); participation in ceremony (n=17; 33.3%); often/always living by traditional culture (n=12; 23.5%); and recent access to traditional foods (n=21; 41.2%). Mean resilience score was 64.5 (SD: 24.6). Substantial proportions reported experiencing intergenerational traumas stemming from colonization, including having parent who attended residential school (n=24; 47.1%) or being unsure if a parent attended (n=20; 39.2%); and experiencing childhood sexual abuse (n=28; 56.0%). A total of 27 (52.9%) reported recent housing instability and 6 (11.5%) reported recent incarceration. In addition, 20 (40.8%) reported recent injection drug use and 8 (16.3%) reported recent sex work involvement. A majority of participants reported currently being on methadone (n=25; 73.5%) and having ever tried to quit using drugs or alcohol (n=45; 88.2%).

Characteristic	Total (n=52)	Viral suppression		p-	Missing
		No (n=27)	Yes (n=24)	value	n (%)
Demographics & Social Determinants					
Age (median, IQR)	31.5 (29-34)	31.0	32.5	0.280	0 (0.0%)
Sex (Female)	32 (61.5%)	18 (66.7%)	14 (58.3%)	0.746	0 (0.0%)
Location (Prince George)	25 (48.1%)	15 (55.6%)	10 (41.7%)	0.478	0 (0.0%)
In a relationship	19 (36.5%)	9 (33.3%)	10 (41.7%)	0.746	0 (0.0%)
Sexual identity (LGBT)	11 (21.2%)	4 (14.8%)	6 (25.0%)	0.485	0 (0.0%)
Education (Did not graduate high school)	42 (82.4%)	6 (22.2%)	3 (13.0%)	0.479	1 (1.9%)
Recent homelessness	11 (21.6%)	5 (19.2%)	6 (25.0%)	0.738	1 (1.9%)
Recent housing instability	27 (52.9%)	13 (50.0%)	13 (54.2%)	0.991	1 (1.9%)
Owned phone at mHealth enrollment	18 (34.6%)	9 (33.3%)	8 (33.3%)	1	0 (0.0%)
Cultural Connection & Resilience					
Language spoke often at home growing up	23 (46.0%)	13 (50.0%)	10 (43.5%)	0.865	2 (3.8%)
Speak traditional language ("yes" or "a bit")	23 (45.1%)	12 (46.1%)	11 (45.8%)	1	1 (1.9%)
Often/always speak traditional language	2 (3.9%)	1 (3.8%)	1 (4.32%)	1	1 (1.9%)
today					
Ever participated in traditional ceremonies	17 (33.3%)	8 (30.8%)	8 (33.3%)	1	1 (1.9%)
Often/always live by traditional culture	12 (23.5%)	7 (26.9%)	4 (16.7%)	0.501	1 (1.9%)
Recent access to traditional food	21 (41.2%)	13 (50.0%)	8 (33.3%)	0.365	1 (1.9%)
Resilience (mean, SD)	64.5 (24.6)	63.4	64.0	0.940	8 (15.4%)
Colonial Violence & Trauma					
Parent attended residential school				0.428	1 (1.9%)
Unsure	20 (39.2%)	13 (48.1%)	7 (30.4%)		
Yes	24 (47.1%)	10 (37.0%)	13 (56.5%)		
Apprehended from biological parents	41 (78.8%)	23 (85.2%)	18 (75.0%)	0.485	0 (0.0%)
Childhood sexual abuse (≤13)	28 (56.0%)	14 (56.0%)	13 (54.2%)	1	2 (3.8%)
Ever had a child apprehended	26 (60.5%)	14 (70.0%)	12 (54.5%)	0.477	1 (1.9%)
Recent incarceration	6 (11.5%)	1 (3.7%)	5 (20.8%)	0.088	0 (0.0%)
Sexual Vulnerability					
Recent sex work	8 (16.3%)	5 (20.0%)	3 (13.0%)	0.703	3 (5.8%)
Recent sexual assault	1 (2.0%)	1 (4.0%)	0 (0.0%)	1	2 (3.8%)
Substance Use & Treatment	00 (40 00)		0 (00 40()	0.004	0 (5 00()
Recent injection drug use	20 (40.8%)	11 (44.0%)	9 (39.1%)	0.961	3 (5.8%)
Ever overdosed	20 (38.5%)	10 (37.0%)	10 (41.7%)	0.960	0 (0.0%)
Recent alconol/drug treatment	27 (52.9%)	11 (42.3%)	15 (62.5%)	0.252	1 (1.9%)
Recently unable to access drug treatment	5 (9.6%)	3 (11.1%)	2 (8.3%)	1	0 (0.0%)
Ever on methadone 2^2	34 (65.4%)	14 (60.9%)	19 (82.6%)	0.184	5 (9.6%)
Current methadone treatment	25 (73.5%)	9 (64.3%)	16 (84.2%)	0.238	0 (0.0%)
Ever tried to quit drugs/alconol	45 (88.2%)	23 (88.5%)	21 (87.5%)	1	1 (1.9%)
	15 (96 59/)	24 (99 09/)	20 (02 20/)	0.602	0 (0 0%)
Revehological distrass (maan SD)	40 (00.0%) 0 02 (0 01)	24 (00.9%) 0 02	20 (03.3%) 0 03	0.090	0(0.0%)
Ever attempted suicide	15 (20 4%)	0.32 8 (30 8%)	0.30 7 (20 20/1)	0.30Z	1(1.0%)
Recent hospitalization	9 (18 0%)	2 (8 0%)	7 (29.2%)	0 074	2 (3.8%)

Table 4.4: Baseline characteristics of young Indigenous participants living with HIV(n=52), by baseline viral suppression

Recent refers to the 6-month period prior to the interview. ¹ Among a subset who reported having children (n=43); ² Among a subset who said yes to ever being on MMT (n=34)

Prevalence of intergenerational child apprehension

A majority (n=41; 78.8%) of participants reported having been apprehended from their parents (Table 4.4). Among 43 (82.7%) parents in the study, 26 (60.5%) reported having had at least one of their own children apprehended.

Effect of intergenerational child apprehension experiences on viral suppression

Unadjusted and adjusted models exploring the effect of intergenerational child apprehension experiences on HIV viral suppression are presented in Table 4.5. In adjusted models, both ever being apprehended (aOR: 0.23; 95%CI: 0.06-0.82) and ever having had a child apprehended (aOR: 0.24; 95%CI: 0.07-0.77) were significantly associated with reduced odds of viral suppression.

 Table 4.5: Longitudinal associations between intergenerational child apprehension

 experiences and viral suppression (GLMM)

Characteristic	uOR	95%CI	p-value	aOR	95%CI	p-value
Apprehended from parents	0.19	0.05-0.74	0.016	0.23	0.06-0.82	0.024
Age (Years)	1.18	1.00-1.40	0.055	1.14	0.98-1.33	0.095
Sex (Female)	0.58	0.18-1.94	0.380	0.68	0.24-1.94	0.473
Recent IDU at baseline	0.49	0.16-1.51	0.214	0.52	0.19-1.43	0.204
Ever had a child apprehended	0.20	0.05-0.77	0.020	0.24	0.07-0.77	0.017
Age (Years)	1.29	1.04-1.60	0.019	1.27	1.06-1.53	0.011
Sex (Female)	0.40	0.09-1.81	0.232	0.50	0.14-1.81	0.294
Recent IDU at baseline	0.53	0.13-2.09	0.364	0.42	0.13-1.34	0.142

4.4 Discussion

"Health to us is actually the result of having a sense of belonging, of knowing who you are, of knowing who your relatives were, of knowing what your place is in community. It's about social responsibility, it's about a whole complex network of relationships. So, health is not the absence or presence of disease. It's a way of relating...and of being." – Gwen Philips, Ktunaxa Nation (First Nations Health Council, 2010)

Gitxsan scholar and child advocate Cindy Blackstock has memorably stated, "If reconciliation means not having to say sorry twice – Canada is failing" (Blackstock, 2007). More than 10 years on from the 2008 Statement of Apology by then Prime Minister Stephen Harper to former residential school survivors, the issue of apprehensions of Indigenous children by Canadian governments remains un-remedied (Harper, 2008). This study's findings contribute to growing literature demonstrating that generations of child apprehensions are a negative social and

structural determinant of health for Indigenous families. The United Nations Declaration on the Rights of Indigenous People affirms Indigenous rights to self-determination and selfgovernment (Article 4), as well as to not be subject to genocide or violence, including forcible removal of children (Article 7.2) (UN General Assembly, 2007). This is echoed in the TRC's very first 'Call to Action' which demands a commitment to reducing the number of Indigenous children in care, and also Call to Action 4 which affirms the right of Indigenous governments to establish and maintain their own child welfare agencies (Truth & Reconcilliation Commission of Canada, 2015). Yet, at present, Splatsin is the only First Nation in BC that has been able to reclaim the right and responsibility to exert sovereign jurisdiction over child welfare (Christian, 2010; Grammond, 2018; TRC, 2015c, pp. 19-20). At a 2005 conference on the territory of the Six Nations of the Grand River, Indigenous leaders and experts created a set of foundational values to guide reconciliation in child welfare (Blackstock et al., 2006). They included recognition that Indigenous peoples are in the best position make decisions affecting Indigenous children, youth, families and communities, including to lead the development of child welfare laws, policies, research, and practice (Blackstock et al., 2006). It is critical that Indigenous individuals, families and communities' rights to self-determination and issues of jurisdiction be respected and reflected in both federal and provincial child welfare policy, and on the whole (Blackstock et al., 2006, p. 10; Grammond, 2018; Monture, 1989; TRC, 2015c, p. 55).

Nearly 80% (92% in the qualitative sample) of participants reported having been apprehended as children, which reflects that Cedar participants are survivors of the Sixties Scoop. They shared that working to (re)connect with family and identity was an important component of overall health and wellbeing (Theme 2). While writing this dissertation, I attended a blanket ceremony led by late Tsleil Waututh Elder *Qut-same* Leonard George (FNHA, 2017a). Former Cedar staff member Janene Erickson (Nak'azdli Whuten) was one of four witnesses to the work as part of her current role at the First Nations Health Authority. In her witnessing, she shared how her father's apprehension from his family and community has had a profound effect on her own connection to her traditional territory and family roots (Erickson, 2017). She used the metaphor of "stitching my blanket back together" to describe the work that she is doing to reclaim her identity (Erickson, 2017). Many Indigenous scholars and leaders have shared the work that they and others have done to maintain and re-claim their identity and family connections undermined by apprehensions by federal and provincial governments (Ansloos, 2017, pp. 1-3; Auger, 2016; Fournier & Crey, 1997, pp. 33-37; Landers & Danes, 2016; Landers et al., 2015; Sinclair, 2007; Varley, 2016). Similarly, the narratives of participants in

this study shared their efforts to break cycles of disconnection and reclaim connections with family and identity, including recognizing their own experiences were an extension of trauma that had begun generations before, seeking to cope in less harmful ways, rebuilding family relationships, and stopping the transmission of trauma in their own families (Pooyak et al., In press). Overall, participants shared a desire to live a good life that reflected a wholistic sense of wellness for themselves and their families – not just related to HIV (Ansloos, 2017, p. 94; Brant Castellano, 2008, p. 384; Henderson, 2008; Hovey et al., 2014; Poonwassie & Charter, 2001).

Just over 60% (100% in the gualitative sample) of parents in the study reported that their own child(ren) had been apprehended, which illustrates that Cedar participants and their children are profoundly affected by the Millennial Scoop. One possible contributor to increased risk of child apprehension among young Indigenous parents who have used drugs living with HIV is economic hardship (TRC, 2015c, p. 24). Colonization has contributed to persistent material inequities among Indigenous people in Canada (Reading, 2015). At the same time, HIV has been identified as both a cause and consequence of socioeconomic disadvantage (Farmer, Connors, & Simmons, 1996; Hogg, Puskas, Parashar, & Montaner, 2016; Joy et al., 2008; Rhodes, 2002; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005; Sumartojo, 2000). Previous research has called into question to what extent apprehensions of Indigenous children are a result of substantiated child abuse, versus perceived neglect resulting from experiences of economic hardship (Blackstock, Trocmé, & Bennett, 2004; Rothwell et al., 2018; Sinha, Delaye, & Orav-Lakaski, 2018; Sinha, Ellenbogen, & Trocmé, 2013). Using data from the 1998 and 2003 Canadian Incidence Study on Reported Child Abuse and Neglect, Blackstock and Trocmé determined that Indigenous children were being removed not because their families were putting children at greater risk, but because their families are themselves at greater risk as a result of social exclusion, poverty, and inadequate housing (Blackstock, 2007; Blackstock & Trocmé, 2005). In the most recent 2008 Canadian Incidence Study on Reported Child Abuse and Neglect, twice as many Indigenous children who were involved in the child apprehension system as a result of substantiated maltreatment also experienced economic hardship, compared to the overall proportion of children in care (35% vs. 15%) (Rothwell et al., 2018). In 2016, 73.9% of Indigenous children in care in BC were there as a result of concerns about neglect, in contrast to physical harm (8.5%), emotional harm (4.1%), sexual abuse (0.7%), other concerns (3.9%), or by agreement with parents (8.9%) (Special Advisor on Indigenous Children in Care, 2016, p. 12). Therefore, in addition to the call for Indigenous selfdetermination over child apprehension processes made earlier in the discussion, it is also vital

to end apprehensions resulting from economic hardship, and instead ensure that families, especially those affected by HIV, receive required supports and resources to provide safe and healthy home environments for their children (Blackstock et al., 2006, p. 11).

Young Indigenous people who have used drugs with intergenerational child apprehension experiences were over 75% less likely to be virally suppressed. These quantitative results affirmed the findings from the qualitative phase. There are multiple possible pathways through which intergenerational child apprehension experiences may affect engagement in HIV care and lack of viral suppression. Traumatic apprehensions and childhood abuse (including while in care of the state), as well as disrupted connections to family, identity, and culture may lead to lack of self-worth or sense of self which have consequences for engagement with healthcare services (Allan & Smylie, 2015; Health Council of Canada, 2012). Further, reliance on substance use to numb and cope with unresolved traumas stemming from colonization including abuse in childhood, traumatic apprehensions, and having a child apprehended – has been shown to be an obstacle to HIV treatment adherence (Socias & Milloy, 2018). As participants shared in Theme 3, navigating the stress and demands of MCFD involvement may take priority over the time and energy it takes to fulfil HIV-related responsibilities. In addition, fear of having children apprehended as a result of engagement with the healthcare system may prevent Indigenous parents, especially those who have used drugs, from accessing healthcare services (Bennett, Spillett, & Dunn, 2012; Denison, Varcoe, & Browne, 2014; Greene et al., 2014; McLachlan, Levy, McClintock, & Tauroa, 2015). Wraparound services that strengthen family and cultural connections, support young Indigenous people to heal from unresolved traumas, help prevent apprehensions, and also integrate HIV and substance use healthcare, are urgently required. It is vital to recognize that parenting, substance use recovery, and sustained engagement with HIV care are interconnected journeys which may require ongoing support (Gartner et al., 2018; McLachlan et al., 2015). Parenting and family connections must be considered a critical part of culturally-safe, healing-centered HIV care.

4.4.1 Limitations

The main limitation of this study was the small sample sizes in both the qualitative and quantitative phases. However, we worked to strengthen our interpretations and conclusions through triangulation using multiple methods. Taken together, the alignment of findings from the qualitative and quantitative phases suggests understanding and addressing the impacts of intergenerational child apprehension among young Indigenous people who have used drugs

living with HIV is important for policy and program development as well as future research. In addition, young men were underrepresented in both the qualitative and quantitative samples. There is a paucity of information about the role of having a child apprehended on the health and wellbeing of young Indigenous fathers and future research must take this into account.

4.4.2 Conclusion

To our knowledge, this is the first study to demonstrate statistical links between intergenerational child apprehensions and negative HIV outcomes among young Indigenous people who have used drugs. However, these findings are not 'new' as the harmful consequences of removing children from their family and cultural ties are well known. The urgent need to address apprehensions of Indigenous children has been asserted in both UNDRIP and the TRC, both of which have been adopted by current Canadian and BC governments (BC NDP, 2018; Trudeau, 2018). Yet, policies that facilitate removals persist and young Indigenous children continue to be apprehended. Addressing these harmful policies is imperative to tackle the underlying root causes of health disparities, including access and engagement with HIV care and treatment.

Chapter 5 Results – Mobile phone use and acceptability of mHealth among young Indigenous people who have used drugs in British Columbia, Canada

5.1 Background

Researchers have started to understand mobile phones as a necessity comparable to other utilities, and argue that gaps in access may re-enforce or exacerbate other disparities, including those related to health (Gonzales, Ems, & Suri, 2014; International Telecommunication Union, 2015). However, marginalized groups may be excluded from access due to structural inequalities (including health, economic, and gender disparities), creating a *digital divide*, or differential access to digital technologies (Van Dijk, 2005). Mobile phones have been identified as a critical resource for individuals who require regular contact with healthcare providers, social services, and social supports (Gonzales, 2016; Gonzales, 2014; Gonzales et al., 2014). Conversely, interruptions in phone connectivity may disrupt important health-related communication networks, such as contact with health providers, social services, and social supports (Gonzales et al., 2014).

Healthcare providers have begun to embrace the potential of widespread mobile phone usage by offering *mHealth* programs: mobile phone-based interventions which aim to improve health outcomes among clients experiencing a variety of health conditions. These mHealth interventions utilize mobile phone functions such as calling, texting, and/or smartphone applications, and may be used to provide reminders, information, or support. mHealth initiatives utilizing text messaging have been found to be successful in supporting engagement in healthcare for people living with HIV (Catalani, Philbrick, Fraser, Mechael, & Israelski, 2013; Finitsis, Pellowski, & Johnson, 2014; Jongbloed, Parmar, et al., 2015; Lester et al., 2010; Mbuagbaw, Ongolo-Zogo, & Thabane, 2013; Muessig, Nekkanti, Bauermeister, Bull, & Hightow-Weidman, 2015; Murray et al., 2015; Smillie, Borek, Abaki, et al., 2014; Smillie, Borek, Kop, et al., 2014). Such initiatives can facilitate real-time problem solving between patients and healthcare providers when medication, health, or other issues arise; remind clients to take medications, attend appointments, and take care of their health; and demonstrate that 'somebody cares' (Mahal et al., 2014; Smillie, Borek, Abaki, et al., 2014; van der Kop et al., 2012). More recently, mHealth initiatives have emerged that aim to reduce or prevent substance use, as well as optimize and expand treatment for substance use and HIV (Cordova

et al., 2016; Cordova et al., 2015; Horvath, Alemu, Danh, Baker, & Carrico, 2016; Kirk, Himelhoch, Westergaard, & Beckwith, 2013; Przybyla, Eliseo-Arras, Krawiec, Gower, & Dermen, 2016; Young, Swendeman, Holloway, Reback, & Kao, 2015). Notably missing is evidence on mobile phone use for health and mHealth interventions for Indigenous people living with or at risk of HIV, including those who use drugs (Jongbloed, Parmar, et al., 2015).

As previous chapters have demonstrated, Indigenous scholars and leaders continue to be concerned about high rates of HIV and other harms among Indigenous young people who use drugs resulting from the ongoing impacts of colonization (Allan & Smylie, 2015; Goldenberg et al., 2015; Jongbloed et al., 2019; Milloy, Montaner, & Wood, 2012; Wolfe, Carrieri, & Shepard, 2010). Substance use, poverty, barriers to healthcare access, and limited mobile phone ownership may be mutually reinforcing, leading to further marginalization from care and services. Despite the potential to connect these young Indigenous people who have used drugs to health services, little is known about mobile phone access and acceptability of mHealth programs for this key population. This study (1) examines patterns of mobile phone ownership and use among young Indigenous people who have used illicit drugs in British Columbia (BC); and (2) explores acceptability of mHealth for this population.

5.2 Methods

5.2.1 Study design and setting

This is a multi-method cross-sectional analysis involving young Indigenous people who have used drugs participating in the Cedar Project WeITel mHealth Study. The Cedar Project Partnership, an independent body of Indigenous Elders, leaders, and health experts governed all aspects of this study. Ethics approval was sought and obtained from the UBC Providence Health Care Research Ethics Board. All participants gave both verbal and written consent and it was emphasized that deciding not to participate in this sub-study would not affect continued involvement with Cedar or support from staff.

The study took place in inner-city settings of two cities in BC, Canada. Vancouver is a large city in southern BC on the traditional territories of the Coast Salish peoples. In 2016, nearly 14,000 Indigenous people lived in Vancouver, accounting for 2.2% of the population (Statistics Canada, 2018b). In BC's northern interior, Prince George is a forestry and mining town located on the traditional territory of the Lheidli T'enneh people. Just over 11,000 Indigenous people lived in

Prince George in 2016, accounting for 15.4% of the population (Statistics Canada, 2018a). Both cities are home to large "away from home" Indigenous populations with people from nations and territories across the province and country.

5.2.2 Participants

The Cedar Project is a prospective cohort of 782 young Indigenous people who have used drugs in Vancouver and Prince George, BC. The term Indigenous is used as Cedar Project participants represent many of the diverse First Nations, Inuit, and Métis communities across Canada, and are often living far away from their home communities. Study methods have been described previously in *Ch 2: Methodology*. Briefly, participants were recruited through healthcare providers, street outreach, and word-of-mouth. Initial recruitment took place between 2003-2007 and was re-opened in 2011. Participants were eligible if they self-identified as Indigenous; were between 14-30 years old; and had smoked or injected illicit drugs (other than cannabis) in the month before enrollment. Drug use was confirmed using saliva screens (ORAL-screen, Avitar Onsite Diagnostics). Follow-up interviews were carried out every six months and blood samples were collected for HIV and hepatitis C antibody tests.

In September 2014, The Cedar Project WeITeI mHealth Study was initiated. Of 60 HIV-positive participants in the Cedar Project Blanket Case Management study, 52 (88.3%) agreed to participate in the mHealth study. In addition, with an aim to recruit 94 HIV-negative Cedar Project participants, 131 were randomly selected to be invited, of whom 79 (78.7%) agreed to join. Thus, 131 Cedar Project participants were enrolled in the mHealth study and provided with a mobile phone and plan; weekly text messaging; and connection to a Case Manager. They also continued with their regular visits to the main Cedar Project cohort study.

5.2.3 Data sources

At enrolment into the mHealth study, participants completed a short questionnaire on mobile phone use. Close- and open-ended questions were related to interest in, and concerns with, using mobile phones and text messaging for health. Data were combined with questionnaires and serodata collected every six months as part of the main Cedar Project cohort. Time-independent variables were obtained from the Cedar Project baseline questionnaire and time-dependent variables were collected from the main Cedar follow-up visit occurring closest to (but <30 days after) the mHealth baseline visit.

5.2.4 Analytical approach

We conducted descriptive analyses related to phone ownership and patterns, and participants' interest and concerns using mobile phones for health. Differences in characteristics and acceptability of mHealth by phone ownership and HIV status were compared using Chi-squared and Fisher's Exact tests (dichotomous variables), and t-tests and Mann-Whitney-Wilcoxon Test (continuous variables). All p-values are two-sided. Analyses were performed using R version 3.5.0 (R Development Core Team, 2019).

Short responses (1-40 words) to open-ended questions were recorded verbatim. Using a rapid qualitative analysis approach (Pan et al., 2013), another Cedar co-investigator (MEP) and I independently read/re-read responses to identify recurring themes. Emerging themes were discussed, defined, and a coding manual was created. Responses were sorted into categories using nVivo software Version 10 (QSR International Pty Ltd, 2014). Representative responses were chosen to highlight themes.

5.3 Results

5.3.1 Baseline characteristics

More than half (n=81; 61.8%) of mHealth participants were women and half of mHealth participants lived in Prince George (n=65; 49.6%) (Table 5.1). Approximately half (n=63; 48.6%) had a parent who attended residential school, and substantial proportions had been apprehended from their parents (n=100; 76.3%) and/or experienced childhood sexual abuse (n=70; 56.9%). Among parents, 61 (53.5%) reported that they had ever had a child apprehended. Fewer participants reported connection to Indigenous cultures either in the past or present, including experiencing a traditional language spoken at home (n=54; 41.5%); speaking a traditional language (n=53; 40.8%); often or always speaking a traditional language today (n=4; 3.1%); participating in ceremony (n=30; 23.1%); recently accessing traditional food (n=63; 48.5%); and living by traditional culture (n=22; 17.3%). Recent involvement in sex work was reported by 15 (16.9%) participants and recent injection drug use was reported by 57 (44.2%) participants. Overall, 79 (60.3%) and 53 (40.5%) were living with Hepatitis C and HIV respectively.

Table 5.1: Baseline characteristics of young Indigenous people who have used drugs enrolled in the mHealth Program (n=131), by phone ownership

Characteristic	Total (n=131)	No phone (n=71)	Own phone (n=59)	p- value			
Demographics & Social Determinants							
Age (median, IQR)	33 (30-36)	34	33	0.264			
Sex (Female)	81 (61.8%)	41 (57.7%)	39 (66.1%)	0.427			
Location (Prince George)	65 (49.6%)	29 (40.8%)	35 (59.3%)	0.055			
In a relationship	33 (25.6%)	19 (27.1%)	14 (22.4%)	0.854			
Sexual identity (LGBT)	23 (17.6%)	7 (9.9%)	16 (27.1%)	0.019			
Education (Did not graduate high school)	106 (82.2%)	58 (84.1%)	47 (79.7%)	0.678			
Recent homelessness	34 (26.0%)	17 (23.9%)	17 (28.8%)	0.668			
Recent housing instability	56 (44.4%)	32 (46.4%)	24 (42.9%)	0.832			
Cultural Connection & Resilience							
Traditional language spoke often at home growing up	54 (41.5%)	34 (47.9%)	19 (32.8%)	0.119			
Speak traditional language ("yes" or "a bit")	53 (40.8%)	32 (45.1%)	20 (34.5%)	0.299			
Often or always speak traditional language today	4 (3.1%)	2 (2.8%)	1 (1.7%)	1			
Ever participated in traditional ceremonies	30 (23.1%)	12 (16.9%)	17 (29.3%)	0.142			
Often or always live by traditional culture	22 (17.3%)	12 (17.1%)	9 (16.1%)	1			
Recent access to traditional food	63 (48.5%)	30 (42.3%)	32 (55.2%)	0.199			
Resilience (mean, SD)	63.4 (21.4)	61.4	65.2	0.330			
Colonial Violence & Trauma							
Either parent at residential school (yes vs. no/unsure)	63 (48.5%)	39 (54.9%)	24 (41.4%)	0.176			
Apprehended from biological parents	100 (76.3%)	54 (76.1%)	46 (78.0%)	0.962			
Childhood sexual abuse (≤13)	70 (56.9%)	30 (45.5%)	39 (69.6%)	0.012			
Ever had a child apprehended	61 (53.5%)	28 (45.9%)	33 (63.5%)	0.093			
Recent incarceration	19 (14.8%)	13 (18.8%)	6 (10.3%)	0.277			
Sexual Vulnerability	/	- /					
Recent sex work ²	15 (16.9%)	8 (18.2%)	7 (15.9%)	1			
Recent sexual assault	5 (3.9%)	2 (2.9%)	3 (5.2%)	0.658			
Substance Use	/		/				
Recent injection drug use	57 (44.2%)	34 (49.3%)	23 (39.0%)	0.322			
Ever overdosed	53 (40.8%)	29 (40.8%)	23 (39.7%)	1			
Recent alcohol/drug treatment	51 (39.2%)	29 (40.8%)	22 (37.9%)	0.876			
Current methadone treatment	38 (57.6%)	25 (65.8%)	13 (46.4%)	0.187			
Ever tried to quit drugs/alcohol	109 (84.5%)	55 (78.6%)	53 (91.4%)	0.081			
Mental & Physical Health	50 (40 40()			0.040			
HIV Infection	53 (40.4%)	35 (49.3%)	18 (30.5%)	0.046			
	79 (60.3%)	46 (64.8%)	33 (55.9%)	0.396			
Psychological distress (mean, SD)	1.00 (0.84)	1.04	0.98	0.706			
Ever attempted suicide	44 (34.1%)	22 (31.9%)	21 (35.6%)	0.799			
Recent nospitalization	15 (11.5%)	5 (7.0%)	10 (16.9%)	0.100			

p-values indicated in bold are statistically significant

Recent refers to the 6-month period prior to the interview

¹ Among a subset of people who were parents (n=114)

² Among a subset of people who said yes to having sex in the past 6 months (n=91)

³Among a subset of people who said yes to ever being on MMT (n=66)

5.3.2 Patterns of mobile phone use

Slightly less than half of participants (n=59; 45.4%) reported owning a phone at baseline (Table 5.2). Among those, the majority owned a smart phone (n=46; 78.0%); had an unlimited texting plan (n=39; 70.9%); used the Internet on their phone (n=44; 74.6%); and texted daily (n=51; 67.1%). No differences in patterns of mobile phone use were observed between men and

women. Those who identified as LGBTQ or reported experiencing childhood sexual abuse were more likely to own a phone at enrollment, while people living with HIV were less likely to own one (Table 5.1).

	Count	Proportion
Own a phone		
Yes	59	45.4%
No	71	54.6%
Type of phone		
Basic	13	22.0%
Smart	46	78.0%
Texting plan		
Yes	53	89.8%
No	6	10.2%
Type of text plan		
Pay as you text	12	21.8%
Unlimited	39	70.9%
Limited	2	3.6%
Unsure	2	3.6%
Access Internet on phone		
Yes	44	74.6%
No	15	25.4%
Share a phone		
Yes	25	24.3%
No	78	75.7%
Frequency of texting		
Never	11	1.3%
Rarely (1x per month)	2	2.6%
Occasionally (1x per week)	4	5.3%
Frequently (2-3x per week)	8	10.5%
Very frequently (daily)	51	67.1%

 Table 5.2: Baseline mobile phone patterns among young Indigenous people who have used drugs enrolled in The Cedar Project WeITel mHealth Study (n=130)

5.3.3 mHealth acceptance

Participants were asked whether they felt using a mobile phone would be helpful for healthcare, and if they had any concerns using text messaging for their health (Table 5.3). A majority reported they felt using a mobile phone for health would be invaluable (n=120; 92.3%). There were no differences in mHealth acceptance among participants who owned a phone and those who did not. All but one participant living with HIV felt using a mobile phone would be helpful for their health, while more HIV-negative participants remained unsure (1.9 vs. 11.7%; p=0.047). No differences in concerns using text messaging for health were observed between those living vs. not living with HIV.

Do you think using a cell phone would help with your healthcare and be helpful to you?							
Total		Phone ownership			HIV status		
(n=130)	Yes	No	р	HIV+	HIV-	р	
	(n=59)	(n=71)		(n=53)	(n=77)		
Yes	120 (92.3%)	55 (93.2%)	65 (91.5%)	1.0	52 (98.1%)	68 (88.3%)	0.047
No	0 (0%)	0 (0%)	0 (0%)		0 (0%)	0 (0%)	
Unsure	10 (7.7%)	4 (6.8%)	6 (8.5%)		1 (1.9%)	9 (11.7%)	
Do you have any concerns about using text messaging for your healthcare?							
	Total	Phone ownership			HIV status		
10tai (n-120)	Yes	No	р	HIV+	HIV-	р	
(1=130)		(n=59)	(n=71)		(n=53)	(n=77)	
Yes	4 (3.1%)	2 (3.4%)	2 (2.8%)	1.0	1 (1.9%)	3 (3.9%)	0.445
No	125 (96.2%)	57 (96.6%)	68 (95.8%)		51 (96.2%)	74 (96.1%)	
Unsure	1 (0.7%)	0 (0%)	1 (1.4%)		1 (1.9%)	0 (0%)	

Table 5.3: Self-reported mHealth acceptance, by phone ownership and HIV status(n=130)

5.3.4 Benefits of phone use for health

The survey included an open-ended question asking why using a mobile phone may be helpful for health. Nearly all participants (n=127; 97.7%) responded, suggesting a diverse set of anticipated benefits. Analysis of these responses revealed six themes: (1) connection for emotional, mental, and spiritual support; (2) connection to family; (3) staying in touch/being reachable; (4) overcoming current barriers to phone use; (5) convenience, privacy, and safety; and (6) access to healthcare and emergency services.

Connection for support

Many participants (n=29; 22.8%) anticipated that a mobile phone would enable them to reach out or be contacted for emotional, mental, and spiritual support. Supporters included health professionals, "workers", spouses, friends, and family. One participant explained, *"I am a social person…I constantly stay in contact with people so I don't get depressed."* [*Female (F), Prince George (PG)*]. Another said, *"Having someone to talk to or someone to call. That helps."* [*F, Van*]. A third said, *"Communicating, letting people know how you are, what mood you're in…if they know you're in a bad mood, they might call you."* [*M, Van*]. Having support reducing or abstaining from substance use was how six (4.7%) participants anticipated using or currently used their phone for support. Participants felt that they could use the phone to call their 12-step/recovery sponsor; remember to take their methadone; access detox; and/or avoid a relapse. For example, one participant explained: *"My mental health hasn't been all that good lately but having someone to talk/text with will be better than turning to the bottle or needle. I won't be so alone."* [*F, Van*].

Connection to family

Connection to family was identified as an important potential health benefit by 11 (8.7%) participants. One participant described how having a phone would facilitate in-person visits with family: *"So I can get ahold of family more and probably go see them for Christmas!"* [*M, Van*]. Seven (5.5%) participants anticipated benefits related to pregnancy and parenting, including being able to stay in touch with social workers; receiving healthcare leading up to and during labour; and calling for help in case of emergency.

Staying in touch

Participants also spoke about the importance of "staying in touch" more broadly, suggesting that a benefit of having a mobile phone was connection in and of itself. Some spoke about how a phone would help reduce feelings of isolation and allow them to "keep connected with the world." One person described how, *"if I don't have a phone I feel cut off, I get anxiety"* [*F, Van*]. Another said, *"It's nice to have someone check up on you sometimes"* [*F, PG*]. Eight (6.3%) participants described the value of being more "reachable," as being unreachable was perceived as a source of stress for themselves and people around them. As one participant put it, *"I don't have to stress – people can reach me. The phone is my lifeline"* [*F, PG*].

Overcoming current barriers to phone use

A number of participants spoke of barriers they currently faced accessing a phone or making calls. Many who did not currently have a phone relied on borrowed phones, including those belonging to friends, in the lobby of their building, or available at local service agencies. Borrowing phones had drawbacks including the time and energy it took to find a phone; time limits on phone calls; inability to receive messages or a call back; lack of privacy; and potential for stigma or disclosure. One participant explained the impact of time limits: *"You have to get hold of people right away or it doesn't work out."* [*F, Van*]. Another described concerns when calling from service agencies, especially those known to serve people who use drugs: *"If you call from [Vancouver's supervised injection facility], it has call display...then people know that you're a drug user."* [*M, Van*].

Convenience, privacy, and safety

Some participants (n=16; 12.6%) indicated that having a mobile phone would make communication more convenient, including reducing the need to seek services and/or support on foot, in order to *"save you the mileage on your shoes"* [*M*, *PG*]. For three participants,

privacy was an important anticipated benefit of having their own phone. One explained that owning her own phone would give her more control over the circumstances of engagement with healthcare providers, whereas currently her partner was too involved: *"I can talk to my doctor one-on-one without having [partner] follow me or know everything"* [*F*, *PG*]. In addition, some participants felt having a phone would afford some degree of safety, including from violence in relationships and street life.

Access to healthcare and emergency services

More than 20% of participants expected to use the study phones, or currently used their own mobile phones, to connect directly to healthcare, including calling doctors, nurses and/or counsellors; arranging out-of-town medical care; making appointments; organizing rides; and receiving messages from health services. Fourteen (11.0%) participants also planned to use their phones to receive medication and appointment reminders. These included reminder calls from healthcare providers, as well as setting a reminder on the phone itself. Owning a mobile phone was also seen as a potentially important resource in case of physical or mental health emergencies faced by the participant themselves or those around them.

5.3.5 Concerns using texting for health

Few participants (n=4; 3.1%) had concerns about using text messaging for health (Table 5.3). Three participants spoke about anticipated challenges with mobile phone technology, including poor eyesight and low literacy making it difficult to read and respond to text messages. Two participants reported fears that mobile phones may cause cancer. One raised issues about confidentiality, explaining that it may be hard to confirm, *"that you're talking to the right person"* [*M*, *Van*]. However, others spoke about how confidentiality was not a concern, either because they did not feel they had serious health concerns, or because they would take steps to protect their privacy. For example, one participant said, *"No. Nobody's going to be looking at my phone. Even if they try there'll be a password"* [*F*, *Van*].

5.4 Discussion

To our knowledge, this is the first study to report on patterns of mobile phone ownership and use among young Indigenous people who have used drugs in Canada. Less than half (45.4%) of the participants in this study owned a mobile phone. Observed phone ownership was considerably lower than rates in Canada and North America in general, and similar or lower

compared to other marginalized groups, including street-involved youth (45-63%); homeless adults (44-78%); and people who use drugs (83-86%) (Asgary et al., 2015; Eyrich-Garg, 2010; Genz et al., 2015; Harpin, Davis, Low, & Gilroy, 2016; Milward, Day, Wadsworth, Strang, & Lynskey, 2014; Selfridge & Mitchell, 2014). Many young Indigenous people have been acutely affected by the legacy of colonization including having parents and family members who were forced into residential schools; removal from family into the child apprehension system; and experiences of childhood sexual abuse (Clarkson et al., 2015; Pearce et al., 2008). Some have turned to substance use as a way to cope with the effects of these historical and lifetime traumas (Pearce, 2014; Shahram et al., 2016; Shahram et al., 2017). Intersections of substance use and poverty likely create barriers to connectedness for these young people, for example by contributing to incarceration and chaotic housing transitions (Jongbloed, Thomas, et al., 2015). Lack of phone ownership must be considered within the context of colonization which continues to impact the wellbeing of Indigenous people across Canada (Greenwood, Leeuw, Lindsay, & Reading, 2015).

Despite low phone connectivity, a majority of participants, including those living with HIV, felt using a mobile phone for their health would be helpful. Mobile phones were viewed as a way to support social connections that were important for health, which may reflect an Indigenous worldview highlighting connectivity, relationships, interconnectedness, and interdependence as critical to health and wellbeing (Assembly of First Nations & Health Canada, 2015; Christian, 2010; Hill-Briggs, Gary, Hill, Bone, & Brancati, 2002; Marshall et al., 2015; McCormick, 1997; Van Uchelen et al., 1997; Waller & Okamoto, 2003). This was demonstrated in participants' emphasis on the role of mobile phones to as a way to (re)connect with family, despite experiences of childhood trauma and, sometimes, many years of separation (Clarkson et al., 2015; Pearce, 2014; Pearce et al., 2008; Shahram et al., 2016; Shahram et al., 2017). Threequarters (76%) of participants had been taken from their parents into the child welfare system, and as a result, many live far from their home communities. Yet, despite experiencing traumatic separations, family connections remain a powerful source of strength and resilience among young Indigenous people, as highlighted in other studies. Cree scholar Sherri Pooyak has noted that for Indigenous women involved in sex work in Saskatchewan, maintaining meaningful connections with family are integral to resilience and sense of belonging (Pooyak, 2009). Among 37 Diné (Navajo) youth, parents, and Elders, family support was identified as a primary coping strategy to address stress (Goodkind, Hess, et al., 2012). From a wholistic

perspective of health and wellbeing, phones may provide an important way of connecting with family and loved ones, especially when living far from home.

Earlier in this dissertation, the vital role of family in health and wellbeing has also been identified specifically among Indigenous people living with HIV (*Chapter 3: Experiences of the HIV cascade of care among Indigenous peoples*) (Jongbloed et al., 2019). Family relationships can be an important source of strength, a foundation of emotional support, and a motivator to stay healthy (Bouey & Duran, 2000; Cain et al., 2013; Reading et al., 2013). Family members, including partners, parents, and children often provide "primary" or "first line" support (Bouey & Duran, 2000; McKay-McNabb, 2012), helping to meet the logistical and emotional demands of dealing with diagnosis (Mill et al., 2008), initiating care (Prentice et al., 2011), and adhering to medication (Ka'opua & Mueller, 2004). Among Cedar participants living with HIV, access to mobile phones may enhance access to family networks and circles of care who may provide social, material, and emotional support as they navigate complex health issues, systems, and treatment regimens (Duran et al., 2010).

Mobile phones were also seen as an opportunity to support health and wellbeing in the context of pregnancy and parenting. Previous Cedar research among young Indigenous mothers observed that being able to parent their children was key to participants' own wellness, while those whose children had been taken into care expressed feelings of deep regret and loss (Shahram et al., 2016). Participants in the present study included pregnant mothers preparing for birth; parents of children currently in care of the state who were interested in visitation and regaining custody; and parents with custody of children who were navigating ongoing relationships with social workers, as well as trying to protect their children's health and safety. Participants identified diverse ways in which being connected by phone would support carrying out their responsibilities as parents, as well as nurturing their connections with children in care.

Indigenous people who have used drugs have described frequent encounters with systemic and interpersonal racism, stigma and judgment within harm reduction and health services (Allan & Smylie, 2015; Goodman et al., 2017; McKenzie et al., 2016; Reading et al., 2013; Simoni, Sehgal, & Walters, 2004). As noted by other researchers, participants in this study reflected that periods of "phonelessness", contribute to substantial burdens of time and energy required to remain in contact with healthcare services through in-person visits or by borrowing a phone (Gonzales et al., 2014). These efforts are not always successful, and can result in missed follow-up calls and appointments, or not receiving test results (Gonzales et al., 2014). Cedar participants anticipated having a mobile phone would support access to healthcare services, such as allowing them to speak directly with a health provider (doctor, clinic, nurse, pharmacist, counsellor), coordinate appointments and visit logistics, or call 911 in an emergency. Participants also viewed mobile phones as potential tools for accessing emotional, mental, and spiritual support from a diverse group of care providers when experiencing crises related to unaddressed trauma, substance use, and/or mental health challenges. This may reflect a desire to access what Indigenous scholars have described as "relational care," which emphasizes connections and takes a "whole person" perspective of wellbeing (Reading et al., 2013).

The impact of phonelessness on overall health may be especially pronounced in the context of HIV care. Findings from the systematic review in *Chapter 3* highlighted profound gaps in access to the HIV cascade of care among Indigenous peoples (Jongbloed et al., 2019). Emerging evidence also indicates that barriers to phone access may be associated with poorer health outcomes among people with HIV. Among people who use drugs living with HIV in Baltimore, those with detectable viral loads were less likely to own a mobile phone than those who were virally suppressed (aOR: 0.4, 95%CI:0.2-1.0) (Genz et al., 2015). Yet, our study indicates that young Indigenous people living with HIV are especially interested in receiving mHealth support to enhance engagement with healthcare. Others have shown mHealth programs may improve relationships between healthcare providers and patients over time (Mbuagbaw, Thabane, & Ongolo-Zogo, 2013; van der Kop et al., 2012), and that strong patientprovider relationships, which are engaging, validating, and emphasize partnership are more likely to facilitate engagement and retention in HIV care (Mallinson, Rajabiun, & Coleman, 2007). For Indigenous people who have used drugs, mHealth programs that take a culturallysafe approach, including avoiding judgement of drug use and honouring Indigenous identities, may help to strengthen relationships with healthcare providers and engagement in care (Maar et al., 2016; McCall & Lauridsen-Hoegh, 2014a).

A mobile phone may also be vital for the safety of young Indigenous people who have used drugs, in the face of housing instability (Jongbloed, Thomas, et al., 2015), unwanted police surveillance (Pan et al., 2013), transitions into injection (Miller et al., 2011), sexual assault (Pearce, Blair, et al., 2015), suicide (Jongbloed et al., 2017; Moniruzzaman et al., 2009), and overdose (Jongbloed et al., 2017). A qualitative study of 43 street-involved youth in Seattle

observed that mobile phones have become intrinsic to safety (Woelfer, Iverson, Hendry, Friedman, & Gill, 2011). Among 100 homeless people in Philadelphia, participants described how with access to a mobile phone, "help is just a phone call away," especially in the context of threats to health and safety (Eyrich-Garg, 2010). Our participants discussed how phones would support their safety through enhancing their privacy, and enabling them to assist others by calling 911 in an emergency. Mobile phones may also be an important source of safety information for people who have used drugs by allowing them to subscribe to relevant text message alerts (Eyrich-Garg, 2010). For example, the Vancouver Community Network Street Messaging System sends emergency text alerts such as extreme weather shelter openings or 'bad batch' incidents to enrolled residents (Vancouver Community Network, 2015). Closely related to safety is the impact of not having a phone on privacy. This may be of particular concern for people living with HIV or using substances, in the context of persistent stigma and criminalization. For example, Gonzales et al. described how reliance on borrowed phones by 29 low-income clients of an HIV clinic created a risk of HIV disclosure, such as if the clinic returned a call or if the owner of the phone was present during the call (2014). For one of our participants who relied on her partner's phone, having a phone of her own presented an opportunity to speak to her doctor privately without her partner "knowing everything." Taken together, these findings suggest that mobile phones may provide a degree of safety and autonomy for young Indigenous people who have used drugs.

Continuity of phone connection was often not consistently available to our participants via a mobile phone and plan (Eyrich-Garg, 2010; Gonzales et al., 2014). Our survey did not differentiate between having a phone versus having a phone with a phone number and airtime credit. Yet, when asked if they had a phone, many participants produced a handset, but explained that it was not connected except through Wi-Fi. Through informal discussions that emerged while administering this survey, we learned that mobile phone handsets are fairly accessible with participants reporting getting phones from various sources including second hand, as gifts, and through trades. However, substantial barriers to maintaining cellular connectivity exist, including high costs and existing debts with providers, preventing participants from having a phone plan (Eyrich-Garg, 2010; Selfridge & Mitchell, 2014). Of note, costs of cellular services are notably higher in Canada than other international markets, especially when the most basic packages are compared (NGL Nordicity Group, 2016). Gonzales offers the concept of *technology maintenance* to highlight the time, energy, and money required to maintain phone connectivity even after a phone handset is acquired, and

uses the term *dependable instability* to refer to the frequent, short-term disconnections among low-income people in the United States (Gonzales, 2016). Many Cedar participants experience such periods as a result of incarceration, housing transitions, relationship breakdowns, phone loss, lack of phone credit, or missed payments. Participants identified the resultant loss of touch with support and service networks as significant barriers to access. In her study of 37 low-income clients attending two free health clinics in the US Midwest, Gonzales et al. found that short-term phonelessness contributed to lost employment, lost welfare benefits, and strains on social support networks, which she describes as critical for health (Gonzales et al., 2014). The authors argued that frequently changing mobile phone numbers may disrupt access to health services, resources, and social support (Gonzales et al., 2014). Homeless adults in Philadelphia also characterized phones as being important tools to fulfill responsibilities to work, housing, and social support – all powerful social determinants of health (Eyrich-Garg, 2010; Loppie Reading & Wien, 2013).

In the absence of a phone number where they can be reached consistently over time, many participants use social media and messaging applications (e.g., Facebook) that can be accessed via Wi-Fi on a smartphone that does not have a cellular plan. High use (≥90%) of Facebook and other online communication tools have been observed among other marginalized groups, including street-involved youth in Denver (Harpin et al., 2016); British Columbia (Selfridge & Mitchell, 2014); and Seattle (Woelfer & Hendry, 2012). When a phone is lost or stolen, these points of digital connection are not severed in the same way as when a phone number is cancelled. However, at present, it is not common practice for healthcare providers to connect using these alternative digital technologies, perhaps as a result of privacy concerns and institutional policies limiting the use of social media (Gonzales et al., 2014). Reaching clients via messaging applications other than SMS may be a useful way to stay connected despite phone disruptions. Previous research has suggested that the success of mHealth programs involving text messages may be a result of capitalizing on technology that is both familiar and part of regular habits and routines, rather than creating something new (such as a new mobile application) that requires behaviour change (Lanham et al., 2013). Given many of our participants had access to a mobile phone without a cellular plan, future programs may be interested in using web-based messaging programs with better continuity in the event of phone loss or missed payments.

Participants' perspectives support growing evidence that two-way, open-ended supportive mHealth interventions may be more effective than those which are more narrowly focused (e.g., reminders only, single health condition) (Lester, 2013; Mills, Lester, & Ford, 2012; Wald et al., 2015). First, participants voiced a broad view of their health that captures physical, emotional, mental, and family wellness. This is affirmed by existing studies articulating a diversity of health priorities among Indigenous people living with and affected by HIV, beyond those directly related to the virus (McCall et al., 2009; Sazegar et al., 2013). Others have described a variety of strategies Indigenous people living with HIV use to stay healthy, which include, but are not limited to, taking ART medications (Prentice et al., 2011). Narrowly focusing on HIV/AIDS prevention and treatment outcomes, such as substance use recovery or ART adherence, may limit the potential for mHealth programs to address a person's own health and wellness priorities and goals. Further, frameworks developed by Indigenous bodies to guide mental wellness and substance use services in BC and Canada call for programs that build on the principle of wholistic wellness (Assembly of First Nations & Health Canada, 2015; FNHA et al., 2013). Second, highly targeted approaches, for example text message reminders to take a specific medication such as ART or methadone may disclose participants' HIV status or drug use if intercepted. Open-ended text messages, such as the "how are you?" approach taken in the original WelTel Kenya trial, minimize the possibility of disclosure by allowing participants to direct the conversation according to their comfort level (Lester et al., 2010). In the context of ongoing stigma and criminalization of drug use and HIV in Canada and elsewhere, avoiding unwanted disclosure is essential (Adam, Elliott, Corriveau, & English, 2014; Wood et al., 2010). However, participants in this study reported few concerns in this regard. It is possible that lack of concern stemmed from the fact that participants already constantly navigate privacy and disclosure related to drug use and HIV status, and have established strategies they would apply in the mHealth context.

5.4.1 Limitations

This study is subject to potential limitations. The cross-sectional design limits identification of trends or causal associations. Our sample may not be representative of all young Indigenous people who have used illicit drugs in BC; however, efforts were made to ensure that a diversity of characteristics were represented, including gender, city of residence, and injection and non-injection drug use. Further, we recognize that Indigenous peoples are diverse. As this survey was conducted among a particularly vulnerable group of young Indigenous people who have used drugs, our findings cannot be generalized to young Indigenous people in general. While

we did not assess landline connections, growing research has shown that these are declining, particularly among low-income groups, and likely do not present a key point of phone access for our participants (Gonzales, 2016; Samal et al., 2010). Finally, our survey did not capture participants' use of mobile handsets that were not connected via a cellular plan. However, this emerged as an area for future research.

5.4.2 Conclusion

While interest in using mobile phones for health was high among young Indigenous people who have used drugs in BC, low rates of phone ownership presented a barrier to engagement in mHealth initiatives. Future mHealth programs will need to take this into account, either by providing mobile phone handsets and cellular plans, or by supporting texting through online platforms currently utilized by their client base. Mobile phones were viewed as a way to support connections and relationships seen as critical to health and wellbeing among the young Indigenous people in this study. In addition, participants articulated a wholistic view of health, which included physical, mental, emotional, and family wellbeing. As a result, open-ended mHealth initiatives for young Indigenous people who have used drugs that: strengthen relationships with care providers and other social supports; enable individuals to set their own priorities for health and wellbeing; and take a culturally-safe approach, are recommended.

Chapter 6 Results – Effect of mHealth for HIV viral suppression among young Indigenous people who have used drugs living with HIV

6.1 Background

Evidence related to engagement in the HIV cascade of care among Indigenous people suggest that the global 90-90-90 targets have not been reached and concerning disparities compared to non-Indigenous people remain (*Chapter 3: Experiences of the HIV cascade of care among Indigenous people*) (Jongbloed et al., 2019; UNAIDS, 2014a, 2014b, 2017). Young Indigenous people living with HIV involved in substance use may face additional barriers to engagement in HIV care as a result of ongoing impacts of colonization, systemic violence, and intergenerational child apprehension experiences (*Chapter 4: Child Apprehension & HIV*). Others have identified persistent stigma and discrimination in healthcare settings that may further serve to impeded access to HIV care among Indigenous people, particularly those involved in substance use (Allan & Smylie, 2015; Goodman et al., 2017; Indigenous Health Working Group of the College of Family Physicians of Canada & Indigenous Physicians Association of Canada, 2016; Jongbloed et al., 2019; UNAIDS, 2014b). As a result, specifically tailored, culturally-safe interventions to support engagement in HIV care among young Indigenous people living with HIV who have used drugs are urgently required.

As noted in previous chapters, the primary clinical goal of the HIV cascade of care is viral suppression, which refers to a state in which HIV viral load in the blood is reduced to undetectable levels. Virological failure can occur when ART therapy fails to suppress and sustain viral load at undetectable levels. In this case, viral load can be said to rebound. In Canada, disparities in viral suppression between Indigenous and non-Indigenous people have been identified in a number of large longitudinal studies. A 2000-2012 Canadian Observational Cohort Collaboration (CANOC) analysis involving 7080 (7.0% Indigenous) people in BC, Ontario, and Quebec demonstrated that Indigenous people were less likely to suppress compared to Caucasian people (aHR:0.58, 95%CI: 0.50-0.68); however, risk of rebound was not significantly different between the two groups (aHR:1.03, 95%CI: 0.84-1.27) (Benoit (a) et al., 2017). Updated CANOC data (to 2014) involving 9031 (6.4% Indigenous) people revealed that being Indigenous was associated with reduced likelihood of suppression (aHR: 0.68; 95%CI: 0.62-0.75) and increased likelihood of rebound (aHR: 1.44; 95%CI: 1.23-1.68) (Palmer

et al., 2018). The BC Drug Treatment program involving 6142 (9.1% Indigenous) people demonstrated that in 2010, 80% of adults living with HIV in the province were suppressed; however, being Indigenous was associated with being unsuppressed (p<0.001) (Cescon et al., 2014). The Northern Alberta HIV Program cohort (1999-2005) involving 461 (37.3% Indigenous) people demonstrated that Indigenous participants, particularly those who used injection drugs, were less likely to suppress compared to non-Indigenous people. Further, Indigenous participants were more likely to experience virological failure, despite still being connected with care (Martin et al., 2010). In an update of this cohort (2006-2012), Indigenous people were less likely to suppress within six months of initiating ART compared to Canadian-born non-Indigenous people (aOR:0.44; 95%CI: 0.20-0.96), with no differences in odds of virological failure (Lefebvre et al., 2014).

However, three studies in major Canadian cities observed mixed results, suggesting disparities in viral suppression may be less pronounced in urban areas. The ACCESS cohort (2005-2014) involving 845 (38.6% Indigenous) people who use drugs in Vancouver observed no differences in viral suppression between Indigenous and non-Indigenous people (aOR: 1.15; 95%CI: 0.91- 1.46) (Milloy et al., 2016). In a cross-sectional analysis among 735 (9.5% Indigenous) Toronto-based participants involved in the Ontario HIV Treatment Network Cohort Study between 2007-2011, no differences in suppression were observed between Indigenous and non-Indigenous participants (p=0.88) (Jaworsky et al., 2016). Finally, a study of clinical records of 215 (70.7% Indigenous) people who used drugs attending the Winnipeg Health Sciences Centre observed that Indigenous people were less likely to be suppressed, compared to non-Indigenous people (p=0.008) (Erickson et al., 2015). These results may reflect that specialized healthcare services for people affected by HIV and substance use are concentrated in urban areas, resulting in more equitable access to treatment within cities. Put differently, concerning lack of HIV services in rural and remote areas, including reserves, may exacerbate disparities between Indigenous and non-Indigenous and non-Indigenous people living with HIV.

Six overarching determinants of engagement in HIV care, and consequently viral suppression, were identified in the systematic review presented in *Chapter 3: Experiences of the HIV cascade of care among Indigenous people* (Jongbloed et al., 2019). Promoting determinants included: (1) Indigenous culture, identity, and ceremony; (2) strength, resilience, and determination; and (3) social support systems (a strong circle of care). Hindering determinants included: (4) historical, intergenerational, and lifetime trauma; (5) stigma and discrimination;

and (6) intersecting health concerns. A growing body of literature suggests that culturally-safe case management that takes a wholistic perspective and combines both Indigenous and mainstream approaches is an effective way to build on strengths and overcome barriers to care for Indigenous people living with HIV (Barlow & Reading, 2008; Barlow et al., 2008; Barney, Rosenthal, & Speier, 2004; Reading et al., 2013). This is illustrated by the following examples:

The Ahalaya HIV/AIDS Case Management program was initiated in 1991 to serve Indigenous people with HIV living in Oklahoma City and Tuscon (Bouey & Duran, 2000). The Ahalaya model recognized the importance of cultural, spiritual, and traditional healing, in addition to mainstream biomedical and ancillary services, to address a broad diversity of needs (Bouey & Duran, 2000). Community-based (as opposed to clinic or hospital) Case Managers built relationships with other organizations to support client access to medical, mental health, spiritual, social, emergency, and educational services (Bouey & Duran, 2000). Case Managers conducted client assessments, worked with clients to develop care plans, made and followed up on referrals to other service providers, supported client engagement with referrals and related activities, and advocated for clients in their relationships with other agencies and providers (Bouey & Duran, 2000). Ahalaya Case Managers also provided or facilitated access to traditional and cultural services (Bouey & Duran, 2000). The Ahalaya model was adapted for use by the Alaska Tribal Health System and has been identified as a 'best practice' for HIV care and treatment among Indigenous people living with HIV (Barney et al., 2004; Speier, 2005). Similarly, in 2002, the Native American Health Center in the San Francisco Bay Area began offering the Holistic System of Care, a culturally-based model for integrated HIV/AIDS. substance use, and mental health services that relied on both Indigenous and mainstream approaches to meet the spiritual, medical, and psychosocial needs of Indigenous clients living with HIV (Nebelkopf & Penagos, 2005; Wright et al., 2011). Cultural approaches included talking circles, sweat lodge ceremony, traditional healers, seasonal ceremonies, prayer, smudging, drumming, herbs, women/men/youth societies, and pow wows (Wright et al., 2011). The model sought to: address multiple challenges faced by clients as a result of historical trauma, rather than taking a siloed approach; promote Indigenous identity and building community; emphasize solutions; and strengthen linkages among providers (Nebelkopf & King, 2003). Professionals, traditional healers, and peer support workers provided a "wraparound" team approach to care to build positive relationships with clients and support client ownership over their health and wellness journeys (Nebelkopf & King, 2003; Nebelkopf & Penagos, 2005). In Chinle, Arizona, the Navajo AIDS Network case management intervention combined medical,
support, and educational services through tribal control, and incorporated tradition and culture to support HIV treatment and prevention (Duran et al., 2010). Again, the model involved simultaneous support for HIV, substance use, and mental health through delivery of both mainstream and Navajo approaches, this time in a rural setting (Duran et al., 2010). The model emphasized building upon spiritual, cultural, and social assets and strengths embedded in Navajo culture – including, language ceremony and kinship connections – to mitigate health problems experienced by clients living with HIV (Duran et al., 2010). What these Indigenous case management models have in common is that they reflect a wholistic perspective of health and wellbeing; embed cultural healing practices and perspectives; and involve a team approach that centered on the relationship between client and provider.

Simultaneously, mobile health (mHealth), the provision of healthcare via mobile phones, has been identified as tool to support engagement in HIV treatment. Trials in sub-Saharan Africa have demonstrated that supportive text message interventions can improve HIV treatment adherence and viral suppression among people living with HIV (Lester et al., 2010; Mbuagbaw, Kop, et al., 2013). Similar results have been observed among people living with HIV in a Canadian setting: in a WeITeI study involving 80 participants attending an HIV clinic in Vancouver, Canada, viral load decreased significantly in the intervention period compared to the pre-intervention period (King et al., 2017). Others have begun to investigate the impact of mHealth for substance use among people living with HIV who use drugs in the United States (Ingersoll et al., 2015; Montoya et al., 2014; Moore et al., 2018; Moore et al., 2015; Reback, Fletcher, Shoptaw, & Mansergh, 2015). However, to our knowledge, no studies have yet established if mHealth integrated with culturally-safe case management is effective in supporting HIV viral suppression among young Indigenous people living with HIV who have used drugs. The aim of this study was to assess the effect of a weekly two-way supportive mHealth program on HIV viral suppression among young Indigenous people living with HIV who have used drugs in two Canadian cities.

6.2 Methods

6.2.1 Study design

This study used repeated measures pre-post design to examine the effect of a supportive text message mHealth program on HIV viral suppression among young Indigenous people living

with HIV who have used drugs. A repeated measures design has been recommended as an alternative when random assignment is not feasible (Shadish, Cook, & Campbell, 2002).

6.2.2 Setting and sample

The Cedar Project WeITel mHealth study is a sub-study nested within the Cedar Project, a cohort study of 782 young Indigenous people who have used injection and non-injection drugs in Vancouver and Prince George, BC, Canada. Initial recruitment into the Cedar Project occurred between 2003-2005, and was re-opened in 2011. Eligibility criteria included being between the ages of 14-30 at enrollment, provision of informed consent, self-identification as having Indigenous ancestry, and smoking or injecting drugs (including crystal methamphetamine, opiates, crack or cocaine), at enrolment. Cedar participants completed an enrolment visit as well as follow-up visits every six months. At each study visit, participants completed detailed questionnaires eliciting demographic, behavioural, and health information, administered by trained interviewers. Participants also provided a venous blood sample for HIV and HCV antibody testing. In gratitude for participants time, honoraria were provided at each follow-up visit.

Since 2011, Cedar Project participants living with HIV have been given the option of enrolling in 'The Cedar Project: Exploring HIV Case Management' study, also known as the Blanket Program. The Blanket Program is an individualized, culturally-safe case management approach connecting HIV positive participants with a Cedar staff member at each study site. Blankets hold a highly important place in many North American Indigenous cultures, as they continue to be used in giveaways and potlatches, honour children with names, and celebrate young people coming-of-age. Blankets are used to symbolically wrap children in love and care, and represent inclusion of young people in the community. Through one-on-one conversations, Cedar Case Managers help participants identify barriers to accessing HIV services and help navigate access and sustained adherence to HIV treatment. In addition, Case Managers help participants deal with food insecurity, and organize gatherings open to all participants at the Cedar study offices where traditional foods, including wild game and fish, are offered in a family-style setting. A critical part of the Blanket Program is regular blood work to monitor CD4 counts and HIV viral load. Case Managers and Cedar nursing staff support participants in interpreting these tests and counsel them about maintaining regular blood work as well as addressing any other health concerns.

In September 2014, all participants enrolled in the Blanket Program were eligible for enrolment in the Cedar Project WeITel mHealth study. As outlined in detail in *Chapter 2: Methodology*, The Cedar Project WeITel mHealth program was a structured mobile phone initiative to connect young Indigenous people living with HIV who have used drugs with Cedar Case Managers in a community-based setting. The program consisted of a bundle of supports, including a mobile phone and cellular plan, weekly two-way text messaging, and support from Cedar Case Managers between September 2014 and January 2016. In total, 52 Blanket Program participants living with HIV participated in the Cedar Project WeITel mHealth study and contributed data to this analysis (Figure 6.1). Reasons for not joining mHealth included: died (n=1), lost to follow-up (n=4), or not interested (n=3). Compared to other participants living with HIV, those in Vancouver and with a history of homelessness were less likely to have joined the mHealth program (see *Chapter 2: Methodology*). No other differences were observed between the two groups.



Figure 6.1: Derivation of the study sample

6.2.3 Data collection & measures

Longitudinal data collected between 2011-2016 were included in the analyses presented here. This study utilized three Cedar Project datasets: (1) main Cedar Project baseline data (collected at enrollment into the cohort); (2) main Cedar Project follow-up data (collected every six months); and (3) Cedar Project Blanket Program laboratory and questionnaire data (collected every three months).

For this analysis "baseline" refers to: (1) time invariant variables collected at enrolment into the main Cedar Project cohort, such as sex or having a parent who attended residential school; (2) time variant variables collected during the follow-up questionnaire closest in time to enrollment into the Blanket Program, such as injection drug use in the past six months or sex work in the past six months; and (3) any variable collected as part of intake into the Blanket Program, such as HIV viral load.

The primary outcome was HIV viral load. HIV Nucleic Acid Amplification Tests were collected quarterly over the study period and used to determine copies of the HIV virus present in the blood. Viral load was dichotomized into suppressed (<40 copies/mL) versus unsuppressed (>40 copies/mL). Effect of mHealth was measured using an indicator variable to identify whether the viral load measure was taken during the pre-program period (January 2011 -August 2014) or the mHealth program period (September 2014 – January 2016). Dose response was assessed as the degree of 'mHealth engagement' between a participant's viral load measures. Participants who responded to weekly text messages from Cedar Case Managers were considered engaged, compared to those who did not respond. The average number of weeks receiving a response was divided by the total number of weeks between two viral load measurements to create a proportion. This measure was dichotomized at the cohort mean (0.65) to represent above average versus below average (high vs. low) mHealth engagement. Additional variables included HIV cascade of care outcomes, socio-demographics, cultural connection, resilience, trauma, sexual vulnerability, substance use and treatment, and other health outcomes (See Chapter 2: Methodology for details about these additional variables).

6.2.4 Analysis

Baseline characteristics and HIV cascade of care outcomes were compared between those who were suppressed versus not suppressed using Pearson's chi-squared tests (dichotomous variables) and t-tests (continuous variables). Non-parametric (Fisher's exact and Wilcoxon rank sum) tests were used where appropriate. To assess changes in the primary outcome data of all measures from the pre-program time period were aggregated to calculate a single median log₁₀

viral load, which was compared to a corresponding median from data collected during the mHealth program using a paired t-test. Next, generalized linear mixed effects logistic regression models (GLMM) were used to assess the effect of being in the mHealth program period (compared to the pre-program period) on viral suppression (Breslow & Clayton, 1993). Two additional secondary analyses were undertaken. First, stratified versions of the main model were used to determine differences in the effect of mHealth by city and gender. Second, an additional GLMM modelled the effect of mHealth engagement on viral suppression in the mHealth program period. As within-participant primary and secondary measures are highly correlated over time, GLMMs were used to account for repeated measures of individual participants. All models were adjusted for hypothesized confounders, including age, sex, city of enrollment, and recent injection drug use. Analyses were conducted using R statistical software (version 3.5.0) with Ime4 and sjPlot packages (Bates et al., 2014; Lüdecke, 2016; R Development Core Team, 2019). P-values of 0.05 were considered statistically significant and 95% confidence intervals are presented.

6.2.5 Ethical considerations

The Cedar Project follows the guidelines provided in the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans – Chapter Nine: Research involving the First Nations, Inuit, and Métis Peoples of Canada (CIHR et al., 2014). In addition, the study adheres to the principles of Ownership, Control, Access and Possession in relation to research with Indigenous people (Schnarch, 2004). Through the Cedar Project Partnership, Indigenous collaborators were involved in the conception, design, and interpretation of the results of the Cedar Project WelTel mHealth study. Further, the Cedar Project WelTel mHealth Study was approved by the University of British Columbia Providence Health Care Research Ethics Board.

6.3 Results

6.3.1 Baseline HIV cascade of care outcomes

HIV cascade of care outcomes at entry into the Blanket Program are presented in Table 6.1 and Figure 6.2. In total, 38 (73.1%) participants reported they had a doctor they saw regularly for HIV care ('retained'). Most (n=47; 92.2%) had been offered ART and 40 (85.1%) reported currently being on ART. Median \log_{10} viral load was 1.6 (IQR: 1.6-3.8), and 24 (47.1%) participants were suppressed.

Table 6.1: Baseline cascade of care outcomes among young Indigenous who have used drugs people living with HIV enrolled in mHealth (n=52)

HIV assasds of asra outcome	Total (n-52)	Viral sup	pression		Missing
HIV cascade of care outcome	10tal (11=52)	No (n=27)	Yes (n=24)	p-value	n (%)
Have a doctor see regularly for HIV	38 (73.1%)	16 (64.0%)	21 (87.5%)	0.095	2 (3.8%)
Ever offered ART	47 (92.2%)	22 (84.6%)	24 (100%)	0.111	1 (1.9%)
On ART ¹	40 (85.1%)	15 (68.2%)	24 (100%)	0.003	0 (0.0%)
HIV viral load (median, IQR)	49 (≤40-6552)	-	-	-	1 (1.9%)
Log ₁₀ viral load (median, IQR)	1.6 (1.6-3.8)	-	-	-	1 (1.9%)
Viral suppression (≤40 copies/ml)	24 (47.1%)	-	-	-	1 (1.9%)

ART: antiretroviral therapy; ¹Among a subset who said yes to ever having been offered ART (n=47);

²Among a subset who said yes to currently being on ART (n=40)



Figure 6.2: Baseline cascade of care outcomes among young Indigenous people living with HIV who have used drugs enrolled in the mHealth Program (n=52)

6.3.2 Participant characteristics

Table 6.2 presents the baseline characteristics of mHealth participants living with HIV. Median age at enrollment into the Blanket Program was 31.5 years (IQR: 29.0-34.0). More than half were women (n=32; 61.5%) and slightly less than half lived in Prince George (n=25; 48.1%). Cultural connection was reported by less than half of participants, including having a traditional language spoken at home growing up (n=23; 46.0%); knowing how to speak a traditional language (n=23; 45.1%); participation in ceremony (n=17; 33.3%); often/always living by traditional culture (n=12; 23.5%); and recent access to traditional foods (n=21; 41.2%). Mean resilience score was 64.5 (SD: 24.6); this is lower than in a general population (Mean: 80.4; SD: 12.8) (Connor & Davidson, 2003), and similar to street-involved youth (Cleverley & Kidd, 2011), young people transitioning out of the child welfare system (Goldstein et al., 2013), and people with generalized anxiety disorder (Connor & Davidson, 2003). Substantial proportions reported experiencing intergenerational traumas stemming from colonization, including having

a parent who attended residential school (n=24; 47.1%) or being unsure if a parent attended residential school (n=20; 39.2%), being apprehended from their parents (n=41; 78.8%); experiencing childhood sexual abuse (n=28; 56.0%); and having had one of their own children apprehended (n=26; 60.5%). A total of 27 (52.9%) reported recent housing instability and 6 (11.5%) reported recent incarceration. In addition, 20 (40.8%) reported recent injection drug use and 8 (16.3%) reported recent sex work involvement. A majority of participants reported currently being on methadone (n=25; 73.5%) and having ever tried to quit using drugs or alcohol (n=45; 88.2%). Additional participant characteristics are available in Table 6.2. There were no statistically significant differences observed between participants who were virally suppressed at their baseline Blanket Program visit, compared to those who were not.

No (n=27)Yes (n=24)valuen (%)Demographics & Social DeterminantsAge (median, IQR) $31.5 (29.34)$ 31.0 32.5 0.280 $0 (0.0\%)$ Sex (Female) $32 (61.5\%)$ $18 (66.7\%)$ $14 (58.3\%)$ 0.746 $0 (0.0\%)$ Location (Prince George) $25 (48.1\%)$ $15 (55.6\%)$ $10 (41.7\%)$ 0.478 $0 (0.0\%)$ In a relationship $19 (36.5\%)$ $9 (33.3\%)$ $10 (41.7\%)$ 0.746 $0 (0.0\%)$ Sexual identity (LGBT) $11 (21.2\%)$ $4 (14.8\%)$ $6 (25.0\%)$ 0.479 $1 (1.9\%)$ Education (Did not graduate high school) $42 (82.4\%)$ $6 (22.2\%)$ $3 (13.0\%)$ 0.479 $1 (1.9\%)$ Recent homelessness $11 (21.6\%)$ $5 (19.2\%)$ $6 (25.0\%)$ 0.738 $1 (1.9\%)$ Recent housing instability $27 (52.9\%)$ $13 (50.0\%)$ $13 (54.2\%)$ 0.991 $1 (1.9\%)$ Owned phone at mHealth enrollment $18 (34.6\%)$ $9 (33.3\%)$ 1 $0 (0.0\%)$ Cultural Connection & Resilience $23 (46.0\%)$ $13 (50.0\%)$ $10 (43.5\%)$ 0.865 $2 (3.8\%)$ Speak traditional language ("yes" or "a bit") $23 (45.1\%)$ $12 (46.1\%)$ $11 (45.8\%)$ 1 $1 (1.9\%)$ Often/always speak traditional culture $12 (23.5\%)$ $7 (26.9\%)$ $4 (16.7\%)$ 0.501 $1 (1.9\%)$ Recent access to traditional culture $12 (23.5\%)$ $7 (26.9\%)$ $4 (16.7\%)$ 0.501 $1 (1.9\%)$ Recent access to traditional food $21 (41.2\%)$ $13 (50.0\%$	Characteristic	Total (n=52)) Viral suppression		p-	Missing
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Resilience (mean, SD) 64.5 (24.6) 63.4 64.0 0.940 8 (15.4%) Colonial Violence & Trauma 0.428 1 (1.9%) Parent attended residential school 0.428 1 (1.9%) Unsure 20 (39.2%) 13 (48.1%) 7 (30.4%) Yes 24 (47.1%) 10 (37.0%) 13 (56.5%) Apprehended from biological parents 41 (78.8%) 23 (85.2%) 18 (75.0%) 0.485 0 (0.0%)	Recent access to traditional food	21 (41.2%)	13 (50.0%)	8 (33.3%)	0.365	1 (1.9%)
Colonial Violence & Trauma 0.428 1 (1.9%) Parent attended residential school 0.428 1 (1.9%) Unsure 20 (39.2%) 13 (48.1%) 7 (30.4%) Yes 24 (47.1%) 10 (37.0%) 13 (56.5%) Apprehended from biological parents 41 (78.8%) 23 (85.2%) 18 (75.0%) 0.485 0 (0.0%)	Resilience (mean, SD)	64.5 (24.6)	63.4	64.0	0.940	8 (15.4%)
Parent attended residential school 0.428 1 (1.9%) Unsure 20 (39.2%) 13 (48.1%) 7 (30.4%) Yes 24 (47.1%) 10 (37.0%) 13 (56.5%) Apprehended from biological parents 41 (78.8%) 23 (85.2%) 18 (75.0%) 0.485 0 (0.0%)	Colonial Violence & Trauma					
Unsure20 (39.2%)13 (48.1%)7 (30.4%)Yes24 (47.1%)10 (37.0%)13 (56.5%)Apprehended from biological parents41 (78.8%)23 (85.2%)18 (75.0%)0.4850 (0.0%)	Parent attended residential school				0.428	1 (1.9%)
Yes 24 (47.1%) 10 (37.0%) 13 (56.5%) Apprehended from biological parents 41 (78.8%) 23 (85.2%) 18 (75.0%) 0.485 0 (0.0%)	Unsure	20 (39.2%)	13 (48.1%)	7 (30.4%)		
Apprehended from biological parents 41 (78.8%) 23 (85.2%) 18 (75.0%) 0.485 0 (0.0%)	Yes	24 (47.1%)	10 (37.0%)	13 (56.5%)		
	Apprehended from biological parents	41 (78.8%)	23 (85.2%)	18 (75.0%)	0.485	0 (0.0%)
Childhood sexual abuse (≤ 13)28 (56.0%)14 (56.0%)13 (54.2%)12 (3.8%)	Childhood sexual abuse (≤13)	28 (56.0%)	14 (56.0%)	13 (54.2%)	1	2 (3.8%)
Ever had a child apprehended $26 (60.5\%)$ $14 (70.0\%)$ $12 (54.5\%)$ 0.477 $1 (1.9\%)$	Ever had a child apprehended ¹	26 (60.5%)	14 (70.0%)	12 (54.5%)	0.477	1 (1.9%)
Recent incarceration 6 (11.5%) 1 (3.7%) 5 (20.8%) 0.088 0 (0.0%)	Recent incarceration	6 (11.5%)	1 (3.7%)	5 (20.8%)	0.088	0 (0.0%)
Sexual Vulnerability	Sexual Vulnerability					
Recent sex work8 (16.3%)5 (20.0%)3 (13.0%)0.7033 (5.8%)	Recent sex work	8 (16.3%)	5 (20.0%)	3 (13.0%)	0.703	3 (5.8%)
Recent sexual assault 1 (2.0%) 1 (4.0%) 0 (0.0%) 1 2 (3.8%)	Recent sexual assault	1 (2.0%)	1 (4.0%)	0 (0.0%)	1	2 (3.8%)
Substance Use & Treatment	Substance Use & Treatment					
Recent injection drug use20 (40.8%)11 (44.0%)9 (39.1%)0.9613 (5.8%)	Recent injection drug use	20 (40.8%)	11 (44.0%)	9 (39.1%)	0.961	3 (5.8%)
Ever overdosed20 (38.5%)10 (37.0%)10 (41.7%)0.9600 (0.0%)	Ever overdosed	20 (38.5%)	10 (37.0%)	10 (41.7%)	0.960	0 (0.0%)

 Table 6.2: Baseline characteristics of young Indigenous people living with HIV who have used drugs enrolled in mHealth (n=52), by baseline viral suppression

Recent alcohol/drug treatment	27 (52.9%)	11 (42.3%)	15 (62.5%)	0.252	1 (1.9%)
Recently unable to access drug treatment	5 (9.6%)	3 (11.1%)	2 (8.3%)	1	0 (0.0%)
Ever on methadone	34 (65.4%)	14 (60.9%)	19 (82.6%)	0.184	5 (9.6%)
Current methadone treatment ²	25 (73.5%)	9 (64.3%)	16 (84.2%)	0.238	0 (0.0%)
Ever tried to quit drugs/alcohol	45 (88.2%)	23 (88.5%)	21 (87.5%)	1	1 (1.9%)
Mental & Physical Health					
Hepatitis C co-infection	45 (86.5%)	24 (88.9%)	20 (83.3%)	0.693	0 (0.0%)
Psychological distress (mean, SD)	0.93 (0.81)	0.92	0.93	0.962	0 (0.0%)
Ever attempted suicide	15 (29.4%)	8 (30.8%)	7 (29.2%)	1	1 (1.9%)
Recent hospitalization	9 (18.0%)	2 (8.0%)	7 (29.2%)	0.074	2 (3.8%)
Becent refers to the 6-month period prior to the interview					

Recent refers to the 6-month period prior to the interview.

¹ Among a subset who reported having children (n=43);

² Among a subset who said yes to ever being on MMT (n=34)

6.3.3 Effect of mHealth on viral suppression

Median log₁₀ viral load significantly decreased from 1.93 in the pre-program period to 1.60 in the mHealth program period (p=0.024). Adjusting for other factors, the mHealth program period was associated with a 2.09 (95%CI: 1.15-3.79) increase in odds of being virally suppressed, compared to the pre-program period (Table 6.3). Stratifying by city of enrollment, the mHealth program period remained significantly associated with suppressed viral load in Prince George (aOR: 3.68; 95% CI: 1.39-9.81) but not in Vancouver (aOR: 1.38; 95%CI: 0.64-2.96). Stratifying by sex, the mHealth program period remained significantly associated with suppressed viral load among women (aOR: 2.90; 95%CI: 1.32-6.34) but not among men (aOR: 1.34; 95%CI: 0.54-3.34). During the mHealth program period, having higher mHealth engagement was associated with 4.48 (95%CI: 1.07-18.85) increased odds of being virally suppressed, compared to lower mHealth engagement (Table 6.4).

	uOR	95% CI	p-value	aOR	95% CI	p-value
All HIV+ participants						
mHealth (Yes)	2.32	1.29-4.18	0.005	2.09	1.15-3.79	0.016
Age	1.17	1.00-1.37	0.046	1.23	1.05-1.45	0.011
Sex (Female)	0.78	0.23-2.64	0.692	0.50	0.15-1.65	0.258
City (Vancouver)	0.59	0.18-1.90	0.374	0.48	0.15-1.57	0.227
Recent IDU at baseline	0.59	0.19-1.90	0.379	0.79	0.24-2.57	0.693
Stratified by city						
Prince George – mHealth (Yes)	3.45	1.32-9.04	0.012	3.69	1.39-9.81	0.009
Vancouver – mHealth (Yes)	1.75	0.82-3.72	0.146	1.38	0.64-2.96	0.412
Stratified by sex						
Women – mHealth (Yes)	2.89	1.33-6.28	0.007	2.90	1.32-6.34	0.008
Men – mHealth (Yes)	1.70	0.69-4.18	0.250	1.34	0.54-3.34	0.528

Table 6.3: Effect of the mHealth program period on HIV viral suppression (GLMM)

	uOR	95% CI	p-value	aOR	95% CI	p-value
High mHealth engagement	3.98	1.07-14.74	0.039	4.48	1.07-18.85	0.041
Age	1.12	0.87-1.46	0.378	1.18	0.91-1.55	0.212
Sex (Female)	0.95	0.14-6.52	0.956	0.32	0.04-2.41	0.271
City (Vancouver)	0.35	0.05-2.29	0.273	0.25	0.03-1.76	0.163
Recent IDU at	0.57	0.08-4.29	0.588	1.18	0.17-8.26	0.866
baseline						

Table 6.4: Effect of high vs. low mHealth engagement on viral suppression (GLMM)

6.4 Discussion

Results indicate that the Cedar Project WeITeI mHealth program may be effective in supporting viral suppression among young Indigenous people who have used drugs living with HIV. Our observation that participants with higher mHealth engagement had over four times greater odds of viral suppression, compared to those with lower mHealth engagement strengthens this conclusion. To our knowledge, this is the first study assessing the effect of a mobile health program to influence HIV outcomes among young Indigenous people who have used drugs living with HIV.

The chapters that follow explore participants' engagement with the mHealth program in-depth to understand how it may support them to move through stages of the HIV cascade of care to reach viral suppression. Briefly, this mHealth program may have supported health and wellbeing of participants living with HIV by providing a consistent connection to trusted circles of care, including both professionals, family, and other loved ones (Jongbloed et al., 2019). Recent mHealth research has shown that by facilitating communication with health services, and supporting connection with peers, two-way communication technology is a formidable vehicle for social support among people living with HIV (Blackstock, Shah, Haughton, Horvath, & Cunningham, 2014; Rana et al., 2015; Smillie et al., 2013; Smillie, Borek, Kop, et al., 2014). Further, our open-ended weekly texting prompt allowed participants to lead the dialogue with Cedar Case Managers and engage about a diverse range of topics and challenges that made sense to them. Previous chapters in this dissertation have highlighted how HIV intersects with positive (e.g. family, culture, resilience, circles of care) and negative (e.g., intergenerational apprehensions, substance use, trauma) determinants to shape young Indigenous peoples' health and wellness (Chapters 3, 4, 5). Similarly, others have taken a "whole-person" approach to digital interventions to support engagement in care which acknowledges and supports multiple health needs and priorities, such as co-morbidities and substance use (Ingersoll et al.,

2014; Ingersoll et al., 2015; Montoya et al., 2014; Moore et al., 2015). Finally, the Cedar Case Managers worked to acknowledge significant intergenerational and lifetime traumas experienced by participants, as discussed in greater depth later in this dissertation. The Cedar Project WeITel mHealth model took a culturally-safe and healing-centered approach that sought to build on participants' strengths, such as supporting family and cultural connections, which have been identified as critical determinants of engagement in HIV care (Barlow & Reading, 2008; Barlow et al., 2008; Jongbloed et al., 2019). This is especially important in the context of intergenerational family disconnections experienced by Cedar participants that have contributed to living away from home territories and extended family (Clarkson et al., 2015; Jongbloed, Thomas, et al., 2015).

Stratifications by city and sex suggested an effect of mHealth in all groups, however statistical significance was only observed among women and participants living in Prince George. The stronger effect observed among people in Prince George may reflect that participants entered the program with poorer HIV-related health and had greater room to improve. Differences in program implementation between the two study sites may have also affected the results. It may also be that connecting to services by phone was especially useful in Prince George as its cold climate and car-dependency are significant barriers to accessing services when a car or ride is not available. Finally, fewer HIV-related services are available in Prince George, which may have limited participants' options for engagement with support. Apparent differences between men and women may have greater implications and at present, there is a paucity of literature exploring gender differences in engagement with mHealth in the context of HIV treatment. Just one study was identified, a pre-trial analysis of 1068 people living with HIV screened for participation in the WelTel Retain study in Kenya, which determined that there were no differences in participation among men and women (van der Kop et al., 2016). In the present study, lack of significance of the effect of the mHealth program among men may be a result of limited power to detect a difference as there were fewer men enrolled (n=20). Or, it may be that the stronger effect observed among women represents that this type of program is more valued or useful among women, and alternative avenues of support should be explored for young Indigenous men who have used drugs living with HIV. What is critical is that young men living with HIV are not left behind.

Overall, the findings of this study have important implications for policy makers and health services. First, immediate and long-term funding should be made available to support

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integration of similar mHealth initiatives with existing community-based and clinical programs that have strong relationships with Indigenous people living with HIV. A recent economic evaluation of the original WelTel Kenya 1 trial observed that the two-way text message intervention was cost-effective by World Health Organization standards and therefore may increase the effectiveness of HIV treatment programs at relatively low cost (Patel et al., 2017). In addition, researchers at Oak Tree HIV clinic in Vancouver determined that implementing a similar WeITel mHealth program among clinic patients resulted in an average annual cost of \$36.72 per participant, and took approximately 43 minutes of healthcare provider time per person per year to administer (Campbell et al., 2018). Similar to our findings, both these WelTel studies observed significant decreases in viral load and increases in adherence among participants during the program period (King et al., 2017; Lester et al., 2010). Second, usefulness of mHealth programs should be explored in other case management settings, including those related to mental health, substance use, and child welfare. BC is currently experiencing an opioid crisis with Indigenous people significantly overrepresented among overdoses and overdose deaths (FNHA, 2017b; Jongbloed et al., 2017). Indigenous leaders and health experts have called for a continuum of services to ensure that those who use drugs stay safe, improve access to substance use treatment, and support people on their healing journeys (FNHA, 2017b). Integrating mHealth into both new and existing substance use programs may be an effective, low-cost, and culturally-safe opportunity to enhance their success and ability to provide "wraparound" care. In addition, Indigenous families in BC continue to experience disproportionate child apprehensions, with profound consequences for the health and wellbeing of all affected, as demonstrated in Chapter 4: Child Apprehension & HIV and elsewhere (Special Advisor on Indigenous Children in Care, 2016). Offering young Indigenous people involved in the child welfare system a bundle of mHealth supports that includes unlimited calling and texting, as well as weekly texting with trusted culturally-safe Case Managers, may support young peoples' agency, family connections, continuity across placements, and real-time problem solving when issues arise. Third, future mHealth programs for young Indigenous people who have used drugs living with HIV may want to integrate a peer-support model. Several studies identified in the systematic review presented in Chapter 3 suggested that being involved in peer support networks was highly valued among Indigenous people living with HIV (Barlow et al., 2008; McCall et al., 2009; Mill (c) et al., 2008; Mill et al., 2008; Reading et al., 2013; Sazegar et al., 2013). Adapting the Cedar Project WelTel mHealth program to build on this source of strength and connection is an important avenue for future research.

Strengths of this study include the repeated measures study design and the duration of the mHealth program. Overall, the study relies on five years of data (2011-2016), including over 16 months of the mHealth program. Using a repeated measures design minimized threats to validity resulting from natural variation between two time points. Previous mHealth studies involving people with HIV, including those who use drugs, have been of shorter duration (6 weeks to 1 year) (King et al., 2017; Moore et al., 2018). Our findings may suggest that two-way supportive mHealth programs are valued and sustainable over a longer term. Finally, we observed high participation and low loss to follow-up over the course of the study.

6.4.1 Limitations

Limitations of this study must be acknowledged. We cannot assess the impact of each component of the mHealth bundle (having a phone, having a cellphone plan with long distance, receiving weekly text messages, and support from Case Managers) separately and it is possible that one element more than another may have contributed to the program's effect. Our study sample did not include all Cedar participants living with HIV as many have died, moved away, become lost to follow-up, or are incarcerated. However, comparison of baseline characteristics suggests that both groups were similar and we believe those who did participate to be a good representation of young Indigenous people who have used drugs living with HIV who are interested in receiving additional ancillary support related to their HIV health and wellbeing. Limited sample size may have limited ability to detect an effect, such as within stratified analyses related to sex and city. It is possible that another program or policy change occurring concurrently with the mHealth program could have caused the observed effect (Shadish et al., 2002). This could have been addressed with inclusion of a control group; however, given the relatively small number of Cedar participants living with HIV, it was infeasible to conduct a randomized controlled trial or an interrupted time series with control analysis. Finally, we do not suggest that this mHealth program is a 'magic bullet'. Rather, it is one approach that may help support young Indigenous people who face barriers to HIV care become engaged and sustain viral suppression. It is vital that a variety of programs are offered to ensure diverse needs and preferences are addressed.

6.4.2 Conclusion

For young Indigenous people who have used drugs living with HIV, having a phone with consistent mobile connectivity, and weekly supportive text messaging with a Cedar Case

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Manager, may be an effective way to navigate barriers towards sustained engagement in the HIV cascade of care. This study adds to mounting evidence that mHealth programs involving weekly two-way text messaging are effective tools that, if taken to scale and offered to all people living with HIV, will support achievement of global 90-90-90 targets and end the AIDS epidemic (UNAIDS, 2014a, 2017).

Chapter 7 Results – Effect of mHealth for HIV-related health and wellness among young Indigenous people who have used drugs

7.1 Background

Mental health and wellness, including substance use, has been identified as a priority by Indigenous leaders in Canada and BC (Assembly of First Nations & Health Canada, 2015; Assembly of First Nations et al., 2010; FNHA, 2019a; FNHA et al., 2013). Mental health and wellness in this context reflects a wholistic perspective that includes balance between interconnected dimensions of mind, body, spirit, and heart (Assembly of First Nations & Health Canada, 2015). As discussed in depth in *Chapter 1: Introduction*, dispossession and control of Indigenous lands, rights, bodies, kinship connections, and identity, through colonial institutions (The Indian Act, residential school system, child welfare system, criminal justice system, and healthcare system) have had direct and intergenerational consequences for wholistic wellness. Despite ongoing resilience and resistance by Indigenous nations and individuals, considerable evidence links intergenerational and lifetime traumas stemming from colonization with mental health concerns including depression, anxiety, suicide ideation, psychological distress, and post-traumatic stress response (Bellamy & Hardy, 2015a, 2015b, 2015c; Bombay et al., 2011, 2014a; Kirmayer et al., 2003; O'Neill et al., 2018; Pearce et al., 2018; Whitbeck et al., 2009). Further, lack of respect for Indigenous self-determination, persistence of colonial institutions, and absence of cultural safety within mainstream health services, continue to impede access to both mainstream and traditional health and wellness systems that support Indigenous peoples' mental health and wellbeing (Allan & Smylie, 2015; FNHA et al., 2013).

Acknowledging the profound effect of colonial traumas on mental health and wellness, and subsequent reliance on the powerful numbing effect of drugs, is critical to understanding HIV vulnerability among young Indigenous people who have used drugs (Barlow, 2003; Christian & Spittal, 2008; Pearce et al., 2008; Pearce, Jongbloed, et al., 2015; Spittal et al., 2007; Yellow Horse Brave Heart, 2003). Walters, Simoni, and Evans-Campbell's 'indigenist stress-coping model' describes a pathway through which colonial traumas contribute to mental illness, substance use, and HIV (Walters et al., 2002; Walters & Simoni, 2002). Coping with ongoing colonial violence, historical or lifetime trauma, discrimination, and material inequities can contribute to high levels of mental and physical stress (Walters et al., 2002; Walters & Simoni,

2002). The stress of complex traumas contributes both directly and indirectly to increased risk of substance use, as well as both mental (e.g., post-traumatic stress, depression, anxiety) and physical illness (e.g., overdose, HIV, hepatitis C) (Walters et al., 2002; Walters & Simoni, 2002). Elders and Knowledge Keepers have also described spiritual consequences of substance use, as alcohol and illicit drug dependence can form an obstacle to achieving balance, which is critical for wellness. However, the stress-coping model also identifies that these negative health and wellness outcomes may be 'buffered' by the protective functions of identity, family, community, spirituality, and Indigenous healing approaches (Walters et al., 2002; Walters & Simoni, 2002). Others have discussed these protective factors in terms of individual and community-level resilience, which refers to the ability to cope with adversity and attain good life outcomes despite emotional, mental, or physical stress (Brant Castellano, 2008, p. 395; Dion Stout & Kipling, 2003, p. iii; Fleming & Ledogar, 2008; Kirmayer et al., 2009; Pearce, Jongbloed, et al., 2015; Pooyak, 2009; Pooyak et al., In press).

A growing number of epidemiological studies have observed relationships between cultural connection and indicators of mental health, wellness, and resilience, including those related to substance use. In their seminal study, Chandler and Lalonde monitored suicide rates in 196 BC First Nations bands between 1987-2000, observing that communities with higher degree of cultural continuity had substantially lower (or zero) rates (Chandler & Lalonde, 1998; Chandler & Lalonde, 2009). The Sacred Mountain Youth Project investigated risk and protective factors related to alcohol and drug use among 221 American Indian youth ages 15-24 in the southwestern United States (Baldwin et al., 2011). It found positive relationships between cultural identity, and both social support and protective family and peer influences (Baldwin et al., 2011). The authors argue that their findings affirm the need for programs that build on cultural strengths and support family connections (Baldwin et al., 2011). Among young Indigenous people who have used drugs in Cedar, cultural connection measures have been significantly linked to increased resilience, decreased psychological distress, and lower likelihood of probable post-traumatic stress response (Pearce et al., 2018; Pearce, Jongbloed, et al., 2015; Sharma et al., 2018). This evidence affirms what Elders and Knowledge Keepers have known for generations: that cultural teachings, values, and languages are the foundations of resilience and mental health and wellbeing among Indigenous peoples (Pearce, Jongbloed, et al., 2015).

Indigenous people affected by substance use also engage with mainstream substance use and HIV prevention services. However, Indigenous people have identified multilayered barriers to mainstream HIV prevention services, including healthcare, harm reduction, and substance use treatment (Duncan et al., 2011; Negin et al., 2015; Pearce et al., 2008; Spittal et al., 2007). Young Indigenous people who have used drugs have described frequent encounters with systemic and interpersonal racism, stigma, and judgment within harm reduction and health services (Allan & Smylie, 2015; Browne & Fiske, 2001; Canadian Aboriginal AIDS Network; Dell & Lyons, 2007; Mill et al., 2009; Simoni et al., 2004). Further, despite compelling evidence that harm reduction programs, including supervised drug consumption facilities (Pinkerton, 2011) and opioid substitution therapy (Gowing, Farrell, Bornemann, Sullivan, & Ali, 2011), are effective at preventing HIV infection, studies indicate that young Indigenous people are marginalized from these services (Kerr, Marsh, Li, Montaner, & Wood, 2005; Miller, Strathdee, et al., 2006; Spittal et al., 2007; Yang et al., 2011). Concerns remain that mainstream mental health and substance use services (including harm reduction) lack cultural safety, do not address the harms caused by colonial violence, and do not provide opportunities to build on the protective functions of cultural connection.

Studies have recently begun to investigate the impact of mHealth for a variety of health concerns, including related to mental health and wellness, substance use, and HIV (Jongbloed, Parmar, et al., 2015; Kazemi et al., 2017; Muessig et al., 2015; Nesvåg & McKay, 2018). The WelTel mHealth model has been identified as an effective approach to support people living with HIV overcome barriers to treatment and improve HIV-related outcomes through weekly supportive two-way text messaging with HIV care providers (Chapter 6: Effect of mHealth for viral suppression) (King et al., 2017; Lester et al., 2010). However, to our knowledge none have sought to use this supportive two-way mHealth approach to engage with young Indigenous people who have used drugs and face significant barriers to mental health and wellness as a result of historical and lifetime colonial traumas, in addition to ongoing challenges accessing care and services. Given the existing evidence related to barriers to substance use and ancillary services, as well as positive effects of cultural connection in supporting health and wellness, we sought to explore whether a bundle of culturally-safe supports including a phone and cellular plan, weekly text messaging with a Cedar Case Manager, integrated within a wraparound case management program, could support HIV-related health and wellness among young Indigenous people who have used drugs.

7.2 Methods

This study used a pre-post design to test the effect of a supportive text message mHealth program on HIV-related health and wellness outcomes among young Indigenous people who have used drugs participating in the Cedar Project WelTel mHealth Study. Both the Cedar Project and The Cedar Project WelTel mHealth program have been described in detail elsewhere in this dissertation (*Chapter 2: Methodology*). Briefly, the mHealth program consisted of a structured mobile phone initiative to connect young Indigenous people who have used drugs with Cedar Case Managers in a community-based setting. It offered a bundle of supports, including a mobile phone and cellular plan, weekly two-way text messaging, and support from Cedar Case Managers. The mHealth program built upon the existing Cedar Project Blanket Program, a culturally-safe, strengths-based case management model designed to support participants living with HIV engage in HIV care and ancillary supports. We had the opportunity to expand the reach of the program to include participants not living with HIV. As a result, we sought to test whether involvement in the mHealth program for all participants (HIV positive and HIV negative alike) could support resilience, cultural connection, and engagement with substance use services, as well as mitigate concerns of psychological distress and harmful substance use.

The mHealth program took place over a 16-month period with continuous enrollment beginning in September 2014 and ending in August 2015. The program came to an end for all participants in January 2016. Of 60 HIV-positive participants in the Blanket Program, 52 (88.3%) agreed to participate in the mHealth study. In addition, with an aim to recruit 94 HIV-negative Cedar participants, 131 were randomly selected to be invited, of whom 79 (78.7%) agreed to join. Thus, 131 Cedar participants were enrolled in the mHealth study and provided a mobile phone and plan; weekly text messaging; and connection to a Case Manager. mHealth participants also continued with their regular visits to the main Cedar cohort study.

The Cedar Project Partnership, an independent body of Indigenous Elders, leaders, and health experts governed all aspects of this study. Ethics approval was sought and obtained from the UBC Providence Health Care Research Ethics Board. All participants gave both verbal and written consent and it was emphasized that deciding not to participate in this sub-study would not affect continued involvement with Cedar or support from staff.

7.2.1 Data sources

Longitudinal data collected between 2011-2016 were included in the analyses presented here. A selection of self-reported binary measures was used to determine the effect of mHealth on HIV-related health and wellness indicators including substance use, mental health, and resilience. These measures were ascertained from questionnaires collected every six months as part of the main Cedar Project cohort. "Recent" refers to experiences and behaviours in the previous six-month period.

Connection to culture: Connection to Indigenous cultural practices has been hypothesized as a key protective factor for young Indigenous people who have used drugs. It was assessed using two dichotomous variables measuring cultural activity in the prior six-month period including: (1) recent access to traditional foods (yes vs. no); and (2) frequently living by traditional culture (never/rarely vs. often/always). These variables were defined by Earl Henderson (Cree & Métis) and Violet Bozoki (Lheidli T'enneh) who are Indigenous Elders, Knowledge Keepers, and members of the Cedar Project Partnership.

Resilience: Resilience, or the ability to cope with adversity, was characterized using the Connor-Davidson Resilience Scale (CD-RISC) previously validated for use with Cedar participants (Pearce, 2014; Pearce, Jongbloed, et al., 2015). The creators of the scale broadly define resilience as "personal qualities that enable one to thrive in the face of adversity" (Connor & Davidson, 2003). The CD-RISC measures resilience via 25 items on a 5-point scale with scores ranging between 0-100, with higher scores indicating greater resilience.

Substance use & treatment: Variables assessing substance use and access to services included recent injection drug use (yes/no); recently having tried to quit using drugs (yes/no); currently being on methadone treatment (yes/no); and recent engagement with any kind of alcohol or substance use treatment (yes/no).

Psychological distress: The Symptom Checklist-90-R (SCL-90-R) is a 90-item self-reported symptom inventory measuring the severity of nine dimensions of psychological distress in the past three months scored on a five-point Likert scale (from not at all to extremely). SCL-90-R scores were transformed into an average Global Severity Index, providing a single average measure profiling overall degree of psychological distress (Derogatis, 1996). This scale and score have been validated for use with Cedar participants (Pearce et al., 2018; Pearce, 2014).

mHealth engagement: Dose response was assessed as the degree of engagement with the mHealth program. Participants who responded to weekly text messages from Cedar Case Managers were considered engaged, compared to those who did not respond. The average number of weeks receiving a response was divided by the total number of weeks enrolled to create a single proportion of mHealth engagement over the whole study period. This measure was dichotomized at the cohort mean (0.55) to represent above average versus below average (high vs. low) mHealth engagement.

7.2.2 Analytical approach

Baseline participant characteristics were described using frequencies and proportions. To assess changes in health and wellness outcomes, all responses from the pre-program time period were used to calculate a single mean (continuous variables) or proportion (dichotomous). These were compared to corresponding means and proportions from data collected during the mHealth program using paired t-tests and tests of equal proportions where appropriate. Factors significant at the level of p < 0.05 were examined further using generalized linear mixed effects regression models (GLMM) to assess relationships between the outcome variable and being in the mHealth program period, compared to the pre-program period (Breslow & Clayton, 1993). Finally, an additional GLMM modelled the effect of mHealth engagement ("dose response") during the program period on factors significantly associated with receiving mHealth. As withinparticipant measures are highly correlated over time, GLMMs were used to account for repeated measures of individual participants. All models were adjusted for hypothesized confounders, including age, sex, and city of enrollment. Analyses were conducted using R statistical software (version 3.5.0) with lme4 and siPlot packages (Bates et al., 2014; Lüdecke, 2016; R Development Core Team, 2019). P-values of 0.05 were considered statistically significant and 95% confidence intervals are presented.

7.3 Results

In total, 131 participants received the mHealth program. Of these 118 (90.1%) had at least one follow-up in both the pre-program and mHealth program period and were included in this analysis. Participants with complete data were more likely to live in Prince George and report that a traditional language had been spoken often at home growing up (Table 7.1). They were less likely to have been involved with sex work at study entry (Table 7.1).

7.3.1 Baseline characteristics

Among participants with complete data, over half (n=72; 61.0%) were women and over half lived in Prince George (n=63; 53.4%) (Table 7.1). Approximately half (n=58; 49.6%) had a parent who attended residential school, and substantial proportions had been apprehended from their parents (n=92; 78.0%) and/or experienced childhood sexual abuse (n=63; 56.8%). Among parents, 56 (54.4%) reported that they had ever had a child apprehended. Fewer participants reported connection to Indigenous cultures either in the past or present, including experiencing a traditional language spoken at home (n=53; 45.3%); speaking a traditional language (n=48; 41.0%); often or always speaking a traditional language today (n=4; 3.4%); participating in ceremony (n=29; 24.8%); recently accessing traditional food (n=60; 51.3%); and living by traditional culture (n=21; 18.3%). Recent involvement in sex work was reported by 11 (13.4%) participants and recent injection drug use was reported by 50 (43.2%) participants. Overall, 49 (41.5%) and 70 (59.3%) were living with HIV and Hepatitis C respectively.

Table 7.1: Baseline characteristics of young Indigenous people who have used drugs enrolled in the Cedar Project WeITel mHealth Program (n=131), by completeness of data

Characteristic	Total	Complete	Incomplete	p-
	(n=131)	(n=118)	(n=13)	value
Demographics & Social Determinants				
Age (median, IQR)	33 (30-36)	33	34	0.420
Sex (Female)	81 (61.8%)	72 (61.0%)	9 (69.2%)	0.765
City (Prince George)	65 (49.6%)	63 (53.4%)	2 (15.4%)	0.016
In a relationship	33 (25.6%)	32 (27.4%)	1 (8.3%)	0.295
Sexual identity (LGBT)	23 (17.6%)	19 (16.1%)	4 (30.8%)	0.243
Education (Did not graduate high school)	106 (82 2%)	95 (81 9%)	11 (84.6%	1.000
Recent housing instability	34 (26.0%)	31 (26.3%)	3 (23.1%)	1.000
	56 (44.4%)	51 (45.1%)	5 (38.5%)	0.772
Cultural Connection & Resilience			4 (7 70)	0.000
Speak traditional language spoke often at nome growing up	54 (41.5%)	53 (45.3%)	1 (7.7%)	0.008
Speak traditional language ("yes" or "a bit")	53 (40.8%)	48 (41.0%)	5 (38.5%)	1.000
Often or always speak traditional language today	4 (3.1%)	4 (3.4%)	0 (0.00%)	1.000
Ever participated in traditional ceremonies	30 (23.1%)	29 (24.8%)	1 (7.7%)	0.297
Often or always live by traditional culture	22 (17.3%)	21 (18.3%)	1 (8.3%)	0.690
Recent access to traditional food	63 (48.5%)	60 (51.3%)	3 (23.0%	0.078
Resilience (mean, SD)	63.4 (21.4)	62.7	68.6	0.432
Colonial Violence & Trauma	· · · · ·			
Either parent at residential school (yes vs. no/unsure)	63 (48.5%)	58 (49.6%)	5 (38.5%)	0.563
Apprehended from biological parents	100 (76.3%)	92 (78.0%)	8 (61.5%)	0.187
Childhood sexual abuse (\leq 13)	70 (56.9%)	63 (56.8%)	7 (58.3%)	1.000
Ever had a child apprehended ¹	61 (53.5%)	56 (54.4%)	5 (45.5%)	0.752
Recent incarceration	19 (14.8%)	18 (15.5%)	1 (8.3%)	1.000
Sexual Vulnerability				
Recent sex work	15 (16.9%)	11 (13.4%)	4 (57.1%)	0.014
Recent sexual assault	5 (3.9%)	4 (3.4%)	1 (7.7%)	0.417
Recent injection drug use	57 (44.2%)	50 (43.1%)	7 (53.8%)	0.560
Ever overdosed	52 (40.0%)	47 (40.2%)	5 (38.5%)	1.000
Recent alcohol/drug treatment	51 (39.2%)	46 (39.3%)	5 (38.5%)	1.000
Current methadone treatment ³	38 (57.6%)	33 (58.9%)	5 (50.0%)	0.732
Ever tried to guit drugs/alcohol	109 (84 5%)	101 (86.3%)	8 (66 7%)	0.091
Health outcomes	100 (01.070)	101 (00.070)	0 (00.1 /0)	0.001
HIV infection	53 (40.4%)	49 (41.5%)	4 (30.8%)	0.560
HCV infection	79 (60.3%)	70 (59.3%)	9 (69.2%)	0.563
Psychological distress (mean, SD)	1.00 (0.84)	1.03	0.86	0.585
Ever attempted suicide	44 (34.1%)	39 (33.6%)	5 (38.4%)	0.763
Recent hospitalization	15 (11.5%)	12 (10.2%)	2 (15.4%)	0.171

p-values indicated in bold are statistically significant

Recent refers to the 6-month period prior to the interview

¹ Among a subset of people who were parents (n=114) ² Among a subset of people who said yes to having sex in the past 6 months (n=91)

³Among a subset of people who said yes to ever being on MMT (n=66)

7.3.2 Effect of mHealth on health and wellness outcomes

Receiving the mHealth program was significantly associated with a small average increase in resilience scores, from 61.60 in the pre-program period to 64.73 in the mHealth program period (p=0.025) (Table 7.2). In contrast, no significant associations were observed between receiving the mHealth program and cultural connection, substance use, substance use treatment, or psychological distress (Table 7.2).

Characteristic	Pre	During	p-value
Cultural Connection & Resilience			
Recent access to traditional foods	48.5%	45.3%	0.480
Often or always live by traditional culture	16.7%	11.4%	0.088
Resilience (mean score)	61.60	64.73	0.025
Substance Use & Treatment			
Recent injection drug use	42.3%	44.1%	0.728
Recently tried to quit	45.1%	35.8%	0.059
Currently on methadone	30.0%	31.4%	0.774
Recent substance use treatment	44.3%	42.3%	0.667
Health Outcomes			
Psychological distress (mean score)	0.96	0.99	0.628

Table 7.2: Comparisons of outcomes in the mHealth period vs. the pre-program period

In a longitudinal model adjusting for age, sex, and city, being in the mHealth program remained associated with a slightly higher mean resilience score (β =3.02; 0.34-5.69; p=0.027) (Table 7.3). However, no dose response relationship was observed as higher mHealth engagement was not significantly associated with increased resilience during the study period (Table 7.4).

Table 7.3: Effect of enrolment in mHealth	n program on resilience (GLMM)
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Characteristic	β	95%CI	p-value	Adj. β	95%CI	p-value
Resilience	2.87	0.20-5.54	0.036	3.02	0.34-5.69	0.027
Age				0.96	0.22-1.70	0.013
Sex (Male)				4.45	-2.22-11.11	0.193
City (Vancouver)				-6.90	-13.49–0.31	0.042

Characteristic	β	95%CI	p-value	Adj. β	95%CI	p-value
Resilience	4.50	-2.60-11.59	0.217	2.47	-4.67-9.60	0.500
Age				1.09	0.25-1.93	0.013
Sex (Male)				5.49	-1.88-12.86	0.147
City (Vancouver)				-6.57	-13.70-0.57	0.074

7.4 Discussion

To our knowledge, this study represents the first time mHealth has been tested as an approach to reduce HIV vulnerability among young Indigenous people who have used drugs. We hypothesized that involvement in a supportive mHealth program may have an effect on supporting resilience, cultural connection, and engagement in substance use services, while contributing to reductions in substance use and psychological distress.

Involvement in the mHealth program was associated with a small but statistically significant increase in mean resilience score. Supporting Indigenous resilience requires: (re)awakening concepts of self and personhood; revitalizing language, culture, and spirituality; strengthening individual and collective agency; supporting families and healthy child development; and building social capital, networks, and support (Kirmayer et al., 2011; Kirmayer et al., 2009). Previous Cedar Project research observed higher mean resilience scores among participants who reported living by traditional culture and speaking traditional languages (Pearce, Jongbloed, et al., 2015). Making changes in this area is not a short-term effort, and it may be that mHealth programs offered over a longer duration may result in larger, more clinically significant increases in resilience. Nevertheless, these are heartening results that demonstrate that with supportive, culturally-safe, participant-led text message engagement with a trusted care provider, there may be an opportunity for young Indigenous people who have used drugs to strengthen their ability to cope with adversity and live a good life.

We observed no associations between receiving the mHealth program and access to traditional foods or living by traditional culture. Seeking to measure cultural connection with quantitative indicators is a challenge, and it is possible that limitations of these variables obscured the ways in which the mHealth program did in fact support cultural connection for young Indigenous participants. In *Chapter 8* that follows, participants shared how they used the mHealth program as a way to (re)connect with children and other family, as well as engage in, or receive referrals to, cultural supports and activities. The qualitative data reflected a diversity of understandings of 'cultural connection', including family and kinship ties; use of traditional medicines (e.g. smudge); relationship to land; participation in ceremonies (e.g., potlatch, feasting, death protocols); making cultural items (e.g. drums); and time spent with Elders (*Chapter 9: Exploring mHealth engagement*). The field of Indigenous health research is undergoing a transformation including a shift to focus on strengths-based indicators of wholistic wellness ('wellness model') and away from deficit-based indicators of illness ('sickness model') (Fogarty et al., 2018; Loppie, Ward, & Marsden, 2016). This is an emerging area of work that has not yet been fully realized.

No associations were observed between substance use or access to substance use services, and involvement in the mHealth program. These null results, and those related to cultural connection, must be interpreted alongside findings presented in other chapters. Our mHealth program was designed as an enhancement to the Cedar Project Blanket Program, a wraparound program designed to support engagement in HIV care and ancillary services. It is possible that supportive text message-based mHealth initiatives work best through integration with existing culturally-safe substance use and cultural wellness programs in order to strengthen relational connection and engagement over time. This echoes findings from a recent systematic review of mHealth programs for substance use that identified a number of programs integrating mHealth within more conventional in-person healing modalities (Nesvåg & McKay, 2018). As a result, we recommend that the Cedar Project WeITel mHealth program may be an effective tool when incorporated into existing programs that support young Indigenous people to heal from traumas, navigate health and wellbeing related to substance use (whatever that looks like for them), and build resilience.

Two recent studies have evaluated promising interventions for Indigenous people who have used drugs that combine cultural and mainstream approaches, which may benefit from integration of a supportive text messaging mHealth component. The Indigenous Healing and Seeking Safety intervention was designed to address intergenerational trauma and substance use disorder together and involved facilitated sharing circles twice per week for 13 weeks (Marsh, Young, et al., 2016). Twenty-four Ojibway, Cree and Métis people who had struggled with intergenerational traumas and substance use living off-reserve in Northern Ontario participated in sharing circles centered on understanding the impact of trauma and substance use, connecting with tools to manage symptoms, and helping participants to stay safe and take good care of themselves (Marsh, Young, et al., 2016). Completing the program was associated with significant improvements in substance use and intergenerational trauma symptoms (Marsh, Young, et al., 2016). Our Life is a 6-month intervention for American Indian youth and families to address root causes of violence, trauma and substance use through healing from historical trauma, reconnecting with traditional culture, building parenting and social skills, and strengthening family relationships (Goodkind, LaNoue, et al., 2012). These, and other similar programs, could consider incorporating an mHealth component to maintain supportive relationships with participants following the intensive face-to-face intervention period.

7.4.1 Limitations

Use of a pre-post design without a control group prevents causal inferences related to study results. However, multiple measurements over time help to increase confidence that differences between the pre-period and program-period are not due to random chance. It remains possible that the differences observed are a result of other policies or programs running concurrently to the mHealth study period. The Cedar Project WeITel mHealth program is complex as it offers a bundle of supports, making it a challenge to tease apart which elements may or may not have contributed to the differences observed. As mentioned previously, limitations in the data alongside diversity of how participants used and engaged with the mHealth program may mean that health and wellness impacts went unmeasured in this study. In total, 13 (10%) of participants who participated in the mHealth program did not have a pre-period or program-period follow-up, which may have biased our results.

7.4.2 Conclusion

For young Indigenous people who have used drugs, having a phone with consistent mobile connectivity, and texting weekly with a Cedar Case Manager may support them to build resilience and ability to cope despite adversity. In its current iteration, however, we observed no associations between receiving the Cedar Project WeITel mHealth program and improvements related to substance use, engagement with substance use services, cultural connection, and psychological distress. However, we recommend that two-way supportive text messaging be considered as a way to facilitate sustained engagement with existing in-person mental health and wellness programs, which are culturally-safe and build on sources of strength and wellbeing inherent in Indigenous cultural systems.

Chapter 8 Results – Characterizing engagement in and perceptions of the Cedar Project WeITel mHealth Program

8.1 Background

Young Indigenous people who have used drugs face significant barriers to health and wellbeing as a result of historical and lifetime traumas stemming from colonization, especially related to substance use, HIV, and hepatitis C, as I have explored in-depth in previous chapters. Previous Cedar findings demonstrated that young Indigenous people who have used drugs in BC are dying at an alarming rate – nearly 13 times that of Canadians their age (Jongbloed et al., 2017). Concerning associations were observed between death and hepatitis C infection, having previously attempted suicide, and recent non-fatal overdose (Jongbloed et al., 2017). Nearly half of deaths were a result of overdose or other drug-related causes (Jongbloed et al., 2017). In addition, 15% of participants died of illnesses related to hepatitis C, HIV or HIV/hepatitis c co-infection, despite being under 40 years old and living in a setting of universal healthcare (Jongbloed et al., 2017). Indigenous leaders and scholars have called for responses to HIV and substance use that are culturally-safe, healing-centered, and strengths-based (Assembly of First Nations et al., 2010; Christian & Spittal, 2008; FNHA, 2017b; Jongbloed et al., 2019). These responses must acknowledge the ongoing impacts of intergenerational traumas while building on Indigenous perspectives, identities, and cultural strengths (Barlow & Reading, 2008; Duran & Walters, 2004; McKenzie et al., 2016; Myhra & Wieling, 2014; Pearce, Jongbloed, et al., 2015; Walters et al., 2002; Walters & Simoni, 1999).

Results from the Cedar Project WeITeI mHealth study presented in the preceding chapters demonstrated that receiving a bundle of mobile phone supports (including a phone, long-distance plan, and weekly text messaging with Case Managers) integrated with a culturally-safe case management program in a community-based setting was associated with increased resilience among young Indigenous people who have used drugs (*Chapter 7*). Among those living with HIV, receiving the program was associated with increased odds of viral suppression (*Chapter 6*). This work builds on global research by the WeITeI team, which observed that receiving a weekly two-way text messaging program improves adherence and viral suppression among people living with HIV in both Nairobi, Kenya and Vancouver, Canada (King et al., 2017; Lester et al., 2010). A growing body of literature has sought to understand engagement with supportive text messaging programs for HIV-related health in greater depth. Among 80 people

enrolled in the one-year WeITel OakTree study in Vancouver, 15% (565 of 3764) of responses to "how are you?" texts indicated that the participant had a problem, with common queries relating to medical advice (26.1%), counselling (9.3%), prescription refill (9.5%), appointment management (13.5%), checking in (9.8%), and study/phone support (6.4%) (Campbell et al., 2018). In Kenya, an in-depth analysis of the patient-clinician text message exchanges during the WeITel Kenya 1 trial involving 271 people living with HIV in Nairobi reported that 3.2% of text responses indicated a problem, with health issues accounting for most (72%) of problem responses (van der Kop et al., 2012). In addition, the authors noted that patients' key perceived benefits of the program included being reminded to take medication and feeling that "somebody cares" (van der Kop et al., 2012). Further, findings from the CAMPS trial of text messaging for ART adherence among 200 people living with HIV in Cameroon demonstrated that two-way text messaging opens alternative avenues for communication with patients, and provides the opportunity for professional assistance in real time (Mbuagbaw, Thabane, et al., 2013).

Yet, greater understanding of the patterns and dynamics of participant engagement with mHealth programs is required to support scale-up and integration of similar initiatives within existing community-based and clinical services (Bardosh, Murray, Khaemba, Smillie, & Lester, 2017; Lanham et al., 2013; Tilahun et al., 2018). Work to determine factors that support adoption and implementation of WelTel in 'real world' settings in Canada and Kenya is emerging and currently underway (Bardosh et al., 2017; Tilahun et al., 2018). An early case study of WelTel's approach in Kenya found that the intervention does not attempt to change clinic organization or patient-provider relationships but rather strengthens existing relationships and organizational infrastructure by opening a new communication pathway (Lanham et al., 2013). An implementation evaluation of WelTel in multiple settings in Canada and Kenya involving 32 key informant interviews found that the two-way texting approach improves cultures of care; helps efficiency and organization of service delivery; and is adaptable to be tailored to local settings and needs (Bardosh et al., 2017). However, despite studies showing that the service is both low cost and cost effective (Campbell et al., 2018; Patel et al., 2017), securing sustainable funding for an innovation less recognizable to the health system than, for example, new medications, has remained a challenge (Bardosh et al., 2017). This analysis seeks to characterize participants' engagement with the Cedar Project WeITel mHealth program, investigate factors associated with engagement, and assess participant perceptions of the program. Understanding engagement with, and perceptions of, the mHealth program is important to scale up and build on the success of this program to support health and wellness

among young Indigenous people who have used drugs. Further, insight into weekly text messaging engagement informs human resource requirements (e.g., training; staff characteristics) for future mHealth programs and suggests important considerations when developing program protocols.

8.2 Methods

The Cedar Project WeITeI mHealth Study evaluated a mobile phone program to support engagement in HIV prevention and treatment among young Indigenous people who have used drugs in BC. The methods have been described elsewhere in detail (*Chapter 2: Methodology*) (Jongbloed et al., 2016). Briefly, a sub-sample of participants enrolled in the Cedar Project, an ongoing cohort study involving young Indigenous people who have used drugs in Vancouver and Prince George (Spittal et al., 2007), were invited to participate in the Cedar Project WeITeI mHealth program between September 2014 to January 2016. Indigenous collaborators, collectively known as the Cedar Project Partnership, governed the entire research process and the research was approved by the UBC Providence Health Care Research Ethics Board. In total, 131 participants enrolled in the mHealth program and provided written informed consent.

8.2.1 Cedar Project WelTel mHealth program

Each participant was provided with a mobile phone and Canada-wide calling/texting plan at the beginning of the mHealth study. If phones were lost or stolen, participants were eligible to receive one replacement. If two phones were lost, the participant could bring in their own sim card-enabled cellular handset to use with the monthly cellular plan provided by the study. An automatic 'how's it going?' text message was sent to enrolled participants automatically via the WeITel mHealth software platform every Monday at noon for the duration of the study (70 weeks). Cedar Case Managers responded to all text messages, and provided active follow-up via text, phone, and in-person with participants who reported a problem. Each study phone was pre-programmed with phone numbers, including the Cedar Project study offices, emergency, health, and substance use related contacts. Emergency numbers were especially important as the WeITel mHealth texting and supports were offered only during business hours. Participants were aware that it was not an emergency service.

8.2.2 Data collection

WeITel platform data. The WeITel software used to deliver the mHealth program automatically recorded all text message interactions between participants and Case Managers for the duration of the study. No other texts sent or received on study phones could be accessed or recorded. Actions taken by Case Managers during follow-up could be recorded as brief notes in the WeITel platform. As a result, the unit of analysis is a 'weekly texting interaction' between the participant and the Cedar Case Manager, beginning with the automatic system-generated, "How's it going?" prompt text message. An example of a weekly texting interaction is presented in Figure 8.1. Weekly texting interactions were grouped by individual participant to understand engagement over the course of the study.



Figure 8.1: Example of a weekly texting interaction (unit of analysis)

mHealth baseline data. With participants' consent, data collected routinely as part of the main Cedar cohort was used to create an "mHealth baseline" which captured socio-demographics, strengths, intergenerational and lifetime trauma, sexual vulnerability, substance use patterns, and health outcomes. Data collected closest to a participant's date of enrollment into the mHealth program, up to a total of 30 days after enrollment, was accessed from the main Cedar baseline (time invariant factors) and follow-up questionnaires (time varying factors) and combined with the WelTel platform data.

mHealth follow-up survey. As the Cedar Project WelTel mHealth Study drew to a close, all participants were invited to complete a brief, one-time follow-up questionnaire related to mobile phone connectivity, use of mobile phones for health and wellness, and perceptions of the program. Data was collected from October 2015 to April 2016. Surveys included a combination of closed- and open-ended questions.

8.2.3 Measures

Primary outcome. The primary outcome of interest was mHealth engagement, which included three levels: (1) inactive; (2) active not responding; and (3) active and responding (Figure 8.2). To understand characteristics associated with the highest level of engagement, we created a dichotomized variable: active and responding vs. inactive or active but not responding. Throughout the study, participants could be categorized as active (currently have phone connectivity) or inactive (no phone connectivity, for example lost or stolen) in the WeITel platform. Each Monday at noon, an automatic system-generated "how's it going?" text was sent to all active participants. Some participants responded by text, while others chose to respond in other ways (e.g., phone call, in person) or did not respond at all. If participants did not reply by Wednesday at noon, a second automatic message went out saying, "haven't heard from you, just checking in" (or a similar variation). If participants did not respond by Thursday or Friday, Cedar Case Managers followed up by phone. After the program came to an end, interactions were reviewed manually and categorized as "not responding" if participants did not respond at any point to our texts or phone call during the week.

Not yet enrolled	Inactive	Active, not responding	Active and responding
Not yet enrolled	 Participant's phone is lost or stolen. No current active number. Marked as "inactive" in the WelTel software. WelTel software is not sending them any messages. 	 Participant is "active" in the WelTel software. On Monday, they were sent the 'how's it going' text message by the system. However, they did not respond (by text or otherwise) to the message that week. 	 Participant is "active" in the WelTel software. On Monday, they were sent the 'how's it going' text message by the system. They responded either by text or otherwise at some point during the week.

Figure 8.2: Level of mHealth engagement

Engaged

Study variables. Based on previous WelTel and Cedar Project studies (Clarkson et al., 2015; Jongbloed, 2012; King et al., 2017; Murray et al., 2015; Pearce et al., 2008; Pearce, Jongbloed, et al., 2015; van der Kop et al., 2012), we hypothesized that a number of factors may influence level of mHealth engagement. Measures assessed at entry into the main Cedar Project

included socio-demographic characteristics (sex, city, age, education); intergenerational colonial trauma (parental residential school attendance, child apprehension, childhood sexual abuse). Measures assessed at entry into the mHealth program included: baseline phone ownership; resilience score; recent traumatic experiences (sexual assault, incarceration; homelessness; housing instability), recent substance use (injection drug use; substance use treatment; opioid substitution therapy); recent sex work; and health outcomes (HIV status; psychological distress score; recent hospitalization).

8.2.4 Analytical approach

Baseline participant characteristics and level of mHealth engagement over the study period were described using frequencies and proportions. Unadjusted and adjusted generalized linear mixed effects logistic regression models (GLMMS) were used to determine participant characteristics associated with the highest level of mHealth engagement over time (Breslow & Clayton, 1993). Study variables significant at p<0.05 were included in the multivariate model. Though not significant at the bivariate level, age and city of enrollment were included in the multivariate model to adjust for potential confounding. Reported p-values are two-sided and <0.05 was considered statistically significant. All statistical models were performed with R version 3.5.0 using lme4 and lmerTest packages (Bates et al., 2014; Kuznetsova, Brockhoff, & Christensen, 2017; R Development Core Team, 2019). Responses to the mHealth follow-up survey were summarized using frequencies and proportions to describe current phone connectivity and use at the end of the study, as well as participant perceptions of the program. A rapid qualitative analysis identified themes emerging from the short-answer responses, which are presented with illustrative quotes.

8.3 Results

8.3.1 Baseline characteristics

More than half (n=81; 61.8%) of mHealth participants were women and half lived in Prince George when they joined Cedar (n=65; 49.6%) (Table 8.1). Slightly less than half (n=59; 45.4%) owned a phone at enrollment into mHealth. Approximately half (n=63; 48.6%) had a parent who attended residential school, and substantial proportions had been taken from their biological parents into care (n=100; 76.3%) and/or experienced childhood sexual abuse (n=70; 56.9%). Among parents, 61 (53.5%) reported that they had ever had a child apprehended. Fewer participants reported connection to traditional culture either in the past or present, including traditional language spoken at home (n=54; 41.5%); speaking a traditional language (n=53; 40.8%); participating in ceremony (n=30; 23.1%); recently accessing traditional food (n=63; 48.5%); and living by traditional culture (n=22; 17.3%). The mean resilience score across the sample was 63.4 (SD: 21.4), which is lower than average resilience in a general population (Mean: 80.4; SD: 12.8) (Connor & Davidson, 2003), and similar to average resilience among street-involved youth (Cleverley & Kidd, 2011), young people transitioning out of the child welfare system (Goldstein et al., 2013), and people with generalized anxiety disorder (Connor & Davidson, 2003). Recent involvement in sex work was reported by 15 (16.9%) participants and recent injection drug use was reported by 57 (44.2%) participants. Overall, 79 (60.3%) were living with hepatitis c and 53 (40.5%) were living with HIV at enrolment. Additional baseline characteristics are presented in Table 8.1.

Characteristic	Obs	Ν	%	Missing n (%)						
Demographics & Social Determinants of Health										
Age (median, IQR)	131	33.0	29.5-36.0	0 (0.0%)						
Sex (Female)	131	81	61.8%	0 (0.0%)						
Location (Prince George)	131	65	49.6%	0 (0.0%)						
In a relationship	129	33	25.6%	2 (1.5%)						
Sexual identity (LGBT)	131	23	17.6%	0 (0.0%)						
Education (Did not graduate high school)	129	106	82.2%	2 (1.5%)						
Recent homelessness	131	34	25.9%	0 (0.0%)						
Recent housing instability	126	56	44.4%	5 (3.8%)						
Owned a phone at enrollment into mHealth	130	59	45.4%	1 (0.8%)						
Cultural Connection & Resilience										
Traditional language spoke often at home growing up	130	54	41.5%	1 (0.8%)						
Speak traditional language ("yes" or "a bit")	130	53	40.8%	1 (0.8%)						
Often or always speak traditional language today	130	4	3.1%	1 (0.8%)						
Ever participated in traditional ceremonies	130	30	23.1%	1 (0.8%)						
Often or always live by traditional culture	127	22	17.3%	4 (3.1%)						
Recent access to traditional food	130	63	48.5%	1 (0.8%)						
Resilience (mean, SD)	123	63.4	21.4	8 (6.1%)						
Colonial Violence & Trauma										
Either parent attended residential school	130	63	48.6%	1 (0.8%)						
Apprehended from biological parents	131	100	76.3%	0 (0.0%)						
Childhood sexual abuse (≤13)	123	70	56.9%	8 (6.1%)						
Ever had a child apprehended ¹	114	61	53.5%	0 (0.0%)						
Recent incarceration	128	19	14.8%	3 (2.3%)						
Sexual Vulnerability										
Recent sex work ²	89	15	16.9%	2 (2.2%)						
Recent sexual assault	129	5	3.9%	2 (1.5%)						
Substance Use										
Recent injection drug use	129	57	44.2%	2 (1.5%)						
Ever overdosed	130	52	40.0%	1 (0.8%)						
Recent alcohol/drug treatment	130	51	39.2%	1 (0.8%)						
Recently tried to access drug treatment but were unable	127	19	15.0%	4 (3.1%)						
Ever on methadone	131	66	50.4%	0 (0.0%)						
Current methadone treatment	66	38	57.6%	0 (0.0%)						
Ever tried to quit drugs/alcohol	129	109	84.5%	2 (1.5%)						
Mental & Physical Health			10							
HIV intection	131	53	40.5%	0 (0.0%)						
HCV intection	131	79	60.3%	0 (0.0%)						
Psychological distress (mean, SD)	131	1.01	0.84	0 (0.0%)						
Ever attempted suicide	129	44	34.1%	2 (1.5%)						
Recent hospitalization	131	15	11.5%	0 (0.0%)						

Table 8.1: Baseline characteristics of young Indigenous people who have used drugsenrolled in the Program (n=131)

Recent refers to the 6-month period prior to the interview

¹Among a subset of people who reported having children (n=114)

²Among a subset of people who said yes to having sex in the past 6 months (n=91)

³Among a subset of people who said yes to ever being on MMT (n=66)

8.3.2 Patterns of mHealth engagement

An overview of mHealth engagement is presented in Figure 8.3. Participants were enrolled in

the mHealth program for a total of 7495 person weeks, with a median duration of 61 weeks per

person with a corresponding interquartile range (IQR) of 52-67 weeks. A week was considered "active" if the participant was enrolled in the WeITeI mHealth platform and was sent an automatic "how's it going?" prompt text on Monday at noon. In total, there were 5217 (69.6%) active person weeks and participants were active for a median duration of 37 weeks (IQR: 24.0-56.5). Reasons for inactivity were primarily related to interruptions in phone access, such as lost or stolen phones and incarceration. Of 5217 weeks where a prompt text was sent, 3982 (76.3%) received a response, of which 3602 (90.5%) involved a response by text message. Offline responses, including a phone call or an in-person visit, accounted for 380 (9.5%) of responses. In total, 1234 (23.7%) prompt texts received no response. Of over 3600 weekly texts that received a response, roughly one third were brief, defined as a positive response consisting of <5 texts in total, with the rest being more of a conversation (data not shown). Level of mHealth engagement over the study period is presented in Figure 8.4.

Figure 8.3: Overview of texting patterns and engagement among 131 participants enrolled in mHealth (September 2014-January 2016)





Figure 8.4: Levels of mHealth engagement over the study period

8.3.3 Characteristics associated with mHealth engagement

In unadjusted models (Table 8.2), characteristics significantly associated with increased likelihood of responding to weekly 'how's it going' text messages included: being female (uOR: 2.91; 95%CI: 1.29-6.59); higher resilience score (uOR: 1.02; 95%CI: 1.00-1.04); having experienced childhood sexual abuse (uOR: 6.20; 95%CI: 2.92-13.31); and owning a phone at mHealth enrollment (uOR: 5.65; 95%CI: 2.62-12.43). In contrast, participants who had experienced recent housing instability (uOR: 0.41; 95%CI: 0.19-0.89), incarceration (uOR: 0.27; 95%CI: 0.09-0.82), or injection drug use (uOR: 0.27; 95%CI: 0.12-0.59) had lower likelihood of responding to weekly text messages compared to those who had not. In the final multivariate model, having experienced childhood sexual abuse (aOR: 3.00; 95%CI: 1.39-6.48); recent injection drug use (aOR: 0.39; 95%CI: 0.19-0.81); and owning a phone at enrollment (aOR: 2.43; 95%CI: 1.19-4.96) remained significantly associated with level of texting engagement.

Characteristic	uOR	95%CI	p-value	aOR*	95%CI	p-value
Demographics & Social Determinants						
Age	1.07	0.98-1.17	0.147	1.07	0.99-1.17	0.087
Sex (Female)	2.91	1.29-6.59	0.010	2.06	0.95-4.48	0.067
City (Prince George)	1.35	0.59-3.04	0.471	1.19	0.58-2.45	0.637
Education (≥high school grad)	1.29	0.44-3.76	0.643	-	-	-
Recent homelessness	0.59	0.23-1.47	0.252	-	-	-
Recent housing instability	0.41	0.19-0.89	0.024	0.56	0.28-1.09	0.090
Resilience						
Resilience	1.02	1.00-1.04	0.034	1.01	0.99-1.03	0.289
Colonial Violence & Trauma						
Either parent at residential school	0.39	0.14-1.07	0.065	-	-	-
(yes/unsure vs. no)						
Removed from biological parents	1.69	0.65-4.38	0.277	-	-	-
Childhood sexual abuse (≤13)	6.20	2.92-13.31	<0.001	3.00	1.39-6.48	0.005
Recent incarceration	0.27	0.09-0.82	0.020	0.63	0.25-1.60	0.329
Sexual Vulnerability						
Recent sex work ¹	0.33	0.09-1.15	0.080	-	-	-
Recent sexual assault	1.26	0.15-10.48	0.826	-	-	-
Substance Use						
Recent injection drug use	0.27	0.12-0.59	0.001	0.39	0.19-0.81	0.011
Recent alcohol/drug treatment	1.06	0.46-2.43	0.894	-	-	-
Current methadone treatment ²	1.40	0.55-3.62	0.476	-	-	-
Mental & Physical Health						
HIV infection	0.77	0.33-1.75	0.525	-	-	-
Psychological distress	0.74	0.45-1.20	0.213	-	-	-
Recent hospitalization	0.60	0.17-2.13	0.423	-	-	-
Mobile Phone Connectivity						
Owned phone at enrollment into mHealth	5.65	2.62-12.43	<0.001	2.43	1.19-4.96	0.015

 Table 8.2: Baseline characteristics associated with weekly level of mHealth engagement

 over the study period (GLMM)

*Adjusted for age, city, and all variables significant at the level of p<0.05 in bivariate analyses.

¹Among a subset of people who reported having sex (n=91)

²Among a subset of people who reported ever being on methadone (n=66)

8.3.4 Mobile phone connectivity and use

Connectivity & loss. In response to the end-of-study survey, 62 (52.5%) participants indicated they currently had a phone that could call and text (Table 8.3). In total, 89 (75.4%) reported losing a mobile phone during the study. Among these, 83 (93.2%) responded to an open-ended question about how losing a phone had affected their health (Figure 8.5). Of the 83 participants who lost a phone, 12 stated there was no effect on their health as exemplified by one participant's comment: *"It didn't really bother me, it just made me a bit mad," [M, Van]*. For some (n=9), *"it sucked"* in general, while others (n=22) spoke about the loss being highly distressing and having an emotional impact. One explained, *"I freaked out. It's how I stay connected to everyone. It affected my emotional health," [F, PG]*. Another said it was, *"Like losing your right arm. I had everything in [my] phone...appointments, contacts," [F, Van]*. Eight
participants mentioned that the loss of stored contacts on their phone affected their health. Some (n=23) participants noted the impact of losing a phone on their connection to social supports, especially family and 'workers'. For example, one participant explained that when she lost her phone, *"It sucked. All my workers used to text me. So, I wasn't able to connect with any of my supports any more"* [*F*, *PG*]. Many (n=22) explained that loss made it harder to make and keep appointments with healthcare providers. One participant explained, *"My phone was my life, [when I lost it I] wasn't able to access [my] doctor or get a hold of D&A counsellor* [M, PG]. Other health and wellness impacts of phone loss included not having a phone for emergencies (n=3) or to find/maintain employment (n=4).

Table 8.3: Phone connectivity and perceptions of mHealth at end of study (n=118)

	N (%)
Phone connectivity	
Currently have a phone that works for calling and texting	62 (52.5%)
Lost a phone during the study	9 (75.4%)
Face any challenges using phone (p3m)	38 (32.2%)
Used pre-programmed numbers	77 (65.3%)
Perceptions of the program	
Responded 'no' to "was there anything you didn't like?"	90 (83.3%)
Text messages from staff were "very useful" *	67 (57.8%)
'Not at all' concerned about a breach of privacy *	107 (90.7%)
Would recommend mHealth program to a friend	114 (96.6%)
Would like mHealth program to continue	112 (94.9%)
Frequency of text messages received was "just right" *	103 (88.0%)
Future text frequency	
Continue 1x per week	69 (58.5%)
Twice a week	31 (26.2%)
Daily	11 (9.3%)
Other	7 (5.9%)

*Note: Refers to Likert scale categories. Reference group is "any other response".

Figure 8.5: Participant perspectives of impact of phone loss on health



Note: Participants who said yes to losing a phone were asked an open-ended follow up question: "What was it like to lose your phone in terms of your health?". Responses were received from 83 participants (93.3% of those who reported losing a phone) and were recorded verbatim. Rapid qualitative analysis identified themes emerging from the shortanswer responses. Responses were coded by theme and frequencies of each response theme were calculated and ranked.

How did you use your phone? Over the duration of the program, participants often informally shared the ways they used their phone. In the end-of-study survey, common uses were compiled into a list and participants were asked to indicate any that applied to them (Figure 8.6). Over half of participants indicated they used their phone to: connect with friends (83.1%) and family (80.5%); make appointments (80.5%); text with Cedar (76.3%); remember appointments (72.0%); for their own safety (66.9%) or the safety of others (62.7%); and/or access healthcare (63.6%). Smaller proportions indicated that they used their phone to: find housing (43.2%); remember medications (39.8%); connect with their kids (38.1%); access harm reduction services (35.6%); find work (33.9%); connect with Elders or other cultural supports (30.5%); or access substance use treatment (28.8%).

Use of mobile phone to access services. Participants were asked if they had connected with any of the services listed in Figure 8.6 using their phones in the past three months. Services most commonly accessed via phone included doctor's offices (n=87; 73.7%) and welfare services (n=79; 66.9%). Those who reported using their phones to connect with other services not on the list added the following: service organizations related to substance use, pregnancy/parenting, and HIV (e.g., Sheway, Positive Living North, AIDS Vancouver Island, VANDU, Lifeskills, recovery houses); research (e.g., Cedar Project, Salome); criminal justice system (e.g., parole officer, drug treatment court, lawyer); First Nations bands; nurse hotline; educational institutions; and employment services. Among 44 participants living with HIV, 33 (75.0%) connected with HIV doctors and 28 (63.6%) connected with HIV services using their phones in the past three months (data not shown).



Figure 8.6: Phone use over the study period

Note: Questions included possible responses that had been identified as important during implementation of the mHealth program. Participants were asked to select 'all that apply for each question. Frequencies of each item were calculated and ranked.

the past 3 months?

20% 30% 40% 50% 60% 70%

80%

0% 10%

Use of pre-programmed numbers. In total, 77 (65.3%) reported that they had used the preprogrammed numbers. Most (n=60; 77.9%) reported using them to contact Cedar. Some reported connecting with substance use services (n=17; 22.1%) and clinics (n=17; 22.1%)using the pre-programmed numbers. A few (n=5) participants noted that because the phone numbers were entered with acronyms (e.g., CP for Cedar Project) to protect privacy, they forgot what they were for and did not use them. Of note, just two participants mentioned using pre-programmed emergency numbers and both said it was for a friend rather than themselves.

Perceptions of the Cedar Project WelTel mHealth program 8.3.5

Most participants reported that they would recommend the program to a friend (n=114; 96.6%) and would like the program to continue (n=112; 94.9%) (Table 8.3). Most felt the text messages were "very useful" (n=67; 57.8%) and the frequency of text messages was "just right" (n=107; 90.7%). Participants were asked open-ended questions about the benefits of the program overall and the texting component specifically, which were summarized into themes presented in Figure 8.7. A closer look at the top two themes from each question is presented in Table 8.4. Both connecting to family and loved ones, and the financial benefit of not having to pay for a phone and plan, were seen as the greatest overall benefits, reported by 21 (17.8%) participants each. When asked about the benefits of the texting component more specifically, the overwhelming response from 43 (36.4%) participants was that it demonstrated that 'someone cares'. Keeping in touch with Cedar in general was also a highly valued benefit, reported by 27 (22.9%) participants.



Figure 8.7: Perceived benefits of the mHealth program at the end of the study

Note: Participants were asked two open-ended questions related to the benefits of the mHealth program. Responses were received from 118 participants and were recorded verbatim. Rapid qualitative analysis identified themes emerging from the short-answer responses. Responses were coded by theme and frequencies of each response theme were calculated and ranked.

Table 8.4: Participant perceptions of greatest benefits of the mHealth program

Theme	Response
Overall benefit	
Connecting to family & loved ones	 Being able to keep in touch with my family. Connected with my sister in [other province], step-dad in [city] and foster parents in [city] [M, Van] Calling my mom and dad whenever I wanted [M, Van] Getting to know my family – I would have never had the opportunity to connect with them otherwise [F, PG]
Financial	 Making it easier on me. Not having to pay the bill. Before [I was] putting addiction before my cell, my dad would have a hard time to get hold of me, I'd have to call him from free phone places [M, Van] Manay we assure [and] being able to call family earned Canada was the best part
Financial	• Money we saved [and] being able to call family across Carlada was the best part [M_PG]
	 Besides getting the phone, having you pay the plan meant that my bosses could always reach me on that number, they liked that a lot [M, Van] Not having to worry about cell phone every month [F, PG]
	 Not being able to afford a phone and having you guys pay for it [F, Van]
Texting benefit	
Someone cares	 Makes me feel good because I know somebody cares. Not anyone from my phone list texts me to see how it's going, what I'm up to. I'm always the one that does that [M, Van]
	 It made us feel special and important and good about ourselves [F, PG] It was nice to hear from somebody that was not drug related, nice to know that I wasn't alone out there. It's hard out there [M, Van]
	 Just knowing you guys were around. Actually, you were the only people who texted me. So, having you text each week was actually pretty cool. Somebody cared, you know? [M. Van]
Keeping in	 You guys can keep ahold of me and know if I'm alright or not [M, PG]
touch	 It was really nice to hear from somebody [M, Van]
	Being able to let you know how I was doing [F, PG]
	 very neiptul staying in touch [F, Van] Being able to keep in contact [F, PG]
	• Deing able to keep in contact [F, PG]

8.3.6 Problems, challenges, & dislikes

Some participants (n=38; 32.2%) reported facing challenges using their phone. Among those, the majority (n=23; 60.5%) felt challenged by not having the phone as theirs had been lost or stolen. Fifteen (12.7%) of respondents identified other challenges including: desire for more phone functionality (e.g., data, more memory); difficulties texting on flip phones; and phone performance (e.g., running slow, restarting). When asked if there was anything they did not like about the mHealth program, 90 (83.3%) participants said no. Some elaborated on why they had no dislikes. One participant in Vancouver said, *"No, because we had control of the program basically, there weren't any additional rules, it was cool, you guys didn't turn around and add rules." [M, Van].* Seventeen (15.3%) participants reported a dislike, with reasons which included: that the program came to an end (n=6), losing a phone (n=4), texting component (n=2), lack of phone functionality (n=2), and other (n=3). Just 3 (2.5%) had problems receiving texts from Cedar and 13 (11.0%) had problems sending texts.

8.4 Discussion

Perceptions of the Cedar Project WelTel mHealth program were largely positive and participants demonstrated a high level of engagement with the program over time, responding to over three guarters (76.3%) of prompt text messages. This proportion of responses is higher than reported in other WelTel studies in Canada and Kenya (King et al., 2017; Murray et al., 2015; van der Kop et al., 2012). In the WelTel Kenya1 study involving 273 participants attending HIV clinics in Nairobi, Kenya, 68.6% of 'how are you' prompt messages received a response (van der Kop et al., 2012). In the WelTel BC1 pilot study involving 25 participants attending an HIV clinic in Vancouver, Canada, an average of 56.9% responded to the 'how are you' message each week during the 6-month program (Murray et al., 2015). This study was followed by a larger trial involving 80 participants (27 of whom were First Nations) attending the same clinic, during which 57.6% of 'how are you?' prompt messages received a response (King et al., 2017). The higher proportion of responses received in the present study may reflect longstanding relationships with Cedar staff. As well, it could be a result of our decision to respond to all text message replies, whether or not they indicated a problem. The original application of the WelTel program was structured so participants could respond that they were fine ('sawa') or had a problem ('shida'), with only the latter prompting follow-up action by clinic staff (Lester et al., 2010). Choosing to respond to all messages reflected an emphasis on relational care consistent with Indigenous values, as well as a growing qualitative literature demonstrating that

a valued component of two-way text message mHealth programs is the sense that 'someone cares,' which was also observed in the present study (Mahal et al., 2014; Smillie, Borek, Abaki, et al., 2014; van der Kop et al., 2012). Further, responding to all messages aligned with the explicit strengths-based focus of the program.

Having experienced childhood sexual abuse was associated with three times greater odds of responding to weekly 'how's it going?' text messages. It is important to discuss the context of abuse experiences among Cedar participants, before considering why this association with mHealth engagement was observed. Sexual abuse is an intergenerational consequence of wide-scale abuses endured by Indigenous children attending Canada's residential schools between 1874-1996 (Christian & Spittal, 2008; Pearce et al., 2008; TRC, 2015a, pp. 205-206). Though the full extent of the abuse cannot be quantified, as part of the Indian Residential Schools Settlement Agreement Independent Assessment Process, over 30,000 former students were awarded claims in recognition of physical and sexual abuse experienced at the schools, and the government's role in them (TRC, 2015a, p. 108). Cedar partners and other Indigenous scholars have shared that the experience of sexual abuse negatively affects mental, emotional, and physical health – and has an especially damaging effect on the spirit. Lack of response by schools, churches, and government while schools were still operating have resulted in some victims of residential school abuses inadvertently passing on these traumas within their own families and communities (Fournier & Crey, 1997, pp. 32, 37-39, 42-43, 85; TRC, 2015a, p. 211). Further, enduring impacts of residential school abuses on the whole have contributed to an overrepresentation of young Indigenous people in the child apprehension system where they face additional risk of sexual abuse (Fournier & Crey, 1997, pp. 32, 37-39, 42-43, 85; TRC, 2015a, p. 211). In previous Cedar analyses, having experienced sexual abuse was associated with having a parent who attended residential school and/or being involved in the child apprehensions system (Clarkson et al., 2015; Pearce et al., 2008).

Links between childhood sexual abuse and mHealth engagement may reflect that Cedar is a safe place to share and engage with supports for those with trauma experiences. Previous Cedar research involving 543 participants demonstrated that more than 25% of those disclosing sexual abuse had never told anyone prior to the study interview, and just 35% had ever received counselling to deal with the abuse (Pearce et al., 2008). Many participants have now been involved with Cedar for over 10 years and have trusted relationships with long-term staff, including nurses and Case Managers. In this way, the mHealth program builds on existing

relationships between Cedar Case Managers and participants, known to be free from stigma and judgement related to both substance use and sexual violence. This is highlighted in a survey response from one participant who shared why weekly texts from Cedar were useful to her: "If things were really crappy, I could get it off my chest. Even if it was just a text with you guys, I knew you were there. Also, because I don't really talk to anyone else, like my family, about how I live down here, but with you guys, I didn't have to hide it" [F, Van]. Another described the relationship with Cedar Case Managers as being "unconditional" [F. PG]. Further, text messaging (rather than face-to-face interactions) may present a safer way to engage for those with experiences of sexual trauma. Finally, consistent access to a mobile phone and long-distance plan may have created opportunities to connect with healing-centered supports that promoted healing from the enduring consequences of childhood sexual abuse, such as Elders, ceremonies, counselling, and/or substance abuse treatment. Recent research involving 125 Indigenous people in Thunder Bay, Ontario highlighted that emotional practices such as connection, listening and being listened to, validation, self-reflection, and belonging were important to healing from sexual violence (Maranzan, Hudson, Scofich, McGregor, & Seguin, 2018). Similar benefits were identified by participants in the mHealth program. Overall, this is consistent with common tenants of healing-centered care, including: (1) understanding the symptoms and impact of trauma; (2) sensitive responses to disclosure; (3) nurturing a sense of safety and connection with providers; (3) supporting patient control over care interactions; and (4) offering multidisciplinary collaboration and referrals (Reeves, 2015). Given the apparent acceptability of two-way supportive text messaging for this population, tailored mHealth programs that respond to unaddressed childhood sexual abuse should be explored. This may include inviting culturally-safe counsellors who have experience working with Indigenous people impacted by intergenerational traumas to be part of the case management team.

Owning a phone at study enrollment was associated with an over two-fold increase in odds of responding to weekly 'how's it going?' text messages. Having owned a phone at enrollment into mHealth may be an indicator of greater stability, contributing to improved ability to avoid phone loss, maintain phone connectivity, and promote mHealth engagement over time. Conversely, lack of phone ownership likely indicates the impacts of economic hardship and substance use stemming from the ongoing colonization and systemic violence experienced by Indigenous peoples in Canada (*Chapter 5: mHealth acceptability*). This is consistent with the emphasis participants placed on the financial benefit of not having to pay for a phone or plan, alongside the finding that recent injection drug use was associated with a decreased likelihood of

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responding to weekly 'how's it going?' text messages. Less than half (45.4%) of participants owned a phone at enrollment into the Cedar Project WelTel mHealth study (Chapter 5: mHealth acceptability). While all participants received a mobile phone at enrollment into mHealth to ensure that lack of phone ownership was not a barrier to participation, phone loss was an issue, with more than three quarters (75.4%) of participants reporting that they had lost at least one study phone. The majority of participants who reported having a problem with the mHealth program said the issue that they faced was phone loss; phone loss was also a primary reason for weeks 'inactive' reported in this study. Similarly, in a review of five mobile phone initiatives to support engagement in HIV care among people leaving prison in the United States, service interruption was a common issue, resulting from lost phones, inability to pay for service, reincarceration, entry into drug treatment, and hospitalization (Christopoulos et al., 2017). As a result, flexible mHealth programs that support continuity of phone connection in the event of service interruptions are critical to their success. For example, allowing a phone number to be maintained if a phone is lost and reconnected when a new handset is found, or keeping a voicemail box active during a period of disconnection may be helpful. Another option is to use a talk/messaging app (e.g., Facebook or Google Voice), which participants can access both online or via mobile to avoid disconnection in periods of phone loss.

Phone loss was detrimental, as mobile phones were used to support health and wellness in a number of ways. Participants used their phones to strengthen reciprocal connections with family, loved ones, and other members of their circles of care. This helped them receive care and connection, as well as take care of those around them. Indigenous scholars and Elders affirm that family connections are fundamental to health and wellbeing from an Indigenous perspective, as we have seen repeatedly throughout this dissertation so far (Christian, 2010; Clark et al., 2011; Grant, 2017; Jongbloed et al., 2019; Marshall et al., 2015; Pooyak, 2009; Van Uchelen et al., 1997). These connections involve reciprocal relationality, including being able to fulfil important spiritual and caring responsibilities to family and community. For example, Hawaiian scholar Lana Sue Ka'opua et al.'s interviews with six Native Hawaiians living with HIV highlighted the critical importance of fulfilling kuleana (responsibilities), such as taking care of an extended family member (Ka'opua, 2001). Ojibwe scholar Laurelle Myhra and colleagues used the term 'investing in others' to describe how sharing and supporting others was a critical component of healing from substance use in a cultural way among two generations of American Indian families involved in her work on substance use (Myhra & Wieling, 2014; Myhra et al., 2015). Similar caring priorities were identified in Cree scholar Sherri Pooyak's interviews

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with five Indigenous women involved in sex work which demonstrated that being able to provide for family and younger siblings was often a motivator to engage in the sex trade, and formed the foundation of the women's resilience (Pooyak, 2009). Examples of this within the present study were abundant and diverse. Over 60% of participants shared that they had used their phones for the safety of others, such as calling 911 in an emergency. Many spoke about how their neighbours, parents, and siblings would visit in order to use the phone to call longdistance to family and loved ones. Sometimes phones were lent out to a family member in times of need. Using phones to strengthen connections with circles of care was also reflected in how participants used them to access a variety of health and social services.

Participants also used their phones to help them to fulfill basic life responsibilities related to the social determinants of health, such as housing, work, and food security. Indigenous people, including young people who have used drugs, continue to be disproportionately impacted by negative social determinants of health (Ion et al., 2018; McKenzie et al., 2016), including: housing instability (Jongbloed, Thomas, et al., 2015); underemployment (Richardson, Wood, Li, & Kerr, 2010); and food insecurity (Anema et al., 2010). Yet, participants in this study demonstrated tremendous efforts to overcome these barriers to their health and wellbeing. For example, many participants reported using their phone to find and maintain secure housing in the face of frequent housing transitions. Others emphasized that having a phone had facilitated getting and maintaining a job, which was important to their health. One participant shared that the biggest overall benefit he experienced from the program was, "*Just getting my job! That was the fun part. In the beginning I was on welfare, and then I got a pay cheque and you start learning how much you can earn by working. It's like, holy fuck!*" [*M*, *Van*]. In addition, about one quarter of participants reported connecting with food banks using their study phones, which exemplifies continued struggles to make ends meet.

It is important to take note of some null results. First, no association was observed between education and level of mHealth engagement. While a majority (82.2%) of participants in this study had not graduated from high school, low educational attainment was not a barrier to participation. Second, no association was observed between living with HIV and level of mHealth engagement. At enrolment into mHealth, almost all participants living with HIV indicated that using a phone for healthcare would be helpful to them; however, 11.7 % of those not living with HIV remained unsure (*Chapter 5: mHealth acceptability*). Previous WelTel studies have shown that mHealth is effective among people living with HIV, but this is the first

study to test it among individuals at risk of infection through involvement in substance use. Results from the present analysis suggest that the mHealth program was similarly valued by both young Indigenous people living with HIV and those who were not.

8.4.1 Limitations

While our sample may not be representative of all young Indigenous people who have used drugs in BC, efforts were made to include participants with a diversity of sociodemographic characteristics and life experiences, including gender, city of enrolment, HIV status, and drug use patterns. Further, we recognize that Indigenous peoples are diverse. As this study involved a particularly vulnerable group of young Indigenous people who have used drugs, our findings cannot be generalized to young Indigenous people more broadly. Previous WelTel studies have used a measure of whether participants responded with 'ok' vs. 'problem' to understand engagement with the program and quantify workload for health providers (Campbell et al., 2018; van der Kop et al., 2012). While most studies focus on participants responding with a problem to determine engagement, we defined 'engaged' as anyone who responded to our weekly text message either on or offline. Selecting a different measure of engagement limited direct comparisons to these other studies. However, given the complexity and diversity of texting interactions between participants and Cedar Case Managers, we feel this unique measure was more reflective of the data. Finally, 10% of participants who enrolled in mHealth were lost to follow-up and did not complete the end-of-study survey, which could have biased the results towards positive experiences and higher engagement with the program.

8.4.2 Conclusion

We observed positive perceptions and high engagement with the Cedar Project WelTel mHealth program among young Indigenous people who have used drugs. Further, findings affirm that mobile phones are important resources impacting health and wellness through offering healing-centered culturally-safe support, strengthening connections to circles of care, and supporting young Indigenous people who have used drugs to access healthcare and navigate the social determinants of health. We recommend that similar supportive mHealth programs be expanded and fully funded for young Indigenous people who have used drugs people who have used drugs in BC and elsewhere.

Chapter 9 Results – Exploring engagement with the Cedar Project WelTel mHealth program among young Indigenous people who have used drugs

9.1 Background

Indigenous scholars and leaders have shared that health and wellness can be understood as a lifelong journey, with individuals, families, communities, and nations all at different places on this journey (Dion Stout, 2015; Gallagher, 2018). Cree scholar Madeleine Dion Stout explains that Indigenous peoples are travelling a path from *ascribed* health and wellness (*atikowisi miýw-āyāwin*) to return to *achieved* health and wellness (*kaskitamasowin miýw-āyāwin*) (Dion Stout, 2015, p. 145). The former (*ascribed / atikowisi*) refers to imposed perspectives, policies, and practices – such as settler state legislation and policy – that amount to being told from the outside how to be healthy and well (Dion Stout, 2015, p. 145). In contrast, the latter (*achieved / kaskitamasowin*) refers to health and wellness coming from within Indigenous peoples, and are built on the foundations of culture, identity, and good relationships (Dion Stout, 2015, p. 145). This is echoed within understandings of self-determination over health in the BC context, where First Nations are (re)claiming control over their own health and wellness journeys rooted in Indigenous knowledges and perspectives, as well as working to transform mainstream healthcare to be culturally-safe for Indigenous people seeking care (Gallagher, 2018).

Indigenous health and wellness journeys are shaped by unique determinants that can promote or hinder health and wellness. Mi'kmaq and Acadian scholar Charlotte Loppie uses the metaphor of a tree as a framework to describe Indigenous-specific social and structural determinants of health (Loppie Reading & Wien, 2013; Reading, 2015). In this conceptualization, the roots of the tree are distal determinants that either promote (e.g., self-determination) or hinder (e.g. colonialism, racism, social exclusion) health and wellness. The trunk describes intermediate determinants that can also either promote (e.g. cultural continuity and community resources) or hinder (e.g. negative experiences in the health system) health and wellness. The leaves represent the proximal social determinants such as health behaviours, housing, work, income, and food security, which have a more direct impact. Each part – the roots, trunk, and leaves – are vital to the overall health and wellness of the tree. Others have shifted and expanded Loppie's conceptualization to reflect that Indigenous peoples' roots, trunk, and leaves are strong and resilient, but their ability to grow and flourish is hindered by soil 'contaminated' by colonial policies and ongoing structural violence.

Nurturing strong trees and forests – Indigenous lands, people, families, nations, and ways of life – requires healing-centered, culturally-safe, and strengths-based approaches for those who have been impacted by the residential school and child apprehension systems, as well as substance use and HIV. Indigenous leaders and scholars have called for responses to HIV and substance use that acknowledge the ongoing impacts of intergenerational traumas while also building on Indigenous perspectives, identities, and cultural strengths (Bouey & Duran, 2000; Duran et al., 2010; Goodkind, LaNoue, et al., 2012; Marsh, Cote-Meek, et al., 2016; Nebelkopf & Penagos, 2005; Rowan et al., 2014). Supporting connections with Indigenous healing practices, values, and identity has been identified as a powerful tool for healing and wellness (Marsh, Cote-Meek, et al., 2016; Marsh, Young, et al., 2016). Culturally-safe, healing centered, strengths-based care takes into account historical trauma, and supports "cultural buffers" – including community resources that facilitate traditional healing practices, spiritual coping mechanisms, cultural connectedness, and pride in Indigenous identities - to mitigate adverse health outcomes of traumatic life stressors (Walters et al., 2002; Walters & Simoni, 2002). These approaches honour Indigenous perspectives of health and wellbeing, recognizing a wholistic approach encompassing physical, spiritual, mental, and emotional health of the individual, family, community, and nation (Assembly of First Nations & Health Canada, 2015; Assembly of First Nations et al., 2010; FNHA et al., 2013). Further, they focus on strengths rather than deficits; build trust-based relationships between the person seeking care and the healthcare provider; create individualized plans to support the person's unique needs; and create links to supportive community resources (Rapp & Goscha, 2008). Throughout, they emphasize that the person seeking care holds control and choice over the form, direction, and substance of the support they receive (Reeves, 2015). The idea of 'taking care of one's self' is also important to the concept of Indigenous healing as it reflects a perspective of selfdetermined health and wellness in which a person is in charge of their own health and wellness journey with important individual and collective responsibilities in that regard (Dion Stout, 2015, p. 144; Gallagher, 2018; Hovey et al., 2014; McCormick, 1997).

The Cedar Project WeITel mHealth program integrated mobile health (mHealth) with a strengths-based case management program to support Cedar participants' healing and wellness, as well as address gaps in access to HIV-related care, treatment, and services. Previous chapters in this dissertation have explored the effect of the mHealth program, as well as participants' engagement with the program from a quantitative perspective. This chapter

draws on qualitative data to provide additional depth and context to shed light on participants' engagement with the mHealth program. Further, it seeks to understand how Cedar Case Managers integrated healing-centered, culturally-safe, and strength-based approaches into our mHealth program. To our knowledge, no other studies have examined Indigenous peoples' engagement with an mHealth bundle including a phone and plan, weekly text-messaging with a Case Manager, and relational supports.

9.1.1 Theoretical framework

This study was informed by the conceptual framework laid out in *Chapter 1: Introduction*. Briefly, it takes a perspective of health and wellbeing that includes the physical, mental, spiritual, and emotional health of the individual, as well as whole families, communities, and nations (FNHA, n.d.; King et al., 2009; Loppie Reading & Wien, 2013) and recognizes ongoing colonization is a negative structural determinant of health and wellbeing (Reading, 2015). Within this context, young Indigenous people who have used drugs may turn to substance use to cope with stress of intergenerational and lifetime traumas stemming from colonization; however, connection to family, cultural strengths, identity, and traditional practices, can serve as buffers to support health and resilience (Pearce, Jongbloed, et al., 2015; Walters et al., 2002; Walters & Simoni, 1999, 2002; Walters et al., 2000).

9.2 Methods

9.2.1 Research relationships

This study took place within the Cedar Project, a cohort study involving 782 young Indigenous people who have used drugs living in Prince George and Vancouver, BC. Since its inception in 2003, The Cedar Project has been governed by the Cedar Project Partnership, an independent body of Indigenous leaders and Elders, experts, and community advocates. As Cedar participants represent many of the diverse communities and nations across BC and Canada, the cedar tree – the tree of life – was identified as a powerful metaphor for healing and wellness that captures the goals of the study. I was accountable to the Cedar Project Partnership in all aspects of the research, from development of research questions to dissemination of findings. This accountability is mediated through being partnered with two Indigenous mentors: Mr. Lou Demerais (Cree and Métis) who has served as Executive Director of Vancouver Native Health Society and Ms. Sherri Pooyak (Cree) who is a Community Based Research Manager at the Aboriginal HIV & AIDS Community-Based Research Collaborative

Centre (AHA Centre). In addition, I signed the *Student Ethics Protocol for Conducting Research with the Cedar Project*. Regular meetings with Indigenous mentors and other Cedar Project partners, as well as attendance at seasonal Partnership meetings, took place throughout the study period.

9.2.2 Setting and participants

This analysis used interpretive description to qualitatively understand engagement with the Cedar Project WeITel mHealth program involving 131 participants. The mHealth sample has been described in detail elsewhere in this dissertation (*Chapters 2 & 5*). Briefly, participants were eligible to receive the mHealth program if they were: (1) enrolled in the Blanket Program HIV case management program; or (2) were HIV-negative and had been randomly selected for an invitation to participate. Median age at enrollment into the mHealth program was 33 (IQR 30-36) years old. More than half (n=81; 61.8%) of participants were women, and approximately half had enrolled in Cedar in Prince George (n=65; 49.6%). In total, 53 (40.4%) of participants were living with HIV.

9.2.3 Cedar Project WelTel mHealth program

The Cedar Project WelTel mHealth program was offered over a 16-month period with continuous enrollment between September 2014-January 2016. It consisted of a bundle of supports, including a mobile phone and cellular plan, weekly two-way text messaging, and support from Cedar Case Managers. Cedar Case Managers included Indigenous and non-Indigenous nurses and staff who have extensive frontline outreach experience working with young Indigenous people who have used drugs. Cedar Case Managers followed a "culturallysafe" approach acknowledging both trauma and strengths, and including an explicit focus on the critical roles of cultural assets and safe relationships with care providers (Barlow & Reading, 2008; Papps & Ramsden, 1996). Participants were provided with a cellular handset donated by TELUS and a monthly cellular plan including unlimited calling and texting within Canada, but no data. Phones were pre-programmed with phone numbers for emergency and health-related services relevant to the study site. Including long-distance calling and texting was an explicit decision to provide the opportunity for participants to connect with family and loved ones living in home communities and elsewhere in Canada. Participants were eligible to receive one study phone replacement in case of phone loss. In the event that a second study phone was lost. participants could bring in their own SIM card-enabled mobile phone which was fitted with a sim to reconnect them with the study cellular plan. All participants were automatically sent a "how's

it going?" check in text message each Monday at noon through the WelTel mHealth platform. Cedar Case Managers logged in within 24 to 48 hours to review participants' responses to the prompt text. All texts received a response, and Cedar Case Managers followed up with those who required additional support. Non-responders received another automatic text message on Wednesday ("Haven't heard from you, are you ok?"). On Thursday or Friday staff attempted to call all remaining participants who had not been in touch that week.

9.2.4 Data collection

This study called on four sources of longitudinal and cross-sectional qualitative data: (1) data from the WelTel platform; (2) in-depth interviews; (3) open-ended responses from the mHealth end-of-study survey; and (4) field notes collected during the mHealth program. All data was combined into a single qualitative dataset and analyzed together. In addition, descriptive statistics of participant characteristics were accessed from the main quantitative Cedar Project cohort database.

WeITel platform data: The bulk of the data used in this analysis are text message conversations occurring between mHealth participants and Cedar Case Managers during implementation of the Cedar Project WeITel mHealth program (September 2014-January 2016). All text message and charting data was downloaded from the WeITel platform. No other texts sent or received on study phones could be accessed or recorded. Weekly texting conversations between the participant and the Cedar Case Manager began each week with the automatic, "How's it going?" prompt message. These were grouped by individual participant to understand engagement over the course of the study. In total, 3602 weekly text message conversations, plus 380 notes where participants responded to weekly prompt texts offline (e.g., in person or phone call), involving 131 mHealth participants, were included in this analysis.

In-depth interviews: In-depth interviews were carried out with a sub-sample of 19 mHealth participants in March/April 2016 who were asked to reflect on involvement in the Cedar Project WeITel mHealth program⁹. Detailed interview methods have been shared earlier in this dissertation *(Chapter 4: Child Apprehension & HIV)*. Briefly, all interviews were conducted by me alone or jointly with one or two Cedar staff. They were deliberately open-ended to allow participants' experiences to direct the interview process and enable them to share stories they

⁹ Participants were also asked about experiences of the HIV cascade of care. Analysis of this part of the interviews is presented in *Chapter 4: Child Apprehension & HIV*.

felt were important. Interviews took place in private offices at Cedar study sites, a staff vehicle, or the participants' home, based on participant preference. Each participant was offered tobacco (a pack of cigarettes) in gratitude for the knowledge they would share (CIHR et al., 2014; Kovach, 2009; Nowgesic, 2015; Pooyak, 2009). A small pouch of sage smudge, picked by Cedar Partner Ms. Margaret Poitras (Cree, Muskowekwan First Nation; Executive Director, All Nations Hope Network), was made available to those who wanted it (Wilson, 2008). A \$20 honorarium was also provided. All interviews were audio recorded and transcribed verbatim by me using f5 transcription software. Transcribed data was checked against the audio recordings at least one additional time to ensure accuracy.

End-of-study survey: Toward the end of the Cedar Project WeITel mHealth Study, all participants were invited to complete a brief, one-time questionnaire related to mobile phone connectivity, use of mobile phones for health and wellness, and perceptions of the mHealth program. Data was collected between October 2015 to April 2016. Surveys included a combination of closed- and open-ended questions. Responses to open-ended questions were included in the qualitative dataset used in this analysis.

Field notes: This analysis was also informed by my in-person and text message engagement with Cedar participants and case managers while the WelTel mHealth program was underway. Field notes involved regularly writing detailed observational and analytical memos about the mHealth program during and immediately following over 400 hours spent in the Vancouver Cedar site office, with additional time in the Prince George office.

mHealth baseline data: Data collected routinely as part of the main Cedar cohort study was used to create an "mHealth baseline" which captured socio-demographics, strengths, intergenerational and lifetime trauma, sexual vulnerability, substance use patterns, and health outcomes. Data collected closest to a participant's date of enrollment into the mHealth program, up to a total of 30 days after enrollment, was accessed from the main Cedar baseline (time invariant factors) and follow-up questionnaires (time varying factors). This baseline data was used to supplement and contextualize the qualitative analysis with relevant descriptive statistics.

9.2.5 Analytical approach

Interpretive description was used to seek an in-depth understanding of participants' engagement with the Cedar Project WeITel mHealth program. This method was selected as it

emphasizes usefulness in applied settings over theory generation (Thorne, 2016, p. 25). I moved iteratively through a series of cognitive operations outlined by Morse – comprehending, synthesizing, theorizing, re-contextualizing (Morse, 1994; Morse & Field, 1996; Thorne, 2016, pp. 184-185). Specific strategies taken at each stage are presented in Table 9.1. Direct participation in the development and delivery of the mHealth program constituted my first point of engagement with the material. This was followed by time spent interviewing and administering the end-of-study surveys. The next phase of analytical engagement occurred after the mHealth program was over. A first round of data immersion began as weekly texting conversations were categorized based on response type for quantitative comparisons presented in *Chapter 8: mHealth engagement & perceptions*. Reflective journaling was used to capture insights and emerging themes throughout this process. Then, text message data was extracted for each participant for the entire study period. This approach provided the opportunity to view the text message conversations between participants and Case Managers as having continuity across the study period, in contrast to fragmenting the dialogue into weeks (Kovach, 2009, p. 130). Text message data was supplemented with field notes collected over the duration of the mHealth program, transcripts from 19 in-depth interviews with participants, and open-ended responses to the mHealth end-of-study survey. Data were read/re-read multiple times and marked up to identify important ideas within the data that were tagged with preliminary conceptual labels (e.g., 'visiting family', 'working to guit', 'phone logistics', 'seeking work', etc.). Repetition of this process across the complete dataset began to reveal important themes and patterns that were organized into an initial hierarchical thematic framework that was interrogated and revised multiple times. Throughout, frequent discussions were held with study staff, investigators, and members of the Cedar Project Partnership to enhance understanding and ensure consistency with what is known about lived experiences of young Indigenous people who have used drugs in BC. A preliminary thematic framework was reviewed with Cedar Case Managers, investigators, and partners for additional insight and input.

Cognitive operation	Aim	Strategies used
Comprehending	Learning everything possible about setting and experiences of study participants. Making sense of the data (Morse & Field, 1996, p. 104).	 Participation in development and implementation of the mHealth program, including visiting and texting with participants on the WelTel platform throughout the study period. Active engagement with the texting data while coding it for quantitative analysis in <i>Ch 8</i>. Immersion in the interview data through interviewing, transcribing, listening, and reading. Administering the mHealth follow-up surveys. Reading, re-reading all data. Reflexive journaling at all stages.
Synthesizing	Exploring patterns and relationships, looking for both typical and disconfirming cases. Decontextualizing from the individual and sifting off the insignificant noise (Morse, 1994, p. 31).	 Marking up and applying conceptual labels while reading and re-reading data in hard copy. Identifying and noting re-occurring conceptual labels. Paying special attention to disconfirming cases and examples. Reflexive journaling.
Theorizing	Building towards a structured conceptual whole which explains a 'best guess' about what I am seeing and why. Sorting phase where different models are tested (Morse & Field, 1996).	 Active, continuous process of assembling "data puzzle" into best fit model. Mind mapping. Compiling themes into a hierarchical thematic framework with examples. Reviewing and revising themes with Cedar staff, investigators, and partners. Arriving at a 'final' thematic framework. Reflexive journaling.
Re-contextualizing	Integrating the interpretive description	 Identifying representative verbatim quotes to highlight themes. Narrative, conversational approach to reporting findings. Reflexive journaling.

Table 9.1: Morse's Taxonomy of Cognitive Operations

9.3 Findings

Three overarching themes emerged related to how participants engaged with the mHealth program (Table 9.2). The first focuses on how participants (re)connected with family using study phones. The second discusses how participants' engagement with the mHealth program reflected ongoing impacts of colonization and structural violence. The third unpacks how participants engaged with Cedar Case Managers over the course of the program. Actions taken by Cedar Case Managers to provide culturally-safe, strengths-based, healing-centered support for participants are woven throughout.

Table 9.2: Summary of themes related to engagement with the mHealth program

Them	Theme 1: (Re)connected with family using study phones				
1.1	CONNECTED with parents, children, and other family				
1.2	NAVIGATED MCFD involvement with their own children				
Theme 2: Reflected ongoing impact of colonization and structural violence					
2.1	Experiencing and witnessing violence				
2.2	Substance use				
2.3	Negative social determinants of health				
2.4	Criminal justice system				
2.5	Intersections				
Them	ne 3: Engaged with Cedar Case Managers				
3.1	CONNECTED relationally with Case Managers				
3.2	SHARED as much / little as desired				
	3.2.1 Good news, milestones, and aspirations				
	3.2.2 Health issues and wellness actions				
	3.2.3 Crises and negative experiences				
3.3	SOUGHT specific support				
	3.3.1 Cultural supports				
	3.3.2 Support to engage with health & social services				
	3.3.3 Support related to social determinants of health				
3.4	NAVIGATED study and phone logistics				
3.5	OR, DID NOT ENGAGE				

9.3.1 Theme 1: (Re)connect with family using study phones

Participants' stories reflected intergenerational family disconnections resulting from colonization. In total, 63 (48.5%) had a parent who attended residential schools and 100 (76.3%) had been apprehended from their parents into the child welfare system. Previous Cedar research, including earlier chapters in this dissertation, have highlighted the work young Indigenous people who have used drugs are doing to (re)connect with family and cultural identity (*Chapter 4: Child Apprehension & HIV*) (Pooyak et al., In press). Connection to family may be important for health and wellbeing through supporting a sense of belonging, as well as helping to strengthen cultural identity (Hatala et al., 2017; Kirmayer et al., 2009; Richmond et al., 2007). Supporting reconnections may further enable young Indigenous people who use drugs to restore kinship ties that help their journeys of self-discovery and identity (Hovey et al., 2014).

Using phones to connect with family was a central part of participants' engagement in the mHealth program. In the end-of-study survey, over 80% of participants reported using study

phones to connect with family, and nearly 40% reported using phones to connect with their own children (*Chapter 8: mHealth engagement & perceptions*). The qualitative data allowed us to dig deeper into the ways in which having a study phone with free Canada-wide long distance calling and texting supported connection to family in the context of intergenerational disconnections.

Theme 1.1: Connected with parents, children, and other family

Having consistent access to a phone with long-distance calling provided an opportunity for participants to (re)connect with family members, including parents. For some this meant starting to talk on the phone with siblings, kids, and parents more regularly. Others were able to arrange in-person visits for the first time in many years. For example, one participant shared in the end-of-study survey that from her perspective, the greatest benefit of the mHealth program was, *"Getting to know my family, I would have never had the opportunity to connect with them otherwise" [Pearl, F, PG, HIV+, survey]*. This was reflected in two texting conversations she had with us during the program:

WelTel system (W11): How's it going?

Pearl: Hey it's going. Uh, going nowhere... Just jokes. How r ya'll? Well, 4 me I'm doing good B-) gonna visit my sis, or she is gonna come here from [city] 4 Christmas or newyears. Awesome right. Last time I saw her, I was like 16! So having dis' phone, has really helped me to reach out to my bro's, & sis's...Thank u so, so much! **Cedar:** That's awesome, I'm so happy for you and that the phone is helping you to keep in touch with your family!!

WelTel system (W34): How's it going? WelTel system: Haven't heard from you, just checking in? Pearl: Hey I'm doing good, Saturday night my DAD & Brother were in town!!!Was SO Awesome!!! I haven't seen them since I was 19! So it was Fun! I thought I seen yall there too!? Well [CCM¹⁰3] & [CCM1] anyways. So yeah, everything is SO good for me! Since having this phone my familia' & I are connected & talking!!!! Hugz,luv Cedar: that's so awesome to hear!!!! So happy you are getting re-connected with your family!!! hugs too you!!! Pearl: Thank you'z!

Some participants linked speaking to family members directly to their health and wellbeing. In this way, participants actively used their phones as tools to support their own self-determining

¹⁰ CCM refers to 'Cedar Case Manager'

health and wellness journeys, goals, and priorities. For example, this participant remarked how a call to his parents supported with his ability to cope with stress:

"When I am upset or mad I would pick up the phone and call my dad and my [m]other and it would calm me down. Hearing my mom or my dad's voice. It was kind of therapeutic. I got so used to it. I never thought I would but I did!" [Logan, M, Van, survey].

Theme 1.2: Navigated child welfare involvement with their own children

At enrollment into the mHealth program, 114 (87.0%) participants were parents, and of these 61 (53.5%) had ever had a child apprehended. Those in the program included pregnant mothers; parents with children in foster care who sought visitation and/or custody; and parents with custody of children who were navigating ongoing engagement with MCFD. Findings presented in previous chapters, as well as other Cedar research, demonstrate that having experienced a child being apprehended is associated with concerning health outcomes, including suicide and lack of HIV viral suppression (*Chapter 4: Child Apprehension & HIV*) (Ritland et al., 2019). Further, qualitative work involving Indigenous mothers in Cedar observed that being able to parent their children was key to participants' own wellness, while those whose children had been apprehended expressed feelings of deep regret and loss (Shahram et al., 2016). As a result, opportunities to connect and strengthen relationships with children not in their custody may support health and wellness. Participants in this study described how consistent phone connectivity supported connections with children not in their custody, as well as helping parents with custody to take care of their children. Some participants shared that they were early in this journey of (re)connecting with kids, as these two texting conversations highlight:

WelTel system (W35): How's it going? *Maple:* Things are great. I had my first phone call with my kids though the ministry. made it easier to have a phone 4 thier wrkr 2 call me back at *Cedar:* That's great. We're glad that it helped up and you had a good call with the kiddos. :)

WelTel system (W65): How's it going? Aurora: I have the best news ever i have contacted my kids on facebook thanx to the phone u guys have provided me with! Thanx this means the world to me:-)

Cedar: That is so Awesome!!!! we are so happy for you:) love you girl!!!!

For others, having a phone with consistent connectivity was an important resource that helped them to navigate the bureaucratic requirements of (re)gaining custody of their children. For example, being reachable by MCFD social workers, using the phone to find/maintain housing, being in touch with school or child care, and connecting with parenting supports. When asked what the greatest benefit of the mHealth program had been, one participant said, *"Everything. Helps me keep in contact with my kids and ministry worker because if I didn't have it they'd have no way to contact me. And my family and legal issues."* [Ada, F, Van, survey].

In addition to directly supporting relational connections between participants and family members through study phones, participants' engagement also illustrated ways in which mHealth supports helped indirectly to nurture good relationships with family and loved ones. Indigenous case management models described in the literature have emphasized that an important role of culturally-safe Case Managers is to support clients to strengthen connections with family and circles of care, including both peers and professionals (Nebelkopf & Penagos, 2005). Cedar Case Managers sought to work together with others in the participant's circle of care, and supported participants to strengthen and maintain these relationships. This relational component of the program is woven throughout the sections that follow, for example with the participant who sought anger management counselling to improve her relationship with her intimate partner and the participant who sought help to report a concerning situation involving her teenage daughter to child protection services.

In sum, supporting connections to family including parents and children in the context of disconnections related to intergenerational child apprehensions was a critical component of the mHealth program. This finding highlights that future mHealth programs should consider providing tools (e.g. phones and long distance) and support (e.g. case management approach that nurtures family connections) that engages young Indigenous people who have used drugs with wider circles of care, rather than focusing solely on participant-Case Manager relationships.

9.3.2 Theme 2: Reflected ongoing impacts of colonization and structural violence

Texting conversations and interviews reflected the strangling impact of colonial laws and institutions that seek to regulate Indigenous lives discussed in-depth in *Chapter 1* of this dissertation. Participants continued to experience the consequences of intergenerational traumas and navigate entanglements other with colonial systems in the present. In the section that follows, participants' texting conversations highlight how instability, uncertainty, and

constraints on their agency continued to be a part of day-to-day life. Cedar Case Managers acknowledged, believed, and validated participants experiences; celebrated diversity of participants with respect to their ancestry, gender, sexuality, spirituality, strengths, and challenges; and offered non-judgmental support. Further, Cedar Case Managers sought to advocate for participants' rights and agency, as well as connecting them with opportunities for healing (Ginwright, 2018; Pihama et al., 2017; Reeves, 2015).

Theme 2.1: Experiencing and witnessing violence

The young men and women in the study reported witnessing and experiencing physical violence and sexual assault both in the past and over the course of the mHealth program. Violence occurred in the context of intimate relationships, substance use, and sex work. Often, violence and assault appeared to take place during a confluence of intersecting challenges, and contributed to setting off a cascade of negative consequences. For example, the following texting conversation reflects a convergence of issues including incarceration, eviction, homelessness, withdrawal symptoms, as well as intimate partner violence for one of our participants living with HIV:

WelTel system (W20): How's it going? *Ivy:* Not good

Cedar: Do you want me to call you, it's [CCM2] ...

Ivy: Yes after im just at [shelter] I am not well im going through so much I was in jail for awhile lost My place lost what I own now homeless struggling so much I now need a drink just sicker than sick I feel sad plus my boyfriend well anyways he beat me I was in deep shock and hurt I got to go for xrays on my face and nose

Ivy: Well im just in shower u can call in 10 min ok is cedar project open today *Cedar:* Sweetheart, that's so much to go through...do you feel safe where you are right now?

Cedar: yes please come by anytime before 4:30

Ivy: Just for Iil while im waiting for housing right now

Ivy: So cedar is open all day ok I be there soon k do u know if im due for my \$5 update of address well now im no longer at r living at [SRO] Im in shelter right now

Cedar: You bet girl, Cedar is open until 4:30pm, so come on by and yes definitely you can do your update:)

Gendered violence was further evidenced by young women in the program who reported witnessing and experiencing violence in the context of sex work. The unresolved issue of missing and murdered Indigenous women was also reflected in participants' mHealth engagement with us. For example, early in program, Highway of Tears serial killer Cody Legebokoff was on trial, which brought up feelings of grief and loss for a participant who knew one of his victims. In this exchange, the participant reached out to share their feelings and the Cedar Case Manager responded by acknowledging the participant's sadness, as well as offering a listening ear and traditional medicine (sage smudge) to support healthy coping and grief:

WeITel system (W3): How's it going?
Dawn: Good thanks im sad for mh girl that was murderd [name]
Cedar: super sad. i still have some sage for you, so you can smudge. we will have to meet up this week
Cedar: I can smudge with you anytime. you know we are here if you need to talk, love ya girl
Dawn: Love you to thank you
Cedar: are you home tomorrow? I can drop the smudge off if you want

Theme 2.2: Substance use

All participants in the mHealth program had at some point been involved in substance use, as this was part of the eligibility criteria for enrollment in the Cedar Project. At the time of the mHealth program, participants were at diverse stages on their substance use journeys. At enrollment, 57 (44.2%) of participants had injected drugs in the past six months. A total of 51 (39.2%) had recently accessed drug or alcohol treatment, and 38 (29.0%) were currently on methadone. A majority (n=109; 84.5%) had ever tried to quit using drugs or alcohol.

No matter where they were on their journey, most participants articulated a deep desire for freedom from addiction and belief that substance use dependence was a barrier to their wellness. Cedar Case Managers took a harm reduction approach that balanced being supportive of participants' steps to move away from substance use if that is what they wanted, while also treating addiction and relapse with kindness and compassion. For example,

WelTel system (W9): How's it going?
Amber: I was wondering if u knew anything about treatment centers.
Cedar: there's a great one in [place] called [treatment centre]
Cedar: you need to get a D&A counsellor and they have to refer you there
Cedar: so i called and [treatment centre] counsellors go to native friendship centre there every tues from 9 - 4 on a drop in basis
Cedar: their address is: [contact details]
Cedar: let me know if there is anything else we can help you with
Amber: Thank u

WelTel system (W10): How's it going?

Amber: Not bad. I got all my stuff together for my [treatment centre] application **Cedar:** woooohooooo!!!! doing a happy dance for you!!! **Amber:** Thank u. Im ready to be a better me.

Theme 2.3: Negative social determinants of health

At enrollment into the mHealth program, 34 (26.0%) of participants reported having recently slept on the street for three nights or more and 56 (44.4%) reported living in an unstable type of housing, such as a single room occupancy hotel. Further, 106 (82.2%) had not graduated from high school. Throughout the mHealth program, participants' stories and engagement demonstrated how they continue to be profoundly affected by negative social determinants of health stemming from colonization.

Housing instability was a pressing concern for most participants, with many housing transitions noted within text conversations. Understandably, evictions were a source of stress, while moving into a new place could be a joyous occasion. Some participants sought support from Cedar Case Managers to help with housing applications and navigate challenges they faced securing a stable home. For example, Fawn told us in W27 that she had submitted housing applications but not heard anything and wanted help to follow-up. Despite her efforts and support from Case Managers captured over the following weeks, her housing issue remained unresolved and she began to lose hope:

WelTel system (W36): How's it going? Fawn: ITZ GOING GOOD. FOUND A TEMPORARY PLACE TO STAY TIL WE GET A MORE PERMANENT HOME TO LIVE IN, RATHER THEN MY MOMZ PLACE. <:0) Cedar: woooohooooo! i am so happy to hear that!! you must enjoy having more of your own space again! Fawn: YES. THA RENT N DAMAGE DEPOSIT SHOULD BE READY TOMORROW AFTERNOON, HOPEFULLY EARLY NOON. BUT I REALLY WANT A APT. WILL TAKE TIME TO GET SOMETHING PERMANENT THO. Cedar: that's so good to hear!! something permanent will come along! i have faith :) Fawn: THANX. IM TRYNG TO KEEP FAITH. Cedar: take care girl. text ya next week!!! Fawn: YA THANX

Related to housing instability were participants' experiences of economic hardship, which contributed to both stress and food insecurity, as illustrated by the following example:

WelTel system (W64): How's it going?
Ember: Stressed out right now and broke as hell ftom fixing my truck but thats ok tomorrow is a new day.
Ember: Sometimes life sucks but it just makes the good moments that much more precious.
Ember: I have no idea how I am even going to get groceries for the next 2 weeks. But again life is about struggle and pulling through that struggle :)
Cedar: awww that is very stressful, vehicles are so expensive!!! you are so right that life sucks at times and is a struggle, but you will get through this !!!! big hugs, call if you need to chat:)
Cedar: are there food banks there you can access?
Ember: Yea im looking into it
Cedar: let me know if there is anything we can help you find!
Ember: will do ladies

Despite these challenges, participants demonstrated the ways in which they were working to confront and overcome the negative social determinants of health, including through use of their study phones. Though a rare occurrence, some participants used their phones strategically in the context of scarce resources by borrowing against it, such as one participant who let us know in week 11 that she was taking her phone to a pawn shop, and subsequently retrieved it at the planned time two weeks later. Another example is participants who used their study phones to seek work and maintain employment. In total, 40 (33.9%) participants who responded to the end-of-study survey said that they used their phones to find work, as this text exchange highlights:

WelTel system (W11): How's it going? Leaf: pretty good working a lot keeping busy Leaf: and just so u know its cause I got a phone boss likes to b able to get ahold of when needed Cedar: we are so happy that the phone is helping you with your work! that's awesome!

Theme 2.4: Criminal justice system

At enrollment into mHealth, 19 (14.8%) of participants had recently been incarcerated. Over a quarter (n=36; 27.5%) reported some sort of involvement with the criminal justice system over the study, including short and long-term incarceration, court appearances, and responsibilities to probation officers. Others spoke about involvement with the criminal justice system to report a crime. A number of participants discussed how involvement with the criminal justice system required them to navigate complicated restrictions such as where they could live or visit (red zones) and who they could spend time with.

"I'm actually kicked out of Vancouver. I believe now I'm allowed back but at the time I was kicked out for 10 years and I haven't I went back once...I had no family staying down there at the time and I was getting into a lot of trouble at the time and the courts decided that because I had no family down there I was red zoned from the whole lower mainland 'cause of the stuff I was doing." [Ben, M, PG, interview]

Adhering to these rules was often not an easy task, and led to fear of additional repercussions.

The following exemplifies how the demands of the court contributes to feelings of powerlessness:

WelTel system (W59): How's it going?
Autumn: Good. Could be Bette.
Cedar: aww, what's going on girl?
Autumn: Court. It got put over. I have a no drinking order and I'm having a hard time with is.
Autumn: Feels like I'm gonna Fuck up and loose my kids.
Cedar: never under estimate how strong you are girl! you are a good strong native woman! never forget that!!!!
Autumn: Yes I know. Jus sucks. I feel like a kid.

Another related example highlighted how even when a decision is made to take steps towards wellness, unresolved legal issues can 'catch up' to you. In Week 16, Nova was hospitalized for an injection related infection which caused her to fear for her life as she had witnessed a friend die from a similar cause. In Week 20, she shared that getting well again offered her a renewed commitment to life. She sought a referral from us for methadone, which she started in Week 22. She began the process of getting a driver's license in Week 23 and got her learner's permit in Week 26, which was a source of pride. In Week 28 she shared that she was taking steps to enroll in a trades training program:

WelTel system (W28): How's it going?
Nova: Good. Going to register & start the application process for welding at [college] this afternoon and tour the trades center
Cedar: aww, girl! that's the best news ever!!!! wooohoooo! doing a happy dance for you!!
Nova: Lol thanks :-) I'll let you know how it goes.
Cedar: yes pls. keep us in the loop!! so excited for you!
Nova: Yes I will, and I am too. I've gotten soo much done and on the way to being successful, even tho my getting sick almost killed me its also given me life :-)
Cedar: you go girl!! never forget how strong you are!!!!

However, unresolved legal issues related to drug possession came up in Week 27, and in Week 29 the participant learned that she would have to do jail time, which contributed to stress that continued for several weeks:

WelTel system (W29): How's it going?
Nova: Shitty. I'm going to jail on weds
Cedar: what?? but you've been working so hard at turning things around?
wont they consider how good youve been doing?
Nova: No, because apparently the government has changed things and made the conditional sentence unavailable for certain charges...

Though the jail time was delayed until Week 42, the momentum and hope reflected in the participants texts in the months after her hospitalization disappeared completely as she anticipated the period of incarceration.

Theme 2.5: Intersections

Often, multiple challenges collided. For example, one participant living with HIV shared how she resorted to shoplifting to provide food for herself and her child. Getting caught and put in jail resulted in missing doses of both her opioid substitution therapy and her antiretroviral medications:

WelTel system (W31): How's it going? WelTel system: Haven't heard from you, just checking in? Iris: JUST GOT BAILED FROM JAIL FOR SHOPLIFTING TO FEED MY KID AND HAV EASTER IT STILL WORKED OUT OK THOUGH WHIL I WAS IN MISSED MY METH AND ARV S 4 DAYS TO Cedar: wow, you have been having a really rough time these last few weeks :(are you doing okay? Iris: IM JUST HAPPY 2 B HOME IT WAS A ROUGH WEEKEND Cedar: yea I bet!! take care of yourself :) chat next weekend

Another example is that during the study period, Poppy was working hard to re-gain custody of her children after they were apprehended. Her text exchange with us in week 45 highlights how important regaining custody was for her, but how she continues to face housing, income, and relationship challenges while being a full-time parent. WelTel system (W45): How's it going?
Poppy: It is ok. I applied for [housing] again. I'm hoping to hear from them soon. Last year it didn't take long for them to respond buti [didn't] have my children home yet. I think I am due to come in, Can I make appointment now?
Cedar: Hey girl, it's [CCM2] you are definitely do for both interviews. Do you want to book for next week?
Poppy: Sure. When next week. I've had kids home since and have no income for them or [partner]. It's getting harder every day
Poppy: Getting kids back was alli could think of for sucha long time. But since Been back I've come into to curves in road
Cedar: Oh honey...I can't say I understand but definitely empathize

In sum, participants' engagement with the mHealth program illustrated how they continued to navigate entanglements with colonial institutions that constrained their ability to make decisions about their own lives. Ongoing impacts of colonization affected participants' safety, where they lived and worked, whether they could parent their children, individual behaviours, and whether they could take steps to pursue what they considered a good life.

9.3.3 Theme 3: Engaged with Cedar Case Managers

This next theme focuses on how participants engaged with Cedar Case Managers through weekly text message conversations. Overall, participants shared and connected relationally with Case Managers, asked for specific supports, navigated study and phone logistics, or did not engage.

Theme 3.1: CONNECTED

In the previous chapter examining mHealth engagement and perceptions from a primarily quantitative perspective, participants shared that knowing someone cares (n=42), keeping in touch (n=27), and talking to/opening up to someone (n=8) were three of the biggest benefits of the texting component of the mHealth program. While this sometimes occurred in 'big' ways, such as in acute crisis moments, it also happened in 'small' everyday ways that helped to strengthen relationships with Cedar Case Managers over time. Building trusting relationships between healthcare providers and clients is critical to culturally-safe care, especially when it relates to sensitive and stigmatizing experiences evident from the previous theme (Nebelkopf & Penagos, 2005; Reading et al., 2013). Participants connected with Cedar Case Managers by text in a relational way through expressions of love and gratitude, small talk, and reciprocal enquiries about Case Manager's own lives, as illustrated in the following examples:

WelTel system (W51): How's it going? Isla: Its great Cedar: awesome kiddo! text ya next week unless there's support you need! Isla: Ok love u tunes Cedar: love you too girl!!! it's so good to be in regular contact with you!! loving it! take care Isla: I know right u guys are amazing to me ill always love all of u Cedar: right back at ya kiddo!!!!! Isla: ;)

WelTel system (W6): How's it going? Piper: Going shoping Cedar: Nice! What are you shopping for? Piper: Odds and ends Cedar: hope it was fun! Piper: Yes it waz Cedar: Great. Chat next week! Piper: Ok

Many participants reached out via text to let us know they appreciated being 'checked on'. This echoes previous WeITel studies which have identified that a valued benefit of the two-way texting program is the sense that 'someone cares' (Smillie, Borek, Abaki, et al., 2014; van der Kop et al., 2012). One example is Camas. For a few weeks, she had been in a conversation with us about seeking substance use treatment as a pathway to reconnect with her children who were not currently in her custody. Her texts to us in Week 20 reflected her ongoing struggle to arrive at readiness to take the next step towards her goal. She spoke about how she was still not ready, but that the weekly check in from us was valuable to her:

WelTel system (W20): How's it going?
Camas: Its going I an just frustrated
Cedar: yeah? what's going on?
Cedar: Hey girl, it's [CCM2] just checking in...how are you?
Camas: I an okay still stalling and freaking out
Cedar: awe. what you're thinking about doing is so tough
Cedar: anything we can do to help?
Camas: yeah not right now thank you so much tho its weird but this check in thing helps tho thanks again :)
Cedar: well, we're here! and we've been thinking about u lots!
Camas: Thanks you guys are awesome have a good weekend
Cedar: you too lady! talk to u next week, kay?
Camas: Thanks see on tues

This was echoed by many participants' comments in interviews and the mHealth survey. For some, Cedar Case Managers represented a point of contact outside of street life and substance use networks. For example, Fern said in her interview,

"I've known [CCMs] for a long time. It's just...just nice to, you know...know that they're always there for support and stuff, right? Just a reminder sometimes because you're in the hood, and in the drug world...surrounded by that, you know what I mean? It's just when you get that little text, you know what I mean, the reminder, you know, that you got that support out there, you know, at any time that you need it pretty much, if you needed it" [Fern, Female, Prince George]

The value of "ask, don't tell" is central to the WeITel mHealth approach and refers to the way in which the weekly text message prompt question ('how's it going?') opens a conversation that is then directed by the participant – not the provider (Lester, 2013). This flexibility made it possible to provide options but respect participants' decisions to engage or not engage with us, or with the referrals provided (Barlow & Reading, 2008; Barlow et al., 2008; Murray et al., 2015). Overall, our approach was to inform, encourage, and support participants' choices with respect for where they were at on their journey and their own agency (Barlow & Reading, 2008; Barlow et al., 2008; Rapp & Goscha, 2008). Individual participants would make their preferences for engagement known to Cedar Case Managers either through their behaviour or by letting us know directly. From the depth of the texting conversations presented in this chapter, it is clear that some welcomed deep sharing via text. Others preferred to signal that something was going on for them and they would like to receive a phone call to discuss it. Cedar Case Managers sought to let participants lead the engagement according to their comfort level. Though rare, a few participants expressed their dislike for the automatic text on Mondays, such as this participant in Vancouver:

WelTel system (W7): How's it going? Connor: I hate that comp txting me Cedar: Oh yea? Even though we're here on the other end? Connor: Its dumb Cedar: That's good for us to know. Luckily, you won't get it forever! Connor: Can u call somtime

By Week 9, this participant mostly stopped responding to our texts but remained engaged through a call from a Cedar Case Manager each week. These weekly conversations included emotional support, touching base about struggles with addiction, criminal justice system

involvement, relationships and parenting, and discussions related to physical wellness. Through referrals from the Case Manager, the participant attended visits with Elders, reduced substance use, and began volunteering. This highlights the flexibility of the program and that participants could direct it to fit their preferences.

Participants also shared how having a phone gave them the opportunity to stay connected with other professionals in their circle of care. Others explained that having a phone provided a degree of independence in the face of high engagement with services demanded of people living with HIV or receiving opioid substitution therapy. This was one way the mHealth resources supported greater agency and control over health encounters for participants. As one young woman living with HIV described having a phone meant that she had an option to call instead of make in-person visits to her clinic, which was preferable to her:

"Then I didn't have to go fucking see anyone face to face or go sit in a doctor's office. It was just asking me questions on the phone or if I wanted to meet I could just phone a doctor and make an appointment or tell her to fax the script, you know, instead of me going and talk to them" [Azalea, F, Van, interview]

In sum, participants used their phones to connect with Cedar Case Managers and others in their circle of care on their own terms. This suggests that integrating mHealth within case management settings may be a way to support relational care that emphasizes participants' agency and choice in directing the form of support that they receive.

Theme 3.2: SHARED

Participants used the mHealth program as a way to share important things going on in their lives with Cedar Case Managers. The open-ended 'patient-centered digital outreach' format supported participants' agency and allowed them to share their experiences and challenges in the way they felt comfortable (Bardosh et al., 2017; Kovach, 2009; Murray et al., 2015; Tilahun et al., 2018). Participants also inquired about how Cedar Case Managers were doing, reflecting the importance of reciprocity in these relationships (Barlow & Reading, 2008; Rapp & Goscha, 2008).

Theme 3.2.1: Good news and milestones

We often heard from participants about triumphs and milestones in their day to day lives. Previous iterations of the WeITel mHealth program were structured so that only 'problem' responses received follow-up by program staff (Campbell et al., 2018; King et al., 2017; Lester et al., 2010; van der Kop et al., 2012). However, at the beginning of our mHealth program, we made the explicit decision to respond to *all* text messages, not just those that indicated a problem. Underlying this decision was an intention to take a strengths-based approach that built on participants' successes to support resilience (Rapp & Goscha, 2008). As you will see in the quotes that follow, Cedar Case Managers responses celebrated participants' strength and honoured their Indigenous identities. Good news shared by participants often related to family, such as becoming an auntie/uncle, or expecting a visit from a relative. In this example, the good news was when a participant living with HIV regained custody of her children who had been apprehended while she was in hospital:

WelTel system (W37): How's it going?
Sage: Good sorry busy
Cedar: happy things are going good for you, love you girl, give us a call and check in when your not busy :)
Sage: Thank you I will
Sage: I miss you all have a good day
Cedar: miss you too, have a good week and we will text you next week
Sage: Thank you we will I got my boys back yesterday I am so happy they right next to me
Sage: I ant letting go this time
Cedar: This is awesome news!!!, we are so happy for you, you are an awesome mom!!! love ya!!!

Participants also frequently shared milestones related to substance use. We heard often about excitement of making a decision to go into detox or treatment, or begin opioid substitution therapy. Others noted recovery and sobriety anniversaries, like these two participants from Prince George:

WelTel system (W3): How's it going? System: Haven't heard from you, just checking in? Avery: Ok just forgot. ..Been doin good...today is 7yrs sober Cedar: wooooohooooo!!! congrats!!!! i can't believe it's already been 7 yrs!!!"

WelTel system (W62): How's it going?
Meadow: Good on my 6th week in day treatment done on the 27th 100 percent attendance so far im surprised and proud of me
Cedar: Im not surprised! you're an amazing, strong Aboriginal woman and don't you ever forget it!!!
Meadow: Thank you love the support you guys are amazing too

For others, the milestones they sought to achieve were still ahead. Many participants shared hopes and goals they had for the future, as well as actions they were taking to achieve them. Common aims included cutting back or quitting substance use, regaining custody of children, finding a stable home, attending school, or securing work. Cedar Case Managers worked to champion participants' hopes and goals, as highlighted in the following text exchanges:

WeITel system (W32): How's it going?

Chloe: Im doing great still strate an sober going treatment for my kids getting them back

Cedar: oh thats WONDERFUL NEWS! were so proud of you :) keep up the good work and keep us posted !! talk to you next week

WeITel system (W55): How's it going?
Petal: Awesome. I.m in school now!!
Cedar: Oh rad! What are you learning about?
Petal: My gr 12 first. Then family counseling before I transfer to [college]
Cedar: Oh awesome! Congrats that is so cool!
Cedar: keep us posted about how it goes, ok?
Petal: For sure :)

WelTel system (W9): How's it going?
Wren: It's going ok I guess
Cedar: what does I guess mean?
Wren: Just struggling wainting to use
Cedar: i know and you know that you have the power to walk away when you want! I believe in you girl!! get a hold of your sponsor
Wren: I have. But still struggling
Cedar: stay strong, keep going to mtg, reach out to your supports. you can do it!!

Some goals remained in progress at the study end, such as one participant who shared that he wanted to enroll in opioid substitution therapy but after multiple missed appointments with both Cedar Case Managers and the doctor, did not reach this aim. This highlights that the Cedar Case Manager's role was to walk beside the participant on their health journey, supporting the participant to engage with care on their own terms when they were ready. There were no judgements or repercussions, and we were always ready to pick up again where we left off.

Theme 3.2.2: Health issues and wellness actions

Participants texted about a diversity of health issues, ranging from cold, flu, and fatigue, to minor and major surgeries, broken bones, injection-related infections, mental health issues, and oral health concerns. Participants also shared day-to-day actions they took to take care of

themselves and support their mental, emotional, physical, and spiritual wellness. This is similar to the concept of *nanâtawihiwêwin*, the 'daily ritual of healing and helping ourselves' shared by Cree scholar Madeleine Dion Stout (Dion Stout, 2015).

WelTel system (W12): How's it going? *Nova:* Good. I got on the methadone program *Cedar:* woohoo!! good for you, that was quite the struggle. Im glad things are looking up, text or call us if you need anything :)

WeITel system (W30): How's it going?

Stella: Im doing well 2morrow wil be doing my 5th step will be emotional but well worth it

Cedar: wow!! good for you girl! I am so impressed with the work u are doing. *Stella:* Thank you kindly

WelTel system (W10): How's it going?
Flint: Ok
Cedar: good, chat next week unless you call!
Flint: K thanks for checking on me
Flint: Kinda had a craving today so I went to my mom's but I sm on my way back home
Cedar: i am so glad you went to your ma's! smart thinking! keep yourself safe you've come so far
Cedar: we know you don't want to go back down that road again. we believe in you 100%
Flint: Thanks girls
Cedar: hugs bud!
Flint: Right back at ya

WelTel system (W64): How's it going? WelTel system: Haven't heard from you, just checking in? Reed: Im good Reed: Taken some anti depression pillz Cedar: good for you, when did you start them? Reed: Monday

These four examples of health actions (i.e., initiating antidepressant medications and opioid substitution therapy; seeking family support and peer support) hint at the diversity of health actions taken by participants over the course of 70 weeks. This underlines the flexibility of the mHealth program to support participants in their own self-determined health and wellness journeys (Dion Stout, 2015; Gallagher, 2018; Reeves, 2015). As well, it demonstrates that texting provided an opportunity for Case Managers to regularly identify, affirm, support, and amplify participants' strengths and their own aspirations for themselves (Rapp & Goscha, 2008).

Further, it recognized and honoured participants' health work (Barlow & Reading, 2008; Barlow et al., 2008), while emphasizing and supporting the central role participants have in managing their own care (Tu et al., 2013).

Theme 3.2.3: Crises and negative experiences

Participants also reached out in crisis moments. Crises were diverse and often reflected ongoing impacts of colonial policies discussed above. Cedar Case Managers were there to listen, validate, and respond. For example, one HIV-positive participant reached out during the Christmas holidays to share her concerns about the safety of her teenage daughter, who was not currently in her custody:

WelTel system (W25): How's it going? WelTel system: Haven't heard from you, just checking in? Petal: I.m not doin very well. Cedar: whats going on? Cedar: my name is [CCM1]...is there anything i can help you with? Petal: I.m just goin thru a hard time w my oldest child. She.s w my adult cousin, using n drinking. Who.s also suicidal Cedar: is it okay if i call you? Petal: Sure

The Cedar Case Manager followed up with the participant by phone to listen to her concerns. Together, the participant and Case Manager decided on a way forward that included making a report to MCFD at the participant's request. The participant reflected on this episode during her in-depth interview, emphasizing that she felt both listened to and validated, and that steps had been taken to address the situation:

Participant: Well yeah, I was gonna say specifically how [the mHealth program] helped me was...I had the text phone and I got a text and I didn't know it was from [CCM1] in [study site] and she text me and said, 'ok how's it going?'. And I was so upset because I'd made reports about an adult that lured my daughter who's under age, who's in care...she lured her for a second time...I was so angry. She said she was suicidal, she's got a toddler in her care, she had my daughter. She'd just gotten a whole bunch of money, and they were in her place using crystal meth, cocaine, heroin, molly – you name it they were doing it – and their daughter was, her daughter was this close from her when she was doing the drugs!

Interviewer: And so you reached out to [CCM1]?

Participant: Yeah and I told her all of that and she said, 'well this is all really, really heavy'. She goes, 'Do you mind if I call you?' So, I spent about a good half an hour on the phone with her and she listened to me and she made the reports as well, and I was really, really thankful for that. I just can't, can't get
over, you know, and I felt so alone, I felt so defeated and I felt that nobody cared about my daughter...yeah that's one huge benefit about that program. [Petal, Female, Vancouver, in-depth interview].

It is important to acknowledge how many participants experienced the death of a family member or loved one during the mHealth program and reached out to us about it. At least 25 (19%) participants reported death of a loved one during the study period; many reported more than one death. For example, one participant shared that their sister, uncle, and cousin had all passed away during the study period. Many of the deaths shared were sudden, and must be understood within the ongoing crises of fatal overdose, suicide, barriers to engagement with healthcare services, and missing and murdered Indigenous women (Allan & Smylie, 2015; Amnesty International, 2004; BC Coroner's Service & FNHA, 2017; FNHA, 2017b; Indigenous Health Working Group of the College of Family Physicians of Canada & Indigenous Physicians Association of Canada, 2016; Jongbloed et al., 2017; Oppal, 2012; Pearce, 2013). Further, they represent a continuation of the multiple losses sustained by families and communities as a result of colonization (Duran et al., 1998; Razack, 2015; Wesley-Esquimaux & Smolewski, 2004).

Accumulation of grief among those left behind may result in loss of hope, and escalation of drug use as a way to cope, contributing to increased vulnerability to drug-related harms, bloodborne infection, and mortality. Young people who have used drugs, as well as their families and loved ones, must have access to culturally-safe resources to support healing and grief coping. The mHealth program helped facilitate a healing-centered approach to support participants who experienced grief and loss (Pihama et al., 2017; Reeves, 2015). Cedar Case Managers worked to support participants by listening, offering cultural supports (e.g., medicines, prayers), and helping with / attending memorials (e.g., bringing traditional foods, fundraisers for funeral costs).

Theme 3.3: SOUGHT SPECIFIC SUPPORTS

In addition to sharing what was going on in their lives, sometimes participants reached out through text message for specific supports, referrals, and information. Requests were diverse and sought to address mental, physical, emotional, and spiritual health and wellness aspirations and goals. Weekly texting with Cedar Case Managers created a point of contact for participants to request and receive referrals and supports from a trusted source.

Theme 3.3.1: Cultural supports

Culture and tradition have been the foundation of wellness among Indigenous people for thousands of years. More recently, the value of culturally rooted approaches to health and wellbeing in the context of intergenerational traumas, substance use, and HIV have been affirmed in research and practice (Bouey & Duran, 2000; Duran et al., 2010; Marsh, Cote-Meek, et al., 2016; Marsh et al., 2015; Nebelkopf & King, 2003; Nebelkopf & Penagos, 2005; Rowan et al., 2014; Wright et al., 2011). Million suggests healing from colonial traumas must involve, "careful rebuilding of Indigenous psyches, families, and communities" (Million, 2013, p. 98).

Texting conversations and interviews reflected the ways in which participants' continue to live Indigenous lifeways through connection to land, ceremony, and kin (Million, 2013, pp. 162-163). Some participants talked about being involved with ceremonies and cultural practices, including potlatch, smudging, and feasting, as well as protocols related to honouring family members who passed away. Others shared they were not currently or had never been involved with traditional wellness practices as a result of intergenerational family disconnections.

Cedar Case Managers sought to support engagement in activities that promote cultural restoration, self-care, and wellness (Duran et al., 2010). This included researching and sharing information about cultural events happening in the two study sites, such as a drum making workshop, a canoe journey, and an urban potlatch. In addition, participants asked for referrals to cultural supports, as was the case with this participant:

WelTel system (W39): How's it going? *Lake:* Ok I need the elders number for native health *Cedar:* just looking it up for you... *Cedar:* It's [phone number] and then just ask for the Elders program.

Cedar Case Managers also directly offered a number of cultural supports, including: prayers; celebrations for arrival of new babies; organizing talking circles when a participant was struggling; attending important cultural events (e.g., funeral for a participant's relative); traditional foods; and smudges. They also organized special celebrations and events rooted in Indigenous traditional healing and wellness practices available to all Cedar participants. Twice over the study period, Cedar hosted holiday dinners with cultural foods (e.g., moose stew, bannock tacos) for participants in both Vancouver and Prince George. We used WelTel's broadcast function to remind participants: *'Don't forget, you're invited to our Christmas party*

tomorrow! Hope to see you there! This invitation was in addition to cards mailed to all Cedar participants at their last known address.

Theme 3.3.2: Support to engage with health and wellness services

Others sought referrals to a variety mainstream services to pursue dreams and aspirations related to their mental, physical, and emotional health. Once again, participants directed and shaped the mHealth program to meet their needs. Case Managers in turn 'walked with' participants to link them to supports, when they were ready to engage. For example, one participant living on reserve reached out for a referral to deal with anger issues that continued to affect her intimate relationship:

WelTel system (W12): How's it going?
Ruby: Good need help for angermanegement
Cedar: hey girl, that's good that you're reaching out. do you trust the counsellor there to start talking about that?
Ruby: They just make me so mad
Cedar: let me look into it and see if there's anything that you can do by phone. i will get back to you
Ruby: Ok

She wanted to avoid accessing the services available in her community as she did not have a good relationship with the band and was concerned about confidentiality. Instead, the Cedar Case Manager arranged for the participant to receive counselling over the phone. This also demonstrates the ways in which the mHealth program supports sought to help participants navigate complex and individualized barriers to engagement with services, such as remoteness, transportation, and confidentiality concerns in this case. In her interview this participant shared,

"Well yeah it was easier because I didn't have a vehicle and I didn't have somebody to bring me down there all the time and he couldn't come up here, so phone conversations were better. We actually took an hour at a time with him every Tuesday." [Ruby, F, PG, interview]

In addition to referrals, some participants faced challenges remembering health-related appointments and asked Case Managers to send a reminder text close to their appointment time. Others who faced additional barriers, for example as a result of having had negative experiences in healthcare settings, asked Case Managers to accompany them to appointments. This highlights the role of the Case Manager to help advocate for participants to ensure their rights were respected and to meet participants out in the community as needed. Participants also spoke about how having consistent phone connectivity through the mHealth program helped them stay in touch with other health and social services. For example, this participant living with HIV talked about how by having a phone, he was able to receive calls and messages directly, whereas previously they had had to get a message to him through the pharmacy where he went to collect his methadone:

"[Clinic] were able to...get a hold of me to, like try to go in to get blood work or if I had an appointment...even now because I have a phone, they're able to contact me whereas before you know they could take a chance and leave a message at, you know, at the pharmacy, right, and hope that I get it," [Linden, M, Van, interview]

Theme 3.3.3: Support to address social determinants of health

Rapp and Goscha have stated that the explicit goal of strength-based case management is to, "assist people to recover, reclaim, and transform their lives by identifying, securing, and sustaining the range of resources—both environmental and personal—needed to live, play, and work in a normal interdependent way in the community," (Rapp & Goscha, 2008, p. 320). Others have emphasized the need for case management to support access to ancillary services to address concerns such as poverty, food, and housing (Bouey & Duran, 2000; Duran et al., 2010). This emerged as an important function of the mHealth program as participants sought assistance to address social determinants of health such as filling in housing applications, creating resumes, or navigating the bureaucratic demands of social assistance.

In sum, this section highlights that participants made specific requests for referrals and support from Case Managers as they sought a variety of health and social services. As result, it is important that Case Managers maintain a sense of community resources available, and work to build connections with them. Of note, requesting specific supports was just one piece of the totality of participants' engagement with us during the mHealth program. It is important for future programs consider the fact that participants do not always ask directly for specific supports, and it is up to Case Managers to work with participants to identify potential resources and navigate access.

Theme 3.4: NAVIGATED STUDY AND PHONE LOGISTICS

Participants also texted with us to navigate research logistics related to their involvement with the Cedar Project generally, such as inquiring about when their next follow-up interview could

be scheduled. Sometimes, participants asked for contact information for other studies in the area. This likely reflects that involvement in research can be a valued form of income for people who face barriers to employment as it can offer a safe, legal way to supplement meager social assistance amounts (Collins et al., 2017). In addition, Cedar Case Managers used texting to connect with people who were due for follow-up, or to invite participants to join other Cedar research opportunities.

Participants also engaged with us to solve issues that came up with study phones. This included dealing with phone loss, getting locked out of the phone, loss of chargers, and breakages. As we encountered these issues we learned how to solve them. One notable issue was that we received some requests to change phone numbers. This occurred when someone was living away from Prince George or Vancouver and wanted to have a local number to avoid friends and loved ones having to dial long distance to reach them. It also occurred when someone was experiencing harassing calls, such as from an ex-partner, as this texting exchange highlights:

WelTel system (W28): How's it going? *Coral:* Aweful. Im saving to move to pg. Wellbeing needs it *Coral:* How big of a problem would it be to get my cell number changed? My ex is harrassing me constantly. I blocked his home number but hes calling from other pols numbers. I reported him to the cops and tbey reccomend I change my number *Cedar:* I will get [CCM3] or [CCM4] to call you tomorrow. they know how to change it. it's a one time only thing. we can't change it more than one. but we sure can do it to help you tomorrow! *Coral:* Ok cool thx¹¹

Phone custody issues also came up frequently over the course of the study. Sometimes, participants shared the phone with family members in a way that worked for them. One example this participant whose wife used his phone to stay in touch with him and other family members while he was incarcerated:

WelTel system (W22): How's it going? WelTel system: Haven't heard from you, just checking in? Forest: Aunty...[participant name]'s in jail and j am back in [city] Forest: Oh i thought u were my aunty. Sorry...but yah this is [name][participant name]'s wife. Hes been put in jail n we r on the mainland. Hez in [city] i think

¹¹ Note: Phone number was successfully changed that week.

Cedar: its [CCM3], thats shitty, how long is he in for? are you going to be keeping his phone while he is in? *Forest:* Yes as its our only way of communication at the moment. *Cedar:* ok no problem, hope your doing ok. just left you a vm message, when you have a minute can you give us a quick call, ty

Other times, the phone was commandeered, stolen, or broken by a controlling partner. There were also times where phones were used as collateral, sold, or stolen and the person who responded to texts or calls was not familiar to Cedar. Each of these situations were navigated on a case-by-case basis by Cedar Case Managers with consideration for the participants' preferences, privacy, and safety.

Theme 3.5: OR, DID NOT ENGAGE

It is important to note that participants engaged, or did not engage, with the mHealth program across a continuum. Some participants engaged in substantial texting conversations with Case Managers each week (deep engagers). Others had long periods of brief, positive responses punctuated by short periods where they texted more and requested extra support, such as during a crisis moment (acute engagers). There were participants who provided brief, positive responses consistently throughout the whole study period (consistent brief engagers). Finally, there were participants who only engaged intermittently with long periods of non-response or inactivity (low engagers). Weekly texting conversations included here are therefore weighted towards the deep and acute engagers.

Understanding the reasons for long periods of non-response or inactivity is challenging. One reason for low engagement was that many participants experienced phone loss during the study period, as reflected in the previous chapter (*Chapter 8: mHealth engagement & perceptions*). Another reason for periods of non-response was incarceration, as this text exchange highlights:

WelTel system (W60): How's it going? Elm: Good just got out of jail Elm: Is this [CCM2] at ceder Elm: I was in jail for 3 months Cedar: it's [CCM5] at cedar! happy to connect with you again :) Sometimes when participants made the decision to enter substance use treatment, such as a recovery house, they were required to give up their phone for a period of time, which resulted in a period of non-response:

WelTel system (W32): How's it going? WelTel system: Haven't heard from you, just checking in? Emma: Hey i'm doing so-so just taking it day by day.:-) i wish i didn't hsve to move but we are going to detox and then recovery. I hope we make it. So pray that [partner] and i make it threw recovery. So i will keep in touch anyway what i do. K. So i will talk to u guys next week ok. Wish us luck ok cz we need it so keep in touch ok. I would like that thanks talk to u later :-) :-) Cedar: what?! this is great news!! you will def be in our thoughts and prayers :) let us know if you lose phone privileges at all so were not worried if youre not checking in every week, wishing you a million good lucks and high fives!

In sum, it is critical that future mHealth programs take a flexible stance to engage with young Indigenous people who have used drugs where they are at, with an emphasis on maintaining good relationships and supporting connectivity.

9.4 Discussion

Study findings highlight that participants are awesome and resilient and caring and hardworking. Their stories and texts reflected that they have and continue to endure significant hardships and barriers to wellness. This study demonstrates that providing young Indigenous people who have used drugs with a bundle of mHealth supports, including a phone, long-distance cellular plan, and weekly two-way supportive text messaging with Case Managers is compatible with Indigenous approaches to addressing intergenerational traumas, substance use, and HIV. First, having a phone and plan facilitated family (re)connections among young Indigenous people who have used drugs who have experienced disconnections as a result of colonial laws and policies which target Indigenous families. Second, actions taken by Case Managers built on young Indigenous peoples' strengths and honoured their identities, while also creating a safe, non-judgmental space to share truths related to trauma and substance use. Third, weekly texting engagement strengthened trusting, culturally-safe relationships between young Indigenous people and Case Managers to facilitate engagement with a variety of mainstream and Indigenous supports. Fourth, the structure of the program allowed it to be participant-led and self-determined. This approach empowered participants to engage about diverse issues that mattered to them in the way they felt most comfortable.

The mHealth program was not without challenges. First, phone loss was an issue and was a source of stress, as well as an obstacle to regular connection between participants and Case Managers. We emphasized a non-judgmental, non-punitive approach to phone loss and recommend this for future programs. While our course of action was clear when a participant reported their phone lost, not all participants told us when phone loss occurred. As a result, it was sometimes a challenge to determine whether a participant was not responding to weekly texts by choice or because they no longer had their phone. Case Managers dealt with these issues on a case-by-case basis; however, future programs may want to establish clearer quidelines related to times when a phone may be in the custody of a family member, during periods of incarceration, or after prolonged non-response. Second, some participants reported experiencing harassing calls from former partners and others. We recommend having procedures in place to respond this type of concern for future mHealth programs, particularly those involving people who may be at high risk of experiencing violence. Third, there were a few cases of additional phone-related costs that were not anticipated, such as when participants used 411 (directory services), purchased games, or made long-distance calls. It is important to plan ahead to minimize potential overages, as well as have procedures in place to address them with participants.

9.4.1 Limitations

Some study limitations must be noted. The Cedar Project and the mHealth study did not involve a representative sample of all young Indigenous people who have used drugs. Texting conversations were complex and diverse, and the volume of data made narrowing down representative quotes a challenge. Participants who liked to engage through text message are overrepresented, as compared to those who preferred to engage by phone or in person, or not at all. I conducted many end-of-study surveys and most of the interviews myself and as I was known to many participants as 'the phone lady', this may have biased participants towards sharing positive experiences and feedback.

9.4.2 Conclusion

The Cedar Project WeITel mHealth program represents a tool to support a culturally-safe, healing-informed, strengths-based response to substance use and HIV among young Indigenous people who have used drugs that nurtures connection to culture and family, as well as supporting self-determination over health and wellness. Immediate and long-term funding should be made available to support integration of similar mHealth initiatives within existing community-based and clinical programs that have strong relationships with young Indigenous people who have used drugs to support healing, health, and wellness.

Chapter 10 Conclusion

10.1 Summary of study findings

The current study explored the experiences of young Indigenous people who have used drugs as they navigate the HIV cascade of care, as well as the impact of an mHealth program to support engagement with HIV treatment and prevention. The research findings provide valuable insights into understanding how a wholistic perspective of health and wellbeing, as well as ongoing colonial traumas, inform experiences of the HIV cascade of care. Moreover, it demonstrated that a supportive mHealth initiative integrated into existing wraparound care from trusted Indigenous and non-Indigenous Case Managers is acceptable and valued by young Indigenous people who have used drugs. Study findings (Table 10.1) provide evidence that mHealth may be an effective tool to support engagement in HIV care for young Indigenous people who have used drugs, and should be considered for application in other program settings as well.

Chapter 1 laid out the conceptual framework guiding research. It identified that a wholistic perspective of health and wellness is supported through Indigenous self-determination and relationships to family, land, and culture. In contrast, wholistic health and wellness are hindered through past and present imposition of colonial laws, policies, and institutions including the Indian Act, residential school system, child apprehension system, criminal justice system, and healthcare system. The historical and present-day consequences of these systems (colonial traumas, physical and sexual violence, racism and discrimination, and material inequities) were discussed in the context of an 'indigenist stress-coping model' developed by Indigenous scholars Walters, Simoni, and Evans-Campbell (Walters et al., 2002). The model posits that colonial trauma experiences contribute both directly and indirectly to increased risk of substance use, as well as both mental and physical illness, but these negative outcomes may be 'buffered' by the protective functions of identity, family, community, spirituality, and traditional healing (Walters et al., 2002). Without the protective effect of culture, resilience, and resistance, substance use for numbing continues to contribute to overrepresentation of Indigenous people among those living with HIV in Canada and marginalization from engagement in the HIV cascade of care. Indigenous led-responses have focused on initiatives that use culture as intervention, and are healing-centered, strengths-based, and culturally-safe. Mobile phones for health (mHealth) is another potential tool, which had not yet been studied in this context.

Chapter 2 described the mixed methods approach used in this dissertation to address four overarching objectives: (O1) Examine experiences of engagement in the HIV cascade of care among Indigenous people, particularly young people who have used drugs; (O2) Assess the feasibility and acceptability of mHealth for HIV-related health and wellness among young Indigenous people who have used drugs; (O3) Evaluate the impact of mHealth on HIV-related health and wellness among young Indigenous people who have used drugs; and (O4) Understand engagement with mHealth for HIV-related health and wellness among young Indigenous people who have used drugs; among young Indigenous people who have used drugs.

The systematic review in **Chapter 3** identified 93 articles published between 1996-2017 that reported primary data on HIV cascade of care outcomes among Indigenous people in Australia, Canada, New Zealand, and the United States. While the majority (50 articles) dealt with HIV testing and diagnosis, relatively few addressed post-diagnosis experiences: linkage to care (14 articles); retention in care (20 articles); treatment initiation (21 articles); adherence (23 articles); and viral suppression (24 articles). Six overarching determinants of engagement in the HIV cascade of care among Indigenous people were identified. Promoting determinants included: (1) Indigenous culture, identity, and ceremony; (2) strength, resilience, and determinants included: (3) social support systems (a strong circle of care). In contrast, hindering determinants included: (4) historical, intergenerational, and lifetime trauma; (5) stigma and discrimination; and (6) intersecting health concerns. It remains essential that the experiences and perspectives of Indigenous people living with HIV are reflected in the currently clinically-focused HIV cascade of care framework, and culturally-safe services are available at all stages.

The exploratory sequential mixed methods study presented in **Chapter 4** focused on where the narratives of Cedar participants living with HIV diverged from the findings of the systematic review. Cedar participants emphasized that having been apprehended from their families as children, and now experiencing their own children being apprehended, was a central concern related to their HIV health and wellness. Themes highlighting intersections of child apprehension and HIV included: (1) impact of participants' removal from their families on long-term health and wellbeing; (2) (re)connecting with family; (3) intersections of substance use, child apprehension, and HIV; (4) fear, stress and demands of maintaining/regaining custody of

children; and (5) traditional wellness practices as valued and complicated. Results from the qualitative phase led us to test for relationships between intergenerational child apprehension experiences and HIV outcomes using quantitative data. We found that in adjusted longitudinal models, being apprehended (aOR: 0.23; 95%CI: 0.06-0.82) and having had a child apprehended (aOR: 0.24; 95%CI: 0.07-0.77) were significantly associated with reduced odds of viral suppression. To our knowledge, this is the first study to investigate the impact of Indigenous peoples' experiences of government child apprehensions on longitudinal HIV health and wellness, building on previous qualitative and cross-sectional work by the Cedar Project and others (Clarkson et al., 2015; Greene et al., 2018; Greene et al., 2014).

Chapter 5 explored patterns of mobile phone ownership and use, as well as interest in an mHealth program, among young Indigenous people who have used drugs enrolled in the Cedar Project WelTel mHealth study. Slightly less than half of participants (n=59; 45.4%) reported owning a phone, of which the majority (n=46; 78%) owned a smart phone. There were no differences in mHealth acceptance between participants who already owned a phone and those who did not. All but one participants living with HIV felt using a mobile phone would be helpful for their health, while a larger proportion of HIV-negative participants remained unsure (1.9 vs. 11.7%; p=0.047). When participants were asked an open-ended question about why using a mobile phone may be helpful for health, they identified a diverse set of anticipated benefits falling into six themes: (1) connection for emotional, mental, and spiritual support; (2) connection to family; (3) staying in touch/being reachable; (4) overcoming current barriers to phone use; (5) convenience, privacy, and safety; and (6) access to healthcare and emergency services. These findings reflected participants' wholistic perspectives of health and wellbeing that extended beyond themselves to include their families, and demonstrated that they felt the mHealth program would be useful for them.

In **Chapters 6 and 7**, we used quantitative longitudinal data to test the effect of mHealth for health and wellness related to HIV and substance use. Receiving the mHealth program was associated with increased odds of viral suppression among Cedar participants living with HIV, a conclusion strengthened through an observed dose-response effect with higher mHealth engagement. As well, results indicated a small but significant increases in mean resilience score among all participants, from 61.60 in the pre-program period to 64.73 in the mHealth program period (p=0.025). However, no effect of mHealth was observed on cultural connection, substance use and treatment, or psychological distress.

Results from **Chapter 8** revealed high engagement with, and acceptance of, the mHealth program. In total, 5217 'how's it going?' texts were sent between September 2014-January 2016 and of these, 3982 (76.3%) received a response. Owning a phone at enrollment into mHealth (aOR: 2.43; 95%CI: 1.19-4.96) and having experienced childhood sexual abuse (aOR: 3.00; 95%CI: 1.39-6.48) were independently associated with increased odds of engagement. In contrast, recent injection drug use (aOR: 0.39; 95%CI: 0.19-0.81) was independently associated with decreased odds of engagement. Most participants told us that they would recommend the program to a friend (96.6%) and would like it to continue (94.9%). They shared that the two greatest benefits of the program <u>overall</u> were connecting with family and loved ones, as well as the financial benefit of being provided with a phone and plan. The two greatest benefits of the <u>texting component</u> more specifically were the feeling that someone cared, and the ability to keep in touch. At study end, 62 (52.5%) participants currently had a phone that could call/text, and 89 (75.4%) reported losing a phone during the study.

Finally, **Chapter 9** used qualitative data to understand how Cedar participants engaged with the mHealth program. Three overarching themes emerged. The first focused on how participants (re)connected with family using study phones. The second discussed how participants' engagement with the mHealth program reflected ongoing impacts of colonization and structural violence. The third unpacked participants' relational engagement with Cedar Case Managers over the course of the program. Actions taken by Cedar Case Managers to provide culturally-safe, strengths-based, healing-centered support for participants were woven throughout. It reaches the conclusion that The Cedar Project WeITel mHealth program represents a culturally-safe, healing-informed, strengths-based response to HIV-related health and wellness young Indigenous people who have used drugs that nurtures connection to culture and family, as well as supporting self-determination over health and wellness.

Chapter	Title	Main findings
Ch 3	Experiences of the HIV cascade of care among Indigenous peoples: A systematic review	 Of 93 articles published between 1996-2017 reporting primary data on cascade outcomes disaggregated by Indigenous identity, the majority dealt with HIV testing/diagnosis (50). Relatively few addressed post- diagnosis experiences: linkage (14); retention (20); treatment initiation (21); adherence (23); and viral suppression (24).
		• Six overarching determinants of engagement in the HIV cascade of care among Indigenous people were identified. Promoting determinants included: (1) Indigenous culture, identity, and ceremony; (2) strength, resilience, and determination; and (3) social support systems (a strong circle of care). Hindering determinants included: (4) historical, intergenerational, and lifetime trauma; (5) stigma and discrimination; and (6) intersecting health concerns.
Ch 4	Exploring	Themes highlighting intersections of child welfare and HIV included:
	intergenerational child welfare experiences and HIV health and wellness among young Indigenous people who have used drugs – a mixed methods study	 impact of participants' removal from their families on long-term health and wellbeing re/connecting with family intersections of substance use, child welfare, and HIV fear, stress and demands of maintaining/regaining custody of children traditional wellness practices as valued and complicated. In adjusted longitudinal models, being apprehended (aOR: 0.23; 95%CI: 0.06-0.82) and having had a child apprehended (aOR: 0.24; 95%CI: 0.07-0.77) were significantly associated with reduced odds of viral suppression.
Ch 5	Mobile phone use and acceptability of mHealth among young Indigenous people who have used drugs in British Columbia, Canada	• Slightly less than half of participants (n=59; 45.4%) reported owning a phone. Among those with a phone, the majority owned a smart phone (n=46; 78%). No differences in mHealth acceptance between participants who already owned a phone and those who did not.
		 All participants living with HIV felt using a mobile phone would be helpful for their health, while a small proportion of HIV-negative participants remained unsure (n=9; 11.7%, p=0.047).
		 In response to open-ended questions asking why using a mobile phone may be helpful for health, participants identified a diverse set of anticipated benefits falling into six themes:
		 connection for emotional, mental and spiritual support connection to family staying in touch/being reachable overcoming current barriers to phone use convenience, privacy, and safety access to healthcare and emergency services.
Ch 6	Effect of mHealth for HIV treatment among young Indigenous people who have used drugs living with HIV	 Receiving mHealth was associated with a 2.09 (95%CI: 1.15-3.79) increase in odds of viral suppression, compared to the pre-program period.
		 Stratifying by city, receiving mHealth remained significantly associated with viral suppression in Prince George (aOR: 3.68; 95% CI: 1.39-9.81) but not Vancouver (aOR: 1.38; 95%CI: 0.64-2.96).
		 Stratifying by sex, receiving mHealth remained significantly associated with viral suppression among women (aOR: 2.90; 95%CI: 1.32-6.34) but not men (aOR: 1.34; 95%CI: 0.54-3.34).
		 Higher (vs. lower) mHealth engagement was associated with 4.48 (95%CI: 1.07-18.85) greater odds of viral suppression during the program.

Table 10.1: Summary of dissertation findings by chapter

Chapter	Title	Main findings
Ch 7	Effect of mHealth for health and wellness among young Indigenous people who have used drugs	 No associations were observed between receiving the mHealth program on access to traditional foods or living by traditional culture.
		 No associations were observed between receiving the mHealth program and substance use or access to substance use services.
		 Receiving the mHealth program was significantly associated with a small average increase in resilience scores, from 61.60 in the pre-program period to 64.73 in the mHealth program period (p=0.025).
		 In a longitudinal model adjusting for age, sex, and city, being in the mHealth program remained associated with a slightly higher mean resilience score (aβ=3.02; 95%CI: 0.34-5.69; p=0.027).
		 Higher mHealth engagement was not associated with increased resilience (aβ=2.47; 95%CI: -4.67-9.60; p=0.500).
Ch 8	Characterizing engagement in and perceptions of the Cedar Project WelTel mHealth Program	• In total, 5217 'how's it going?' texts were sent between September 2014-January 2016. Of these, 3982 (76.3%) received a response.
		 Owning a phone at enrollment into mhealth (aOR: 2.43; 95%CI: 1.19-4.96) and having experienced childhood sexual abuse (aOR: 3.00; 95%CI: 1.39-6.48) were independently associated with increased odds of engagement.
		 Recent injection drug use (aOR: 0.39; 95%CI: 0.19-0.81) was independently associated with decreased odds of engagement.
		 At study end, 62 (52.5%) participants currently had a phone that could call/text, and 89 (75.4%) reported losing a phone during the study.
		• Most would recommend the program to a friend (96.6%) and would like it to continue (94.9%).
Ch 9	Exploring engagement with the Cedar Project	Three overarching themes emerged related to how participants engaged with the mHealth program:
		1. Participants (re)connected with family using study phones.
	Weilel mHealth	2. Engagement with the mHealth program reflected ongoing impacts of colonization and structural
	Indigenous people who	3. Relational mHealth engagement with Cedar Case Managers.
	have used drugs in BC	

10.2 Strengths, contributions, & limitations

10.2.1 Strengths

Indigenous governance. This dissertation would not have been possible without the governance of the Cedar Project Partnership whose members have provided oversight to the Cedar Project since the study's inception in 2003. The Partnership provided protection, leadership, support, and ensured self-determining ethical principles and Indigenous knowledges were respected. Dissertation mentorship from Mr. Demerais and Ms. Pooyak, along with additional one-on-one guidance from Kukpi7 Wayne Christian, Mary Teegee, Earl Henderson, and Vicky Thomas, has helped to make sure that the study approach and findings are reflective of, and useful to, the communities most impacted by them. Leaders involved in the Partnership use the evidence contributed by the Cedar Project, including this dissertation, to advocate for their young people.

Research team. This study benefitted immensely from the contributions of an excellent team of Indigenous and non-Indigenous Cedar Project staff working in the Vancouver and Prince George study offices. The team included three Case Managers (Jill, Amanda, and Shawna), two nurses (Matt and Sharon) and one study coordinator (Vicky). Each brought a tremendous amount of caring and experience working with young Indigenous people engaged in substance use. The team worked tirelessly to create a culturally-safe environment and nurture good relationships with participants, as well as to ensure data quality and consistency. The mHealth program provided the opportunity for Cedar Case Managers and nurses to amplify the culturally-safe relationships they had already worked hard to create with participants, in order to stay in touch and support connections to family, care, and services. In addition, this research was also strengthened through support from the WeITeI team, which provided technical expertise regarding the software platform, troubleshooting, and staff training before and during the program.

Mixed methods. Consistent with the transformative paradigm underlying this dissertation, a mixed methods approach was used to answer its overarching research questions and constitutes one of its major strengths. As discussed in the introduction and methods sections, transformative research seeks to make visible systemic violence and socially constructed power structures with an explicit agenda to shift the balance of power. Use of quantitative

approaches in this dissertation – specifically, Indigenous-led epidemiology – privileged Indigenous knowledges while upholding rigorous scientific methods to address its transformative goal. Scholars Cindy Blackstock (Gitxsan Nation) and Janet Smylie (Métis) have argued that quantitative health and wellness research, when reflective of Indigenous perspectives and priorities, is a vital translational tool that is necessary to address health inequalities (Blackstock, 2009; Smylie & Firestone, 2015). Inclusion of qualitative findings was essential to provide context and honour the voices, stories, and perspectives of the young Indigenous people involved. The qualitative and quantitative approaches were integrated and mixed at multiple points in a way that aligned best with each specific research objective. Mixed methods provided the opportunity to engage with the complexity of HIV health and wellness in the context of ongoing colonization and systemic violence. Similarly, the mixed methods approach provided opportunity to engage with the complexity of an mHealth program involving a bundle of supports, which was flexible, and participant-led, and therefore looked slightly different for each participant.

Ethical considerations. Ethical considerations were a central component and were informed by ongoing learning about Indigenous ethics and research standards. Ethical accountability was navigated through engagement with the UBC Providence Health Care Research Ethics Board and the Indigenous study governance. I was guided to learn and uphold a number of key concepts developed by Indigenous scholars and teams, specifically: Ownership, Control, Access, and Possession (OCAP) (Schnarch, 2004), research as ceremony (Wilson, 2008), and the ethical space of engagement (Ermine, 2007). Engagement with these ethical standards is a dynamic and iterative process of learning that took place from day one of this work, and is still ongoing. Various steps were taken to incorporate them into the research process that are worth highlighting. We offered the mHealth program to all Cedar participants living with HIV regardless of current enrollment in the Blanket Program based on existing knowledge about challenges they face accessing HIV care. This was more important than having a control group. Cultural components were woven throughout the study activities, including both within the mHealth program itself and during data collection, such as providing food and traditional medicines during qualitative interviews (Wilson, 2008). Further, the mHealth program itself centered participant decision making and allowed participants to determine their approach to engagement – whatever felt comfortable to them. We were explicit in making the program as flexible as possible, including using an open-ended 'how's it going' text message each week to begin a conversation but not direct its content; being open to texting, in-person, and telephone

responses according to participant preference; and providing a phone plan with unlimited calling and texting in Canada with no restrictions (whereas other programs have restricted calling out to a specified list of phone numbers). In addition, we took a non-punitive, harm reduction approach with regard to phone loss. Finally, the study approach, development of research tools, and interpretation of findings privileged Indigenous knowledges and perspectives to support an ethical space of engagement (Ermine, 2007) which was possible through opportunities for experiential learning provided to me by my mentors and The Cedar Project Partnership.

10.2.2 Methodological contributions

Brief Indigenous research standards checklist. Systematic review methodology is a powerful tool to identify and appraise existing evidence to answer a specific research question and support health decision making. To decolonize literature reviews in the context of Indigenous health and wellness, Indigenous scholars have recommended that: priority review topics be identified by Indigenous people themselves; contexts and unique determinants of Indigenous health are taken into account; and Indigenous research standards are considered in assessment of study rigour (Chambers et al., 2017; McDonald et al., 2010). Therefore, one methodological contribution of this dissertation was collaborative development and implementation of a brief Indigenous research standards checklist through engagement with the literature on Indigenous research methodologies and ethics, as well as drawing on the related expertise of a team of Indigenous and non-Indigenous scholars. It was used alongside a more conventional quality assessment in the systematic review presented in Chapter 3, which has now been published in AIDS & Behavior (Jongbloed et al., 2019). To date, uptake of the checklist involves application in a scoping review of culturally-safe parenting interventions to support Indigenous families impacted by substance use conducted by our research team (Ritland et al., 2020).

Wellness & strengths-based epidemiology and intervention research. Deficit-based research that centers ill health and disease dominates the epidemiological landscape (Fogarty et al., 2018; Walter & Andersen, 2013, p. 16). The emphasis is on what makes us sick, rather than what makes us well. In the context of Indigenous health, deficit-based research has been a tool of colonization that portrays Indigenous people as inherently sick. This dissertation has sought to counter a deficit perspective through attention to Indigenous perspectives of health

and wellbeing in all chapters. This included using measures of cultural connection developed by Cedar Study Elders, capturing resilience through a scale validated with Cedar participants, and weaving considerations of wellness, resilience, and resistance more generally throughout the entire work. Wellness and strengths-based research is an emerging area in mainstream science; this dissertation offers one example in the growing literature of how a strengths-based lens can be applied to epidemiological research involving Indigenous people. Necessarily, attention is also given to the colonial institutions and systemic violence that continue to impede health and wellbeing of young Indigenous people who have used drugs. Focus on these root determinants of Indigenous health – both the strengths and systems of wellness that have existed for thousands of years, as well as the colonial structures that disrupt and undermine them – avoids narrowly placing the burden and responsibility for 'healthy living' on individuals. This shift seeks to 'pathologize' colonial state structures and institutions, rather than Indigenous peoples, while recognizing individuals' rights and autonomy to self-determine their own health and wellness journeys.

Interpretive description analysis of text message data. Despite tremendous growth of the field in the past decade, mHealth research methods are still emerging. To our knowledge, this dissertation represents the first time that text message conversations have been analyzed using interpretive description with an explicit pragmatic focus on strengthening programs and services, while building on existing expertise and knowledge. Previous qualitative analyses related to mHealth for HIV have either relied on data generated through in-depth interviews following program implementation, or has sought to "quanticize" qualitative text message data by categorizing and tallying the frequency of occurrence. Use of interpretive description in this context allowed a rich examination of how an mHealth program involving young Indigenous people who have used drugs looked and functioned in practice.

10.2.3 Policy & program contributions

Helped to address gap in HIV cascade of care epidemiology among Indigenous peoples. Ending the HIV epidemic is within reach (UNAIDS, 2014a). Yet, lack of population-level epidemiological evidence on HIV cascade of care outcomes among Indigenous people living with HIV in Canada and globally may further marginalize this population from care. Specifically, lack of data may obscure how systemic oppression and lack of culturally-safe care impede Indigenous people living with HIV from accessing health services making up the HIV care cascade. In the absence of Indigenous-specific cascade of care statistics, the systematic review presented within this dissertation represents the first attempt at a comprehensive look at Indigenous peoples' experiences through the lens of this framework. By drawing on both qualitative and quantitative data, it sought to highlight the HIV health and wellness perspectives of Indigenous people, alongside clinical priorities emphasized within the stages of the cascade of care. Importantly, the review represents collaboration between Indigenous and non-Indigenous scholars that drew from included studies to support decolonization of the HIV cascade of care framework, as well as identify gaps in existing evidence. The systematic review is now being accessed by Indigenous people living with HIV in BC. We expect the findings to have important implications for delivery of culturally-safe HIV care for Indigenous people living with HIV globally.

Identified links between child apprehension and poorer HIV cascade of care outcomes.

To our knowledge, findings presented in this dissertation are the first to identify concerning statistical links between child apprehension experiences rooted in colonial legislation and violence, and reduced odds of HIV viral suppression among Indigenous people. While the impact of child apprehension on HIV-related health and wellness has been highlighted in a few qualitative studies, it is largely absent from the epidemiological literature relating to the HIV cascade of care among Indigenous peoples. This is an important finding as it illustrates that over 140 years of state-sanctioned apprehensions of Indigenous children did not end with the closing of residential schools but endure into the present, and continue to have profound consequences for health and wellbeing of Indigenous families. Study findings contribute to the evidence base required to advocate for changes in existing legislation and practice related to child protection in BC and Canada. In addition, these results are critical to informing wellness-focused, self-determined relationships between Indigenous people living with HIV and their HIV clinicians, as discussed in more detail within the recommendations section that follows.

Tested a supportive mHealth program for HIV treatment and prevention among young Indigenous people who have used drugs. This study was the first to test a supportive mHealth program for HIV treatment and prevention among young Indigenous people who have used drugs. Previous WeITel and other mHealth research has involved generalized populations of people living with HIV. Yet, as demonstrated in the early chapters of this dissertation, Indigenous peoples have a unique set of overarching determinants related to substance use and engagement in HIV care. The mHealth program was developed and evaluated from the perspective of these promoting and hindering determinants that sought to honour Indigenous ways of knowing. To our knowledge, it is the first mHealth program that has taken this approach. Further, the participant-led nature of the mHealth program represented application of key principles that have been identified as essential to HIV and substance use responses among Indigenous peoples – culturally-safe, strengths-based, healing-centered, and involving culture as intervention. What we found is that access to supportive mHealth that includes ability to call and connect with family and circles of care, including structured weekly interactions with a Cedar Case Manager, represents a feasible and valued programmatic response to HIV among young Indigenous people who have used drugs.

10.2.4 Limitations

A number of limitations specific to each analysis are described in Chapters 3 through 9, including related to qualitative analyses, quantitative analyses, and mHealth program implementation. However, some overarching limitations must be acknowledged:

Sample. Briefly, concerns may be raised about the representativeness of the study sample and thus the generalizability of study results. As no *a priori* sampling frame of young Indigenous people who have used drugs exists, The Cedar Project study involves a non-probabilistic sample and it is possible that the most vulnerable young Indigenous people who have used drugs may be over or underrepresented in this study. Although we cannot rule out selection bias and its impact, we are confident that our recruitment methods and rigorous eligibility criteria ensured that our cohort sample is representative of young Indigenous who have used drugs in Vancouver and Prince George. As presented in *Chapter 2: Methodology*, among participants eligible for mHealth there were some differences between those who enrolled and those who did not. Living in Vancouver and history of homelessness were associated with lower likelihood of enrolment among participants with HIV. Older age and history of overdose were associated with lower likelihood of enrolment among participants with HIV. As a result, findings presented here may not be generalizable to all young Indigenous people who have used drugs, including those living with HIV. However, through self-selection, participants likely do represent those who would be open to participating in a similar program.

Study design. In addition, this study used qualitative and quantitative observational data collected over time to understand Cedar participants' experiences of the HIV cascade of care,

and determine whether an mHealth program was useful for supporting engagement in HIVrelated care and services. We did not conduct a randomized controlled trial, which represents the gold standard within intervention research and therefore are cautious about making causal inferences from our findings. However, the mixed methods approach allowed us to examine both the "status quo" prior to the program and the impact of the program, from multiple angles. In this way, the quantitative components were strengthened through the use of longitudinal data and contextualization possible through inclusion of qualitative components utilized throughout the dissertation.

Quality of measures. A number of types of measures were used in this dissertation, including objective measures of HIV, viral suppression, and mHealth engagement; validated scales related to resilience and psychological distress; and a number of variables that were self-reported. It is possible that participants under reported behaviours or experiences that are painful to recall or stigmatizing, potentially introducing a social desirability bias. To minimize the potential for social desirability bias and increase the reliability of responses, interviewers were extensively trained to establish rapport with participants, and all interviews and testing took place in a private and quiet place of the participant's choosing.

10.3 Recommendations

Four overarching recommendations arise out of this dissertation as a whole and were developed in collaboration with Cedar mentors, committee members, and investigators. They include: (1) upholding a wholistic perspective to walk *with* young Indigenous people who have used drugs on their health and wellness journeys; (2) urgently addressing child apprehensions; (3) offering the Cedar Project WeITel mHealth model for HIV health and wellness; and (4) exploring integrating mHealth with healing modalities for substance use and other aspects of wholistic health and wellness. The audience for these recommendations are Canadian and BC policy makers, health decision makers, and health providers.

Recommendation 1 – Uphold a wholistic perspective to walk with young Indigenous people who have used drugs on their health and wellness journeys.

Young Indigenous participants in this study shared a wholistic perspective of health, wellness, and healthcare services that included the mental, physical, emotional, and spiritual health of

themselves and their families. They emphasized the critical importance of family in their health and wellbeing. Participants shared a desire to live 'a good life' that reflected a wholistic and relational sense of wellness that has been articulated by many Indigenous knowledge keepers and scholars (Ansloos, 2017, p. 94; Brant Castellano, 2008, p. 384; Henderson, 2008; Hovey et al., 2014; Poonwassie & Charter, 2001). This was illustrated in the overarching determinants that supported Indigenous peoples' engagement in the HIV cascade of care identified in the systematic review, which included cultural connection, resilience, and a strong circle of care *Chapter 3: Systematic Review*) (Jongbloed et al., 2019). We also heard from Cedar participants that from their perspective, elements of a good life include the opportunity to parent their kids and connect with family; participation in ceremony and traditional practices; harm reduction and/or freedom from substance use dependence; struggling less with housing and making ends meet; freedom from violence; and good relationships with those around them, including health providers (*Chapter 4: Child Apprehension & HIV; Chapter 5: mHealth Acceptability; Chapter 9: Exploring mHealth Engagement*). What 'a good life' is, is up to the person living that life.

Our findings also affirm that a person should not have to travel their journey alone. Circles of care, which can include family members and loved ones, community, and health and social service providers, are important to wholistic and relational understandings of health and wellness. Therefore, we add our voices to recommendations already articulated and sought by Indigenous people in BC, Canada, and globally: that young Indigenous people who have used drugs must have access to healing-centered, culturally-safe and humble care that respects the self-determination of those seeking care and their families, and represents the best of what both mainstream and cultural approaches have to offer. This includes access to traditional healing, harm reduction and other substance use services, mental health services, healthcare, in addition to services related to the social determinants of health (e.g., housing, education, economic security, and strong families).

Recommendation 2 – Urgently address child apprehensions

Participants' stories reflected harmful entanglements with colonial systems, particularly the child apprehension system, criminal justice system, and healthcare system, that impeded their ability to be healthy and well (*Chapter 4: Child Apprehension & HIV; Chapter 9: Exploring mHealth Engagement*). Our systematic review revealed that colonial traumas, stigma and

discrimination, as well as presence of other co-occurring health concerns such as substance use and mental illness, impede engagement in HIV cascade of care services for Indigenous people around the globe (*Chapter 3: Systematic Review*) (Jongbloed et al., 2019). Here in BC, the ongoing impact of child apprehensions on the health and wellbeing of young Indigenous people who have used drugs living with or at risk of HIV infection surfaced over and over again as a present-day harm rooted in generations of child apprehensions that began with the residential school system and have continued for more than 140 years (*Chapter 1: Introduction; Chapter 4: Child Apprehension & HIV; Chapter 9: Exploring mHealth Engagement*). Cedar participants are intergenerational survivors of the residential school system, survivors of the Sixties Scoop, and currently face their own children being apprehended through the Millennial Scoop. These experiences were associated with 75% reduced odds of viral suppression among Cedar participants living with HIV (*Chapter 4: Child Apprehension & HIV*). Findings from this dissertation add to mounting evidence affirming what Indigenous Elders, leaders, and parents have known for generations: that child apprehensions are a negative determinant of health for Indigenous individuals, families, communities, and nations.

State apprehension of Indigenous children from their families, territories, and nations must be stopped. Breaking cycles of Indigenous child apprehensions requires significant structural changes involving federal, provincial, and Indigenous governments. We recommend that Canadian federal and provincial governments make good on promises they have already made to reset the relationship with the Indigenous peoples of these lands and waters, including through upholding the self-determination of Indigenous nations, families, and individuals related to child protection. Significant legislative and policy changes have taken place in the years this dissertation was underway. Current BC and Canadian governments have affirmed their commitments to UNDRIP and implementing the Truth and Reconciliation Commission's Calls to Action, both of which include clear messages calling for the end of mass apprehensions of Indigenous children (BC NDP, 2018; Trudeau, 2018). Recently, in June 2019, Bill C-92 received Royal Assent and will come into force in January 2020 (Parliament of Canada, 2019a). The bill represents decades of advocacy by Indigenous leaders and its purpose is to recognize Indigenous Peoples' jurisdiction over child and family services (Parliament of Canada, 2019a). Even more recently, in November 2019, BC's Legislative Assembly passed Bill 41 -Declaration on the Rights of Indigenous Peoples Act to begin the process of bringing the province's laws into alignment with UNDRIP (Legislative Assembly of British Columbia, 2019). This will include responding to Article 7, which condemns forcible removal Indigenous children

(UN General Assembly, 2007). What is critical is that these important legislative changes are accompanied by provision of financial resources to First Nations and Indigenous communities to ensure that implementation is community driven and Nation based. Currently, millions of dollars flow to the province for child and family services in which Indigenous children are vastly overrepresented; however, these resources are required by Indigenous governments as they reclaim control over child protection and address social determinants of health and wellness for families including housing, education, and employment. Therefore, we recommend that the promising changes in legislation and policy at federal and provincial levels include comprehensive and sustainable funding to Indigenous communities for self-determined child and family services, capacity building, and related essential services (Metallic, Friedland, & Morales, 2019).

Addressing the health and wellness impacts of intergenerational child apprehensions must also take place within healthcare services, such as substance use and HIV services. Health systems, services, and providers must recognize that parenting, substance use recovery, and sustained engagement with HIV care are interconnected journeys which may require ongoing support (Gartner et al., 2018; McLachlan et al., 2015). Yet, healthcare services are unsafe if they are places where Indigenous people face increased risk of having their children apprehended. Therefore, we recommend that HIV clinicians and services adopt an explicit 'keeping families together' approach which recognizes the importance of family health and wellbeing in regard to HIV health and wellness. A 'keeping families together' approach may mean taking steps beyond clinical actions narrowly focused on reducing HIV viremia but still constitute "the highest standard of care" according to medical ethics. Recently, I was invited to be part of the ceremony that took place as the First Nations Health Authority and Doctors of BC came together to sign a Declaration of Commitment to Cultural Safety and Humility in Health Services Delivery for First Nations and Indigenous people in BC (FNHA, 2019b). x*mə@k*əyam family member and Knowledge Keeper Te'ta-in Shane Pointe led the protocols and also shared a story that helped me to understand what this type of culturally-safe and humble care might look like (FNHA, 2019b). He explained that growing up, his family received care from a physician who he described as a family doctor "in every sense". Recognizing the authority that doctors hold in society, as well as his trusted relationship with the family, Te'ta-in's mother approached the physician and asked that he write a letter saying *Te'ta-in* could not go to residential school. The physician wrote the letter and it was signed by the Indian Agent. When the school's representatives came to take *Te'ta-in*, the letter was presented and the authority of the doctor's signature held. He was not taken to residential school and continued to live and be raised at home with his family. Today, he is recognized as someone who carries Coast Salish cultural teachings, medicine, wisdom, and knowledge. A 'keeping families together' approach is critical to culturally-safe HIV care and should involve wraparound services that uphold young Indigenous peoples' rights, strengthen family and cultural connections, support healing from unresolved traumas, help prevent new apprehensions, and integrate HIV and substance use healthcare.

Recommendation 3 – Offer the Cedar Project WeITel mHealth model for HIV health and wellness

The Cedar Project WelTel mHealth bundle of supports (a mobile phone, weekly two-way texting, and culturally-safe case management) was an acceptable model for providing relational, participant-led support for young Indigenous people who have used drugs, including those living with HIV (Chapter 5: mHealth Acceptability; Chapter 8: Characteristics of mHealth engagement; Chapter 9: Exploring mHealth engagement). Digital technology interventions are diverse, harnessing the power of mobile phones (mHealth); computers and the internet (eHealth); and telephones (telehealth) (Jongbloed, Parmar, et al., 2015). Even within the area of mHealth there are a variety of approaches, including use of apps, smartphones, tablets, and text messaging. The Cedar Project WelTel mHealth program involved providing participants with a basic phone that could call and text anywhere in Canada but did not include data. From there, we used an evolving computer-based software program developed by the WelTel team to send out an automatic message ('how's it going?') on Mondays and navigate back-and-forth texting between participants and Case Managers throughout the rest of the week. The program also involved an 'offline' component where participants connected with a team of trusted Case Managers through phone calls and in-person visits (Chapter 8: Characteristics of mHealth engagement).

We learned that mobile phones and phone connectivity may represent an important determinant of health for young Indigenous people who have used drugs through the role phones play in housing, employment, economic security, parenting, connection to family and children in care, and access to healthcare and services (*Chapter 5: mHealth Acceptability; Chapter 8: Characteristics of mHealth engagement; Chapter 9: Exploring mHealth engagement*). In the context of disconnections which have characterized the colonization of BC

and Canada, consistent phone connectivity is one tool to nurture connections that are helpful to health. Taken together, the dissertation findings support the idea that lack of phone connectivity can contribute to further marginalization and disparities in health and the social determinants of health. As a result, we recommend expansion of policies and programs that seek to make mobile phone connectivity more accessible for young Indigenous people who have used drugs.

Further, we observed that the mHealth program facilitated family connections, including with children in care, which, as mentioned, is an important part of wholistic health and wellbeing (*Chapter 5: mHealth Acceptability; Chapter 8: Characteristics of mHealth engagement; Chapter 9: Exploring mHealth engagement*). The program supported connections with other trusted members of participants' circles of care, including, but not limited to, Cedar Case Managers (*Chapter 8: Characteristics of mHealth engagement; Chapter 9: Exploring mHealth engagement*). Most importantly, the structure of the program allowed it to be self-determined and participant-led, in which participants decided the form, direction, and substance of their engagement, as well as how they would use their phone and plan (*Chapter 9: Exploring mHealth engagement*). This is consistent with shifts towards patient-centered care in the mainstream health system more broadly, as well as calls by Indigenous leaders for relational care that ensures that Indigenous people accessing healthcare remain in the driver's seat as decision makers in control of their own health and wellness journeys (Barlow & Reading, 2008; Gallagher, 2018; Montague et al., 2017).

Of note, it is very important to be explicit about what the Cedar Project WelTel mHealth program was <u>not</u>, as mHealth programs are often lumped into a single category of interventions which are expected to have similar effects. Our program <u>did not</u> involve a mobile phone app. It was <u>not</u> a system of medication reminders or a way to 'push' health information out to participants. It was <u>not</u> a research tool used to collect 'real time' data on participants' behaviours. It is therefore important that this study's findings not be used to justify or advocate for these other types of programs.

Receiving the mHealth program was associated with increased odds of viral suppression among participants living with HIV *(Chapter 6: Effect of mHealth for Viral Suppression).* Achieving and sustaining undetectable viral load is the gold standard of 'success' when it comes to HIV health from a clinical perspective. Yet, as demonstrated in Chapters 3 and 4, narrowly focusing on the virus instead of the *human being* living with the virus does not capture the full picture of HIV-related health and wellbeing (*Chapter 3: Systematic Review; Chapter 4: Child Apprehension & HIV*). Therefore, it is also important to recognize the other aspects of health and wellness related to HIV that were supported through the mHealth program, particularly family connection, social support, and economic support. Participants shared how having a free phone and plan in particular offered economic benefits in the context of constrained resources, and some indicated that the consistent connectivity made it easier to find and maintain employment. Thus, programs and services addressing determinants of HIV health and wellbeing are not extra, but essential.

As the Cedar Project WeITeI mHealth program was feasible, valued, and effective in supporting HIV-related health and wellbeing for young Indigenous people who have used drugs, we recommend it be incorporated into existing and future HIV cascade of care services for this population. Further, the results brought forward in this dissertation add to the growing body of evidence in Canada and globally that demonstrates that the WeITeI model more broadly is an effective tool to support engagement in HIV care (King et al., 2017; Lester et al., 2010; Smillie, Borek, Abaki, et al., 2014). As a result, it should be scaled up across the province through integration with all existing HIV clinical services.

Recommendation 4 – Explore integrating mHealth with other healing modalities for substance use and other aspects of wholistic health and wellness

We observed mixed results related to the program's impact for substance use and cultural connection. While the quantitative data showed no association between indicators of substance use and cultural connection and involvement in mHealth *(Chapter 7: Effect of mHealth for other HIV-related health and wellness outcomes)*, the qualitative data demonstrated that the program was supportive in strengthening family connections, affirming Indigenous identities, and creating opportunities to access services *(Chapter 9: Exploring mHealth engagement)*. These mixed results mean that further research is required to understand the ways in which mHealth may prove useful to support young Indigenous people who have used drugs, including those living with HIV, to engage with a range of health and wellness services. The findings from this dissertation, combined with emerging research demonstrating mHealth to be highly effective when building upon existing evidence-based programs and services (for example, wraparound clinical HIV cascade of care services), have contributed to our recommendation for future

programs to test the effectiveness of the Cedar Project WeITel mHealth model in diverse settings and contexts.

Results informing the second recommendation to urgently address child apprehensions are important to consider in the context of supportive mHealth as well. This dissertation demonstrated that Cedar participants planned to, and did, use their phones to connect with family (Chapter 5: mHealth acceptability; Chapter 8: Characteristics of mHealth engagement; Chapter 9: Exploring mHealth engagement). mHealth programs may be a valuable tool to support young Indigenous people who have used drugs with the work they are already doing to break cycles of disconnection in their own families, for a number of reasons. First, we observed that receiving the mHealth program was associated with small but significant increases in resilience, which may have implications for positive parenting (Chapter 7: mHealth overall). Second, participants told us their phone was a way to maintain good connections with family, including kids in care as they: used phones to contact and coordinate meetups with family members such as kids, parents, siblings, grandparents, aunts, and uncles, some of whom they had been out of touch with for a long time; used phones to stay in touch with social workers in order to speak to and arrange visits with their kids who were currently not in their custody; used their phones as part of their parenting responsibilities; and sought help from Case Managers related to their kids' health and wellbeing (Chapter 5: mHealth acceptability; Chapter 9: Exploring mHealth engagement). Third, we also learned that providing this bundle of mHealth supports helped to relieve a financial burden of phone ownership and connectivity that within the context of constrained resources was sometimes out of reach for participants (Chapter 8: Characteristics of mHealth engagement). This is particularly important as we know that apprehensions continue to occur related to family poverty (Blackstock, 2007; Blackstock & Trocmé, 2005; Rothwell et al., 2018). Taken together, the impact of mHealth supports on resilience, family connection, and economic hardship may mean that it is an effective tool to support Indigenous parents to seek and maintain connection and custody of their own children. We recommend that future research explore this application further.

10.4 Conclusion

I am immensely grateful to the Cedar participants, Elders, partners, and investigators for their kindness and patience to teach me these lessons and allowing me to bring them forward. You have changed how I see the world, and also my place in it. What I know now is this: Imposed

Canadian and BC legislation continues to be an obstacle to health and wellbeing for young Indigenous people who have used drugs, including those who are working hard to live well with HIV. As Canadian researchers and health leaders we have a responsibility to hold our governments accountable to commitments they have made to respecting Indigenous rights and self-determination. We have a responsibility to ensure that the health and other systems we work within move towards being culturally-safe and humble, taking action to prevent systemic harms, and ensure that Indigenous perspectives are respected. Especially, we must stop largescale apprehension of Indigenous children from their families. This work affirmed for me that as individual care providers and the health system as a whole, we must change the way we participate in young Indigenous peoples' circles of care to ensure that we are walking with, not exerting power over. Access to a mobile phone and consistent cellular connectivity are tools for health and wellness in that they support self-determination, strengthen connections and relationships that are important to health, and play a role in navigating social determinants of health. Finally, I learned that supportive mHealth offers a great opportunity to strengthen relationships with care providers, allow participants to lead their own journey, nurture family connections, and overcome barriers to care.

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