$\label{thm:continuous} Urban\ Homelessness\ and\ Emergency\ Department\ Usage:$ 

Predictors and User Narratives of Emergency Care

by

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#### Abstract

Emergency Department (ED) usage among people who are homeless is higher than in the general population; however, myths regarding people who are homeless inappropriately using the ED are present in public and scholarly discourse. Further, minimal research has investigated ED use among those who are homeless in a Canadian context, or regarding how those who are homeless understand the role of the ED in their healthcare. Study 1 explores the question of which factors predict ED use among people who are homeless in a Canadian sample. Participants (n = 483) from a local, longitudinal Housing First demonstration project consented to the linkage of their survey responses regarding housing, health and social service use to the provincial administrative health data repository. Predictor relationships were analyzed using negative binomial longitudinal mixed modelling. In the full model ED visits were positively and reliably predicted by Indigenous ancestry, high needs mental illness, pre-baseline ED use, and concurrent increased social assistance, primary care visits, ratings of physical health, substance use problems and case management visits. Study 2 addresses the question of how participants understand the role of the ED in their healthcare and day-to-day lives. A subset of participants from Study 1 were recruited (n = 16) to participate in semi-structured interviews regarding their ED stories and experiences. Interviews were analyzed using narrative analysis. Set within the context of narratives of disempowerment, participants storied the ED in differing ways. The findings indicate that participants understand the ED to be a public, accessible space where they could exert agency in obtaining necessary healthcare. ED narratives were also paradoxical, storying it as a fixed place of transient care in their transient lives; as a result, they were isolated, and yet belonged. Each study is accompanied by a discussion of the implications of their respective findings. The thesis includes a synthesis of the findings from the quantitative and qualitative studies. Overall, the

findings from the combined research challenge misconceptions about the inappropriateness of ED use among people who are homeless and call for a cessation of propagating societal narratives that risk compromising the quality of their healthcare.

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#### **Chapter 1: General Introduction**

On September 19<sup>th</sup>, 2008, a 45-year-old man entered the Emergency Department of a prominent Canadian hospital in Winnipeg, Manitoba, propelling his wheelchair under his own power. He was alert, but in pain, having been sent by a family physician from a local community health clinic who had determined that the man's catheter needed to be changed. After being greeted by the triage aid the gentleman was instructed to proceed to the waiting room; however, for reasons unknown, he was never recorded as a patient and never called back to the triage desk for assessment. Over the next several hours, various members of the hospital staff observed him, even interacted with him. His condition gradually worsened. He vomited on several occasions, which other waiting patients brought to the attention of hospital staff. A patient who had left the hospital after the man's arrival returned to find him the following evening, slumped over in his wheelchair. When she reported her concern to a student nurse, she was told that "[some] people stay in the waiting room after they are released because they have nowhere else to go and that homeless people use the [Emergency Department] to sleep and stay warm" (Browne, Hill, Lavallee, Lavoie, & McCallum, 2017, p. 3). After 34 hours in the Emergency Department waiting room, he was finally granted medical intervention: the failed attempts that were made to resuscitate him and his passing declared. As others have previously written, Brian Sinclair was ignored to death (Browne et al., 2017).

This thesis is about stories and data from people who occupy the intersection of several marginalized identities, embodying those stereotypes that permeate Mr. Sinclair's story. An Ojibwa man, Mr. Sinclair's case exemplified stereotypes conflating homelessness, Indigenous ethnicity, and substance abuse, despite Mr. Sinclair being neither homeless nor inebriated. Many have argued that racism and prejudice – that is, the stereotype – killed him (Browne et al., 2017).

The majority of the people who participated in my dissertation research were homeless and Indigenous. They were further disenfranchised in that they have all been diagnosed with mental illness. Some of the participants are further disempowered in that they have brain injuries or cognitive impairments, and some abuse drugs and/or alcohol. Many of the participants who I spoke to about the Emergency Department (ED) picked up Mr. Sinclair's story as a symbol of how they understood their ED experience.

Mr. Sinclair's (lack of) treatment was partially driven by a persistent "urban myth" (Manitoba Health Seniors and Active Living [MHSAL], 2018, p. 40) that ED overcrowding is a result of people being in the ED who are not in need of emergency medical care. And yet, the presence of low-acuity patients in the ED is only one input factor of the input-throughput-output model that frames how we understand ED wait times (Asplin et al., 2003). Input factors involve who is arriving to the ED and what their reasons are for presenting to the ED. People may present with care needs ranging from emergent to "inappropriate." Input may also be affected by such things as seasonal variation in illness presentation. Throughput factors include processes of the ED, such as triage decision-making, the number of staff available, or the number of diagnostic procedures a patient is prescribed to receive. Output factors include processes and resources available to facilitate the transfer of patients out of the ED into the community or hospital. Despite extensive research in the area, misconceptions regarding the cause of overcrowding in EDs – often referred to as "access block" (MHSAL, 2017) – contribute to the problematic stereotypes that contributed to the death of Mr. Sinclair. In reality, access block has little to do with input factors (Affleck, Parks, Drummond, & Rowe, 2013; Doupe et al., 2017; MHSAL, 2017; Schull, Kiss, & Szalai, 2007). In fact, "Contrary to public opinion, ED overcrowding is not caused by inappropriate use of EDs or by high numbers of lower acuity

patients presenting to the ED," (Wait Time Alliance, 2014). Rather, throughput and output factors are significant contributors to ED wait times. A recent analysis of local data highlighted throughput factors as the largest contributor to ED wait times in Winnipeg, followed by output factors, which had a moderate effect on wait times. The presence of low acuity patients (i.e., patients with non-emergent healthcare needs) in the ED had little to no impact on overcrowding and wait times (Doupe et al., 2017).

And yet, the myth of inappropriate ED use by people who are homeless permeates the cultural narrative surrounding the ED. The introductory chapter of this thesis will outline findings that show how occupying a disenfranchised social position can have deleterious effects on health and the quality of healthcare one receives as a patient, summarizing literature regarding the health and healthcare experiences of people who are of Indigenous descent within the nation of Canada and of those who are homeless. The chapter will then describe the theoretical framework that organizes the research studies described in chapters 2 and 3, and then summarize the research questions that I seek to answer through the research programme, as a whole. Finally, the first chapter will close with a summary of the research context and a broad sketch of the methodological approach taken in my research.

### **Indigenous Ancestry, Health and Healthcare Encounters**

Mr. Sinclair's death prompted a furor regarding racism in Canada's healthcare system. Maclean's magazine, a major Canadian periodical, published a series of articles related to Mr. Sinclair. In one of their related pieces, another Indigenous man shared his own personal anecdote: "[He] recently visited an ER with an indigenous friend. They'd dropped a painting, and the broken glass had cut his friend. 'Aw!' a nurse exclaimed in greeting them. 'Have we been drinking and fighting again?'... [He said] 'This was someone responsible for treating

Native people in our hospitals. We all know racism exists in our health care system" (Macdonald, 2015).

Although the accuracy and claims of the Maclean's article have been subject to justifiable criticism, it is not inaccurate to say that experiences of racist behaviour towards Indigenous peoples in Canada's healthcare system have been observed beyond the popular media. Browne and colleagues (2011) conducted an ethnographic investigation of Indigenous Canadians attending an urban emergency department who had been triaged as 'non-urgent'. A prevailing theme in the participant reports was that of anticipating provider's perceptions of them based on their race. As a result of perceived racial stigma, individuals can experience stress in anticipation of negative treatment, healthcare encounters can be strained, and healthcare may be avoided. One participant was quoted as saying, "They have an attitude, especially the admitting clerks... I don't know, maybe because I'm a drug addict... maybe because I'm Native... Today they're nice... But I avoid coming here in a big way" (p. 338, ellipses in original). In their study of Indigenous mothers, Smith and colleagues (2006) reported that negative experiences with mainstream health services significantly reduced the participants' subsequent engagement. The findings of these two studies echo those of previous research which observed that Indigenous participants report perceiving significant stigma within the healthcare system (Benoit Carroll, & Chaudry, 2003; Levin & Herbert, 2004), avoid seeking preventative health services as a result (Kurtz, Nyberg, Van Den Tillart, Mills, & OUAHRC, 2008), and report feeling a sense of freedom from that stigma when accessing Indigenous-led service environments (Van Herk, Smith, & Gold, 2012).

The roots of the marginalization of Canada's Indigenous peoples are deep. Today's Indigenous children are born into a culture shaped by a history of colonialism and paternalism

(Smith, 2012). Examples of this were borne out in historically recent policies such as the Indian Residential School system and Sixties Scoop, the effects of which are still being observed today. The Sixties Scoop was a period of Indigenous children being apprehended by government-run child welfare agencies and subsequently adopted out-of-community – even out-of-country. The residential school system was a government-funded, church-run education system of boarding schools which served the purpose, among other goals, of weakening cultural ties among Indigenous peoples and assimilating them into the broader Eurocentric culture. In addition to disrupted family relationships and removal from their culture, students often experienced various forms of abuse at the hands of the residential school workers (Truth and Reconciliation Commission of Canada, 2015).

Such colonial history has led researchers to begin investigating the potential implications of intergenerational trauma (Bombay, Matheson, & Anisman, 2009) passed down within Indigenous cultures. These historical factors are hypothesized to be among the largest contributors to the current social and health inequities for Indigenous peoples in Canada (Adelson, 2005; Frohlich, Ross, & Richmond, 2006; Lavallee & Poole, 2010). For instance, Indigenous people in Canada have significantly more physical and mental health concerns than the general population, as well as greater mortality and lower life expectancy (Adelson, 2005). A recent review identified a high level of chronic physical illness within the Indigenous population, including diagnoses of diabetes, cancer, heart disease, HIV/AIDS, and tuberculosis (Patrick, 2014).

Following class-action lawsuits brought about in response to Canada's residential school system, the Indian Residential School System Settlement Agreement established the Truth and Reconciliation Commission of Canada (TRCC) in 2008 (TRCC, 2015). After its five-year

mandate, the TRCC published its final report in 2015. In it, 94 calls to action were delineated, including 7 dedicated to the health disparities faced by Canada's Indigenous peoples. Anti-racist and cultural awareness training was called for among healthcare students and professionals as part of the effort to affect positive change in health disparity.

#### Homelessness, Health and Healthcare Encounters

Disparities faced by Canada's Indigenous peoples go beyond health and illness. The colonial legacy has left the Indigenous population overrepresented within Canada's justice and child welfare systems and among people living in poverty (TRCC, 2015). This is no less the case within the Canadian homeless population (Gaetz, Donaldson, Richter, & Gulliver, 2013). In Winnipeg, the 2016 census indicated that 1 in 10 individuals self-identifies as of Indigenous ethnicity (Statistics Canada, 2017). In contrast, over 60% of the homeless population in Winnipeg reports Indigenous ethnicity (Belanger, Weasel Head, & Awosoga, 2012). Across Canada, Indigenous people are nearly 8 times more likely than the remaining population to be homeless, with nearly 7% of the Indigenous population experiencing homelessness compared to less than 1% prevalence in the general population (Belanger, Awosoga, & Weasel Head, 2013).

Independent of race and ethnicity, the social determinants of physical and mental health are well-studied and a clear, positive relationship exists between social standing and health (Patel et al., 2010; Adler et al., 1994). This remains particularly true for people who are homeless, who experience higher rates of morbidity than the general population and are at an increased risk for physical health complications, including higher levels of chronic illness and communicable disease (Hwang, 2001; Hwang, Wilkins, Tjepkema, O'Campo, & Dunn, 2009). In addition to greater physical health concerns, mental health problems also have a higher prevalence among homeless populations. A 2008 meta-regression (Fazel, Khosla, Doll, & Geddes) found the

prevalence of psychotic illnesses significantly outstripped corresponding numbers in the general population, as did rates of personality disorders and alcohol and drug dependence. Estimated rates of affective disorders range between 20-40% (Hwang et al., 20009). As well, it has been found that homeless individuals who demonstrate chronic patterns of homelessness are more likely to have mental health concerns (Kuhn & Culhane, 1998).

Unfortunately, similar to Indigenous populations, homeless populations are subject to prejudice and discrimination in the healthcare system. In the example of Mr. Sinclair, hospital staff assumed he was homeless based on his race and shabby appearance and, as a result, assumed he was just there for shelter rather than medical care. Many studies have documented that people who are homeless believe their homeless status negatively influenced the quality of the healthcare they were given. Martins (2008) conducted a phenomenological study with 15 homeless adults and found that participants reported various social barriers to receiving care, including being judged, treated with disrespect, triaged based on their social position, and being invisible or overlooked while in the healthcare system. Wen, Hudak, and Hwang (2007), in their content analysis of interviews from 17 men and women who were homeless, indicated that the participants had experienced both welcoming and unwelcoming situations in healthcare encounters. In unwelcoming interactions, participants used language of dehumanization, or being treated in ways consistent with conceptualizations of inanimate objects. Welcoming interactions, on the other hand, involved being valued, listened to or empowered. In unwelcoming interactions, participants believed their homelessness was the primary reason for being discriminated against. One participant was quoted as saying, "I had reason to believe that because I'm in a shelter, it's like secondary treatment, not as how we envisage it should be when you go to accident and emergency [an emergency department]" (p. 1012). Referring to an

interaction with a hospital information clerk, who referred the patient to the ED, another stated, "I got treated like that the first time over there, and I'm not going to get treated like that, I'm not going through that again. I'd rather sit here and f\_\_\_\_n' die on a bench than go over there" (p. 1013).

Similar findings to the Martin (2008) and Wen and colleagues (2007) studies have been observed in women (Biederman & Nichols, 2014; Gelberg, Browner, Lejano, & Arangua, 2004) and youth (Hudson, et al., 2010) who are homeless and among people who are homeless with mental illness seeking mental health care (Bui, Shanahan, & Harding, 2006). Very little quantitative research has explored the experience of homeless people in the healthcare system, though Chrystal and colleagues (2016) found that hospitals offering tailored services for people who are homeless had higher ratings of patient satisfaction among those people who are homeless with severe mental illness; however, such services did not improve satisfaction ratings among those without severe mental illness.

Rae and Rees (2015), in their phenomenological investigation of homeless participants' perceptions of healthcare needs and experiences, observed that participant reports of obstacles to care could be classified as "actual" and "perceived." The aforementioned experiences of judgment, invisibility and discrimination in the healthcare system of people who are homeless would, by their classification, fall under the umbrella of perceived obstacles to healthcare. (In contrast, actual obstacles to good healthcare would include such things as difficulty finding a general practitioner or lack of transportation to a healthcare facility.) This is an exemplar of the overall trend in the literature to portray interpretations of discrimination and marginalization in healthcare as psychological constructions of the individual who is homeless. In fact, little to no literature has been written that outlines the incidence rates of discriminatory actions or practices

towards them (Torino & Sisselman-Borgia, 2017).

Without empirical evaluations of observable discrimination or prejudice, we are left to speculate from research regarding the self-reported opinions of people who encounter those who are homeless. A handful of studies have found that some of the general public may hold prejudiced attitudes towards people who are homeless, such as the finding from Baumgartner and colleagues (2012) that people who believe that those who are homeless are responsible for their own fate have less compassion than those who believe they are victims of systemic societal problems. Research has also evaluated the beliefs that healthcare professionals hold of people who are homeless. Parkinson (2009) conducted a review of the literature on nurses' perceptions of people who are homeless and found that the majority of studies reported highly negative evaluations among nurses of those who are homeless. There were however, clearly contradictory findings from other studies in the review, with a handful of studies reporting only positive associations with homelessness among nurses. Research among physicians also gives findings that are difficult to draw firm conclusions and speculations from. A small branch of research, using a questionnaire called the Health Professionals Attitudes Toward the Homeless Inventory (HPATHI), has been used to evaluate differences between learners and teachers (Fine, Zhang, & Hwang, 2013), emergency medicine physicians and psychiatrists (Morrison, Roman, & Borges, 2012) and change in perceptions among medical students over time (Sibley, Dong, & Rowe, 2017). Among medical learners, exposure to patients who are homeless did not improve their ratings (Sibley et al., 2017). In fact, when compared to their teachers, learners in emergency medicine actually had more positive views of people who are homeless (Fine et al., 2013). Consistent with this finding, Morrison and colleagues reported that psychiatrists had more positive views of people who are homeless than emergency medicine physicians. Taken

together, these findings suggest, at the very least, that exposure is not enough to improve perceptions of patients who are homeless. At worst, the modelling that junior physicians witness may have a negative effect on their ability to be empathic towards the care needs of their patients (Fine et al., 2013). Despite such unfavourable findings, ratings, on the whole, were largely positive across the groups that filled in the questionnaires. Even though ratings may have resulted in statistically significant differences, whether physician views of homelessness are negative enough to result in discriminatory practices is unknown. Similarly, Doran and colleagues (2013) conducted semi-structured interviews with emergency medicine residents, who reported that they relied on stereotypes and heuristics to help identify patients who are homeless, but also acknowledged the need to provide care that addressed their additional needs and barriers. These participants (Doran, 2014), among others (McNeil, Guirguis-Younger, Dilley, Turnbull & Hwang, 2013), also reported that working with patients who are homeless is a challenging, frustrating task that their training had not prepared them for. At the same time, emotions were conflicting in that the residents found the work rewarding and fulfilling.

Unfortunately, the presence of compassionate or empathic beliefs and views of people who are homeless is not guaranteed to help reduce stigma and increase empowering practices. Schneider and Remillard (2013) held focus group interviews with members of the general public and, in their analysis of the transcripts, probed the positive and compassionate statements made by the participants regarding their encounters with people who are homeless. What they found was that, in a paradoxical fashion, the participants' work of constructing identities that were empathic and caring towards people who are homeless resulted in "the participants inevitably engag[ing] in dividing practices that describe homeless people as culpable for their state, yet incapable of correcting that state, and in need of proper management and control, for their own

good" (p. 105). In like fashion, statements such as "just like us" to identify with people who are homeless, despite apparent attempts to reduce hierarchical distance between helper and homeless, were "repeatedly entangled with qualifications of differences" (p. 108) and served to further divide and other the speaker from the homeless population.

In summary, it is unknown how frequent are the acts of discrimination, othering and marginalization in the ED for people who are homeless. Research into perceptions of patients and health care providers shows a mix of both positive and negative views. However, even if we could extrapolate from the presence of both the positive and negative on both sides of the healthcare encounter, overall, the research suggests that positive discursive practices have difficulty existing in the absence of disempowering and othering discursive practices.

It is not just in the practice of healthcare, however, that evidence of discrimination against those who are homeless can be sought. The academic literature is rife with examples of hypotheses and conclusions that contribute to the disempowerment and othering of people who are homeless. Some authors continue make inferences with a bias towards the hypothesis that patients who are homeless use the healthcare system inappropriately – that is, they use it for food, shelter or to support addictive behaviours. For example, a recent American study by Ku and colleagues (2014) found that the hospital admission rate following ED visits was slightly lower for people who are homeless than the total admission rate following all population ED visits in the same year. The implication inferred by the authors is that patients who are homeless may be presenting with health concerns that are not severe enough to warrant admission to hospital subsequent to the ED visit, therefore using the ED in ways inconsistent with its purpose. However, it also may be reasonable to posit that admission rates are lower due to the aforementioned stigmatization and reduced care quality that patients who are homeless may

receive. Other researchers have used terminology that explicitly identifies ED use among those who are homeless as inappropriate (e.g., Wang et al., 2015). A recent literature review regarding frequent ED users in the United States did not support the inappropriate use hypothesis (Lacalle & Rabin, 2010) and a growing number of voices are advocating that the academic community discontinue using terminology that suggests people who are homeless are abusing the healthcare system (Doran, 2016).

## The Behavioural Model for Vulnerable Populations

The perceptions of people who are homeless regarding their medical care is of tremendous importance when one considers their increased burden of illness and concomitantly higher utilization of the resources of the healthcare system. Predictors of health service use (i.e., accessing healthcare), such as comorbid physical health conditions and mental illness, are more common in homeless populations than the general population (Ku, Scott, Kertesz, & Pitts, 2010; Kushel, Vittinghoff, & Haas, 2001). In addition, elements unique to homelessness may also increase use of acute care facilities. For example, homeless individuals may need to dedicate their effort towards accessing the basic requirements for survival, such as obtaining food and shelter. As a result, the amount of attention they are able to dedicate to managing potential health conditions is restricted. Health, then, may only be addressed when symptoms become acutely severe (Gelberg, Gallagher, Andersen, & Koegel, 1997).

The use of acute care facilities by people who are homeless is markedly apparent in ED utilization. The cost of ED use in Canada neared \$2 billion in 2005-2006, and provinces spent an average of 4% of their healthcare budgets on ED use (Dawson & Zinck, 2009). Homeless populations account for these costs disproportionately to their representation, as these populations have significantly elevated rates of ED utilization when compared to the general

population. Some research reports ED visits at levels three-to-four times higher (Kushel, Perry, Bangsberg, Clark, & Moss, 2002; Kushel, et al., 2001). A recent Canadian study using administrative health records assessed the ED utilization rates of 1165 homeless adults and found they utilized the ED at eight times the rate of a matched low-income comparison group (Hwang et al., 2013). In addition to their general over-representation in the ED, homeless individuals have also been found to be disproportionately represented among frequent users who visit the ED several times per year (Ku, et al., 2014; Mandelberg, Kuhn, & Kohn, 2000).

The majority of research into health service use patterns among disenfranchised populations, such as ED use among people who are homeless, has been framed by the Gelberg-Anderson Behavioral Model for Vulnerable Populations (Gelberg, Anderson, & Leake, 2000). The model is an extension of the Anderson Behavioral Model (Anderson, 1968, 1995), originally used to understand health care use by, and health outcomes for, the general population.

Compared to similar models of health service use and access, the original model has garnered the largest amount of research attention and is the most well-accepted by the research community at present (Ricketts & Goldsmith, 2005). It is particularly suited to the current research context due to the special consideration given to vulnerable populations in the recent revision.

Slightly revised over time, the model suggests that health behaviours, such as use of health services, are a function of predisposing characteristics (e.g., age, gender, ethnicity, health beliefs, etc.), societal and personal factors that enable or hinder use (e.g., personal and/or community resources, barriers to care), and actual or perceived health needs (e.g., health conditions and perceived health). Each domain of characteristics is respectively referred to as *Predisposing*, *Enabling*, and *Need* domains. The Gelberg-Anderson model (see Figure 1) acknowledges that certain predictive factors that are pertinent to individuals who are homeless,

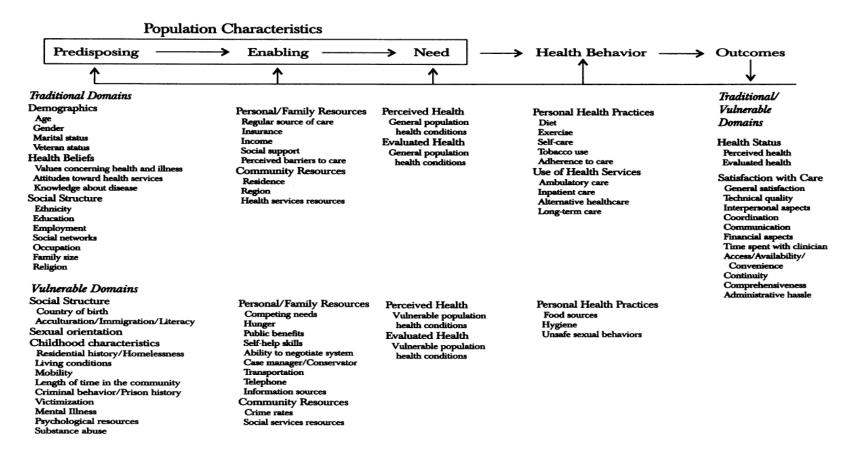


Figure 1. In the Behavioral Model for Vulnerable Populations, Predisposing, Enabling, and Need characteristics predict health behaviours (e.g., Health Service Use), which, in turn, influence health outcomes. Health outcomes are then hypothesized to influence or modify earlier predictors of the model. Vulnerable domains were added due to perceived relevance for homeless and other vulnerable populations. From "The Behavioral Model for Vulnerable Populations: Application to Medical Care Use and Outcomes for Homeless People" by L. Gelberg, R. M. Andersen, and B. D., Leake, 2000, Health Services Research, 34, p. 1278. Copyright (2000) by Health Research and Educational Trust. Reprinted with permission.

and other vulnerable groups, were not accounted for in the original model. For example, predisposing characteristics common among, or unique to, homeless individuals include mental illness, early life experiences of trauma, and homelessness duration and severity. Enabling characteristics may include needing to cope with competing material needs or having adequate social assistance. Finally, need characteristics may include traumatic brain injury, skin problems, or podiatric concerns.

Previous research has evaluated the predictive utility of the Behavioral Model regarding ED usage in a Canadian homeless sample (Chambers, et al., 2013), though research in this context of universal health coverage remains limited. Few studies at this point have investigated the role of 'health beliefs' in any investigation of health service utilization. A predisposing factor within the behavioral model of health service utilization, Andersen (1995) defines health beliefs as follows: "Health beliefs are attitudes, values, and knowledge that people have about health and health services that might influence their subsequent perceptions of need and use of health services" (p. 2). The lack of research into health beliefs is true of the original model and the recent revision for vulnerable populations. The Chambers study investigated the role of health locus of control, but I am unaware of other quantitative investigations into health beliefs. Qualitative investigations have looked at perceived barriers to care (e.g., Martins, 2008; Rae & Rees, 2015), and qualities of the healthcare interaction that may influence participants' later inclinations to access the healthcare system (e.g., Wen et al., 2007), but little other exploration has been conducted. Although this aspect of the model may be more difficult to measure with quantitative approaches – the primary approach in the current literature – the beliefs of this population may be of particular importance to consider. Health beliefs may have a strong influence on individuals' use of health services, and the health beliefs of this population

may be markedly different from the population at large. In the current context of applying the model to ED use among people who are homeless, the research described within this thesis will seek to understand how people who are homeless understand the ED's role in their healthcare.

#### **Research Questions and Methodology**

In summary, ED use among people who are homeless is higher than in the general population in North America. The Gelberg-Anderson Behavioral Model for Vulnerable Populations posits that there are various contributors to such an observation. Among those who are homeless this may include predisposing factors such as duration of lifetime homelessness, enabling factors such as competing needs to obtain food and shelter, and need-related factors such as physical and/or mental illness. The factors that predict usage may vary based on the context within which those who are homeless live. In Canada, universal health insurance allows those who are homeless, and any member of the population, to access the entire healthcare system – primary preventative care, chronic illness management, emergent care, and so on – with no out-of-pocket costs. Research regarding the ED use of people who are homeless has been less frequent in the context of universal health insurance. As such, factors that have been found to predict ED use among American samples of people who are homeless may not be applicable to universal health care contexts, and the majority of research has taken place in American samples. Research into the Canadian context is warranted.

Further, research directed towards the predisposing factor of health beliefs has been largely absent when considering how people who are homeless understand their experiences of healthcare in the ED. Only one quantitative study investigating this factor is known, finding that health locus of control may help differentiate frequent from non-frequent users of ED services (Chambers et al., 2013). Qualitative studies have found that qualities of the healthcare

interaction may affect willingness to seek care at a later date (Wen et al., 2007) and that there are various social and practical barriers to accessing healthcare (e.g., Martins, 2008; Rae & Rees, 2015). However, no research has been done that interrogates the beliefs that the participants hold about the role of the ED in their healthcare. With people who are homeless accessing the ED at higher rates than the general population, this is important to understand if we wish to better the quality of their healthcare and, by extension, their health.

The research questions, then, are threefold. First, which predisposing, enabling and need factors from the Gelberg-Anderson Behavioral Model for Vulnerable Populations predict ED use among people who are homeless in a Canadian sample? Second, how do participants understand the role of the ED in their healthcare and day-to-day lives? Third, what implications for theory and practice emerge from a synthesis of the quantitative and qualitative inquiry into ED use among people who are homeless?

To explore these questions, two studies in a convergent parallel mixed methods design were conducted (Creswell & Plano Clark, 2011). In other words, both qualitative and quantitative data were collected and analyzed independently during the research process and the findings were brought together for interpretation. Data collection for the quantitative study took place first, followed by data collection for the qualitative study. The qualitative analysis then took place, followed by analysis of the quantitative study. Writing and interpretation of the findings of each study took place concurrently.

The second chapter of the thesis addresses the question of which factors of the Behavioural Model predict ED use among a sample of people who are homeless, presenting a quantitative analysis of administrative and survey health data from a sample of people who are homeless. A sample of 483 participants participated in a two-year longitudinal study where they

were asked about their housing status, food security, income, use of case management services, victimizations, self-report ratings of physical health, mental health, and substance use, and self-reported gender, ethnicity, and family history of residential school attendance. This self-report data was paired with provincial administrative data tracking ED visits, primary care visits, and receipt of social welfare income. Pairing self-report and administrative data allowed for longitudinal analysis of a plethora of predisposing, enabling and need factors that have not been previously evaluated in the context of universal health insurance.

The third chapter of the thesis addresses the second research question, of how people who are homeless understand the role of the ED in their healthcare and day-to-day lives. To address this question, 16 of the participants who were enrolled in the quantitative study were recruited for semi-structured interviews soliciting their stories of ED healthcare experiences. Interviews were analyzed using narrative analysis to evaluate how they positioned themselves and the ED in relation to one another, and in the context of the broader healthcare system and social discourse around homelessness.

The fourth chapter addresses the third question: what implications for theory and practice emerge from a synthesis of the quantitative and qualitative inquiry into ED use among people who are homeless? This chapter summarizes the findings from each study and then exposits issues of convergence and divergence. Implications for the broader literature on ED use among people who are homeless is discussed, including directions for practice and future research. The thesis closes with a final chapter of personal reflection on the research project as a whole.

#### **Methodological Approach**

The mixed methodology chosen to address the research questions proceeds from a pragmatist paradigm. Pragmatism is primarily concerned with using whatever means are most

appropriate for addressing the research question(s) at hand (Teddlie & Tashakkori, 2003). It also rejects the idea of a duality between knowing and reality. A schism exists between postpositivist and constructivist paradigms on this topic. On the one hand, a postpositivist paradigm posits a singular reality that is reflected in our knowledge and observation; that is, reality is objective. On the other hand, a constructivist paradigm posits that the multiplicity of viewpoints and ways of knowing indicates that knowledge cannot reflect reality and there are, therefore, multiple subjective realities. By rejecting the dualism, pragmatism posits there is a common world that is non-objective (Maxcy, 2003). This allows for the potential evaluation of singular or multiple realities, testing hypotheses about the common world while providing multiple perspectives (Cresswell & Plano Clark, 2011).

From the perspective of the pragmatist paradigm, the convergent parallel design suits the present study well. The first question – that of which factors of the Behavioral Model for Vulnerable Populations predict ED use in the present context – is most suited to the collection of quantitative data on ED use and is, therefore, best addressed through quantitative hypothesis testing. The second question, regarding how people who are homeless understand the ED, is best assessed through qualitative methodology. Answering the final question of the implications of the synthesis requires the presence of both qualitative and quantitative methods. One of the purposes of the convergent parallel design is, "synthesizing complementary quantitative and qualitative results to develop a more complete understanding of a phenomenon" (Cresswell & Plano Clark, 2011, p. 77). Therefore, addressing the third question is best done through the convergent parallel design, allowing comment on the phenomenon of the ED and how the knowledge gained informs our understanding of the Behavioral Model for Vulnerable Populations.

Although pragmatism is the umbrella philosophy that governs the research program described within this thesis, the reporting of the findings aims to be consistent with an emancipatory framework (Mertens, 2003). Transformative-emancipatory mixed methods research assumes "that all knowledge reflects the power and social relationships within society" (Mertens, 1999, p.4). Most of the participants in the presented research studies occupy the intersection of multiple disempowered positions, including being homeless and of Indigenous descent. In the context of the ED, this has various negative implications. As outlined earlier, participants who are homeless understand their healthcare encounters to be a mixture of positive and negative, and healthcare professionals hold a mixture of positive and negative views regarding people who are homeless. In the literature, there is also a mixture of voices labelling ED use by those who are homeless as 'inappropriate' or advocating in opposition to these claims.

There are, then, competing explanations for health service use among those who are homeless. Krumer-Nevo and Benjamin (2010) identify various narratives of social inequality and poverty that researchers, policy makers and service providers draw on to understand the lives of those who are in disadvantaged positions. Of these narratives, there is a dominant narrative and three counter-narratives. The dominant narrative is what the authors identify as the conservative narrative. It interprets the social position of people who are homeless as being a result of their personal, immutable attributes, and their free choice. Healthcare utilization statistics may prime or reinforce such thinking. Because of the hegemony of the conservative narrative, such statistics tend to reinforce stereotypes and prepotent thoughts of people who are homeless using the ED to stay warm, obtain medications for addictions, or use the ED for medical care that 'should' have been sought through a primary care provider. This narrative promotes conclusions and inferences that attribute over-representation in the ED to be a result of

misuse of emergency medical services (e.g., Ku et al., 2014; Wang et al., 2015).

There are alternatives to such interpretation. Krumer-Nevo and Benjamin (2010) also outline three counter-narratives in the research literature: the structure/context counter-narrative, the agency/resistance counter-narrative, and the voice and action counter-narrative. The structure/context counter-narrative understands poverty and homelessness occurring as a result of structural social inequality, such as limited work or educational opportunities as a result of the position those in poverty are born into or find themselves in. Restrictive social policy would be another example of structural social inequality. In the structure/context counter-narrative, individuals in poverty are often portrayed as having normative values and the structural inequities result in them acting contrary to their values, rather than because of them. The agency/resistance counter-narrative builds on the structure/context narrative, emphasizing the ability of those in poverty to adapt to and resist structure and power imbalances. Finally, the voice and action counter-narrative, building on the premises of the first two counter-narratives, portrays people in poverty as experts on their own lived experience, as well as on society and the powerful social institutions they interact with, such as welfare or other social services.

Returning to the emancipatory framework, the research in this thesis is presented in a way that acknowledges the presence of these narratives and counter-narratives and the power imbalance inherent in the participants' social position. The findings could be interpreted through the lens of one or more of Krumer-Nevo and Benjamin's (2010) narrative storylines. As observed by Tashakkori and Teddlie (2003), pragmatism and the transformative-emancipatory approaches to qualitative research are not incompatible. Therefore, in the spirit of the pragmatist paradigm, the research question is given primacy in the selection of the methods chosen. In the spirit of the emancipatory framework, multiple perspectives are revealed throughout the thesis

with an intention to privilege the goal of social justice, favouring interpretations that develop empathy and understanding for people in positions of disempowerment, humanizing them rather than othering them.

## Reflexivity

Disclosing the balance between the pragmatism and emancipatory approaches is also done in the spirit of adopting a reflexive approach to the research. Reflexivity is concerned with self-reflection for the purpose of understanding how one's pre-existing viewpoints are influencing, or have influenced, the research process (Shaw, 2010). Reflexivity is most often an important feature of qualitative, rather than quantitative research, but quantitative studies are no less situated within the context of individuals and societies: "Whether we are involved in ethnography or statistics heavy research...we are all producing orderliness in our writings...putting pieces together, picking and choosing to pay attention and ignore.... excluding, including, concealing, favoring some people, some topics, some questions, some forms of representation, some values" (Calás & Smircich, 1999, p. 644). My own location influences the process for the quantitative and qualitative studies, from conceptualization to presentation. I tried to adopt an attitude of reflexivity, reflecting on how my role as the researcher may have influenced the narrative construction, analysis, and presentation of the findings. In this regard, my goal was not to try and minimize or eliminate my own impact on the findings and their presentation, but understand and explicate how my position, experiences, preconceptions and personal narratives may have influenced the findings. This process would not only allow me to properly articulate the scope and limitations of the research findings, but also allow the reader to critically assess this for themselves.

I am a white, middle-class male, raised in a suburban, Canadian neighbourhood. To

begin, I have never known the levels of marginalization experienced by the participants in this study. I have never experienced mental illness or homelessness, and, unlike the majority of the sample, disadvantage as a result of colonialism is not part of the cultural narrative I was raised in. My knowledge of these three positions (mentally ill, homeless, and Indigenous), is either academic or as a result of my direct interactions with these populations and their representations within the media.

Regarding the first, the experience of mental illness, having nearly graduated from my doctoral studies in clinical psychology, I have an early-career professional's viewpoint of mental illness. The majority of my training has focused on aiming to conceptualize and, if possible, resolve the symptoms of someone's emotional and mental distress. My program has immersed me in cognitive-behavioural therapies and deficit models of mental illness from a biopsychosocial viewpoint. Most of my intervention training is individualistic, consisting of one-on-one therapy where change is made at the level of the individual. This training risks narrowing my focus on identifying deficits and storylines as residing within the individuals I interviewed and categorizing maladaptive thinking strategies. It has also taught me valuable clinical skills that allow me to empathize with and understand the participants and develop an awareness of the ways I may project my own thoughts and experiences into the research. Beyond the cognitive-focused training I have acquired, I have been personally impacted by courses in community and cross-cultural psychology and have come to incorporate personcentered and systems-level approaches to my professional work. As may be evident in the choice of thesis topic and my choice to adopt an emancipatory approach to this project, I hold deep personal convictions regarding social justice and using my professional training and power to help the marginalized. My clinical and academic training, then, has contributed to the

dynamic tension in my own mind between the individual and the social and the impact of each on behaviours, including the behaviour of thinking, which I, as an observer, can only infer through limited pieces of information. The tension between the individual and the social has also influenced my choice to adopt a *storied resource* perspective of narrative, whereby, "...narrative selves and identities are socio-cultural phenomena, realized within active relationships, and...are taken up, modified and individualized" (Smith & Sparkes, p. 20). As a result, personal agency and choice of the participants is allowed weight in the interviews, the analysis and the discussion of the findings. Although I am also sensitive to the influences of culture and power, the reader will never find a purely social interpretation of human behaviour within the analyses and inferences in the discussion of either study's findings.

My inferences regarding personal choice is likely also a reflection of the individualistic culture that I have been raised within. This makes me an outsider to Indigenous ways of knowing, including "Indigenous concepts of the person... [that] may be relational or communalistic, ecocentric (connected to the land and to animals), and cosmocentric (connecting the person to an ancestral lineage or the spirit world)" (Kirmayer, Simpson, & Cargo, 2003, p. S18-S19). Worse than being an outsider, I was raised in a settler culture that has inculcated stereotypes of Indigenous peoples in the foreground and background of my own personal narratives. That being said, over the last several years I have developed a deep respect for Indigenous perspectives on life, such as their views of spirituality, the self, the community, and the world. In recent years, I have been witness to sharing circles, smudging and a sweat lodge, and participated in some of these practices myself. I have visited Sagkeeng First Nation's reserve. I have sat with and watched elders and community leaders as they spoke of their people, their pride and their pain. For one year I worked at the Child Protection Centre, a service

provider in contract with the child welfare system – where Indigenous peoples are, again, grossly overrepresented – and sat with parents who have lost their children and children who have lost their parents. I am also a licensed foster parent, and there resides in my home a beautiful, vibrant, joyful Ojibwe daughter whom I love and care for deeply. While this does not immerse me in her cultural heritage, she has permeated mine. She is a living, daily example and reminder of the immense value of our nation's oldest ancestors. Through various experiences, then, I have been sensitized to my position as a white male in a position of relative social power. However, sensitivity to such power dynamics does not rebuild the individualistic framework I have inherited. There may have been communalistic cues and narrative threads that I missed in the interviews because I was unable to hear them without a personal knowledge context to situate them within.

What sensitization to my position role has done is nuance the tension between the social and the individual that was mentioned earlier. As a western settler, the individualistic narrative of personal agency and choice that I have been raised in has been intertwined with the cultural narrative of personal responsibility for one's own life circumstances. My training and recent life experiences have broadened this understanding to incorporate the influence of structural power dynamics. This moves beyond ethnicity and begins to influence my own understandings of homelessness. My knowledge regarding homelessness is limited to the work that has been related to this thesis. Although I have had the privilege of interacting with homeless participants through the At Home/Chez Soi study, it has been in the context of a sanitized hospital office. Homeless participants have interacted with me in my world, whereas I have, as yet, to enter theirs. As such, I entered the interviews and analyses with the genuine aim to allow the participants and their data to speak so that I could learn from them. As well, being sensitized to

my own position of relative power has also sensitized me to my responsibility to use that power responsibly and morally. This has influenced the adoption of a transformative-emancipatory approach to the project and has resulted in my choice to emphasize some findings over others. For instance, I have attempted to intentionally frame the thesis in a way that promotes narratives of empowerment and empathy for people who are homeless, rather than propagating narratives that continue to disempower and disenfranchise those in powerless positions.

Finally, the submission of this thesis is an ongoing part of the reflexivity process, rather than the presentation of a crystallized piece of knowledge. Already, each revised version of this paper has incorporated challenges and thoughts from members of my thesis committee, the Lived Experience Circle from the At Home/Chez Soi project, and the Health Information Research Governance Committee of the Assembly of Manitoba Chiefs. By extension, to make this document a part of the public record means submitting it to the scrutiny of experts and society. The final submission of this thesis, then, does not end this process, but, instead, continues it as I remain humbly open to correction and education, to being made aware of my own thoughts and assumptions, and to expanding the views and perspectives that have influenced the process thus far.

#### **Research Context**

The participants and data for each project were obtained through the Winnipeg site of the At Home/Chez Soi Housing First demonstration study in Winnipeg, Manitoba. The study was a two-year longitudinal project with recruitment over a two-year period, occurring between 2009 and 2013. At Home/Chez Soi was a multi-site study in five Canadian cities aiming to evaluate the feasibility of implementing Housing First in the Canadian context, recruiting a sample of people who were homeless and had mental illness. Housing First (HF) is an intervention

founded on the principle that housing is a basic human right (Tsemberis & Eisenberg, 2000). Participants are provided access to the fiscal resources required to facilitate the acquisition of stable housing, with no requisite expectations for treatment compliance or drug/alcohol abstinence. Winnipeg was selected for the larger Canadian study for a particular local focus on HF administration with a predominately Indigenous sample. The Winnipeg site had a target of representation of Indigenous peoples within the sample of approximately 70%, with a final total of 71% (Distasio, Sareen & Isaak, 2014).

Participants were recruited via referral from approximately 50 health and social services agencies across the city of Winnipeg, with the majority of participants recruited from homeless shelters. Recruitment took place between fall of 2009 and June of 2011, with a total of 513 participants enrolled. Eligibility criteria included the presence of a mental disorder and legal adult status. Mental disorders may or may not have been actively treated and were diagnosed using the MINI (Lecrubrier et al., 1997). Regarding eligible homelessness status, participants could be absolutely homeless or be precariously housed with two episodes of absolute homelessness in the previous year. 'Absolute homelessness' refers to those, "...who lack a regular, fixed, physical shelter" (Goering et al., 2011, p. 18). 'Precariously housed' refers to those living in a single room occupancy, rooming house, or hotel/motel (Goering et al.).

Participants at the Winnipeg site were primarily male (64%), unemployed (91%), between the ages of 35 and 54 (57%), and had less than a high school education (69%). Many participants had a history of living in foster care (49%), with the whole sample being exposed to an average of 6 categories of child abuse and/or neglect (i.e., physical/emotional/sexual abuse, physical/emotional neglect, and exposure to a battered mother, household substance use, parental discord, mental illness in household, or incarcerated household member) prior to the age of 18.

Many had either had a parent or grandparent in the residential school system (42%), and some participants had been involved in residential schools themselves (11%). Regarding their mental health, approximately one quarter had a psychotic disorder (28%), while 86% had a non-psychotic disorder, such as a major depressive, manic, or hypomanic episode. Forty-five per cent of the sample had concurrent post-traumatic stress disorder. Over three quarters had a concurrent substance-related problem (77%). Regarding their physical health, nearly all (>99%) reported a chronic physical health condition such as diabetes or cardiovascular disease, and 82% reported a history of at least one traumatic brain injury. Finally, regarding housing history, 69% were absolutely homeless at the time of recruitment and 31% were precariously housed. The majority of the sample had prior instances of homelessness, with only one in five participants having become homeless for the first time in the year preceding their recruitment.

Upon recruitment, participants were randomly assigned to receive housing first or treatment as usual. Participants were stratified into high needs and moderate needs groups, primarily determined by mental illness severity (Goering et al., 2011). Following random assignment and need-stratification, participants were then interviewed at three-month intervals over a two-year period, where they reported their housing and vocational history over the previous three months. Various measures of health, social functioning, service access, and so on, were administered at six-month intervals. At recruitment, participants also provided consent for the research team to access their anonymized administrative health records, which are stored at the Manitoba Centre for Health Policy (MCHP). The provincial repository tracks a plethora of healthcare use patterns across the province of Manitoba, such as hospitalizations, ED visits, filled medication prescriptions, and so on. To facilitate this access, participants provided their personal health information number (PHIN). The participant PHIN allowed for data linkages to be made

between the At Home/Chez Soi study's self-report participant data and the participants' administrative health record. Participants were also given the option to consent to be contacted regarding other opportunities to participate in research projects.

The data linkages between self-report and administrative data facilitated the feasibility of the first research project described within this thesis, a statistical evaluation of predictors of ED use over the course of the At Home/Chez Soi research study (see Chapter 2). The participants for the qualitative inquiry into the understandings of the ED among people who are homeless were drawn from among those who had consented to participate in follow-up research projects. The findings from the qualitative study are described in the third chapter. The thesis closes with a synthesis of the findings from the two studies, a discussion of the implications for theory and future research (see Chapter 4), and personal reflections on the research project (Chapter 5).

# **Chapter 2: Quantitative Study**

# Longitudinal Mixed Modelling of Emergency Department Use Among a Sample of Homeless Participants in a Housing First Demonstration Trial

### **Abstract**

**Objectives:** Emergency Department (ED) use is higher among homeless populations but inconsistencies exist in the literature regarding what accounts for it. The present Canadian study sought to identify predictors of ED use in a sample of primarily Indigenous participants who were homeless and diagnosed with a psychological disorder.

Methods: The study included 483<sup>1</sup> participants enrolled in the Winnipeg site of the At Home/Chez Soi housing first demonstration trial, a two-year longitudinal study. Participants were interviewed quarterly, reporting their housing status, case management visits, instances of victimization and total income, and completing survey measures of physical and mental health, substance use and food security. Survey data was linked to administrative health and social services data through the Manitoba Centre for Health Policy. Predictors of participants' ED visits over the two-year follow-up were analyzed using negative binomial longitudinal mixed modelling.

**Results:** ED visits over the two-year follow-up were positively and reliably predicted by pre-baseline ED use, and concurrent increased social assistance, primary care visits, ratings of physical health, substance use problems and case management visits. Increased concurrent housing instability and food insecurity, and decreased homelessness history, positively predicted ED visits, but effect reliability was lower.

<sup>&</sup>lt;sup>1</sup> Although the At Home/Chez Soi Winnipeg site had 513 participants, self-report data could only be successfully linked to administrative health data for 483 of them.

**Conclusions:** Participant ill-health appears to be a primary driver of ED utilization, but significant variability remains. Future research should seek to explain variability in ED use patterns. The present study supports a growing body of literature that challenges misconceptions about the appropriateness of ED use among homeless populations.

**Keywords:** homelessness, Emergency Department use, multilevel mixed modelling **Introduction** 

Emergency Department (ED) use has been consistently found to be higher among homeless populations than among the general population (Salhi, White, Pitts, & Wright, 2017). Previous theory and research has sought to explain reasons for this, with findings indicating that increased ED use among people who are homeless is predicted by lower physical and mental health (e.g., Weinreb, Perloff, Goldberg, Lessard, & Hosmer, 2006), female gender and Canadian Indigenous ethnicity (e.g., Chambers et al., 2013), lower food security (Parashar et al., 2014), and past ED use patterns (Weinreb et al., 2006). Researchers have investigated the possibility of lowering ED use among people who are homeless by providing them with direct access to primary care, but found that this had no effect on ED use (Wang et al., 2015).

Intervention studies investigating the role of providing stable housing and case management to participants have produced mixed results. Considering studies in American contexts, some have found that case management and housing reduces ED use (e.g., Moore & Rosenheck, 2017), while others have found no effect (West, Patterson, Mastronardi, Brown, & Strum, 2014). In Canada, results from the five-city At Home/Chez Soi Housing First research demonstration trial have also been variable. Among participants who received Assertive Community Treatment (ACT) in addition to Housing First, participants showed a reduction in ED use at the six-month follow-up time point, when compared to treatment as usual (TAU), but

group differences had reduced to nil at the two-year follow-up time point (Aubry et al., 2016). Participants receiving Housing First and Intensive Case Management (ICM) had a similar number of ED visits over the two-year study when compared to TAU participants (Stergiopoulos et al, 2015). When considering the study overall, all participants (i.e., Housing First with ACT or ICM, and TAU) showed a reduction in ED visits over time, but there were no notable group differences. A follow-up analysis aimed to disentangle the role of housing and found that participants who became unstably housed after a year of stable housing tended to use the ED more than participants who remained stably housed and participants who never became stably housed (Kerman, Sylvestre, Aubry, & Distasio, 2018).

The present study seeks to add to the pool of findings available using combined survey and administrative health data from the Winnipeg site of the At Home/Chez Soi research project, a longitudinal Housing First (HF) intervention study. The study occurs in the context of universal health coverage in that the participants, and the local population, do not have to pay for healthcare and can access primary care and hospital-based care at no cost. In addition, the Winnipeg site adapted its approach to include culturally relevant supports for Indigenous<sup>2</sup> peoples. Winnipeg is a mid-sized Canadian city with a population over 700,000. The city is home to Canada's largest concentration of Indigenous persons with 84,000 or approximately 12% (Statistics Canada, 2017). However, Indigenous persons are disproportionately represented within the homeless population, with estimates of 60% or higher (Belanger, Weasel Head, & Awosoga, 2012). As such, this sample included a large proportion of Indigenous participants (~70%). Similar to the study by West and colleagues (2014), previous analyses on self-report data found no effect of the HF intervention on ED use in the sample. The present study, then,

<sup>&</sup>lt;sup>2</sup> Our use of the term Indigenous refers to people who identify as members of the Inuit, Métis or First Nations of Canada (O'Campo et al., 2017).

seeks to clarify which health, intervention and social determinants of health variables account for ED use. Consistent with the Gelberg-Anderson Behavioral Model for Vulnerable Populations (Gelberg, Anderson, & Leake, 2000), it was expected that:

- 1) ED use would be higher among female and Indigenous participants, and those with a family history of residential school attendance;
- 2) ED use would be positively predicted by age, past lifetime homelessness, past ED use, substance use problems, reports of being victimized, mental illness severity and chronic physical health conditions; and
- 3) ED use would be negatively predicted by education, housing stability, food security, income, visits to primary care physicians, case management meetings, and ratings of current mental and physical health.

## Methods

Participants and Procedure. The present study utilized longitudinally collected survey data from participants enrolled in the Winnipeg site of the At Home/Chez Soi project, linked to their administrative health data housed at the Manitoba Centre for Health Policy<sup>3</sup> (MCHP). The methodology of the At Home/Chez Soi project has been described previously (Goering et al., 2011). Characteristics of the Winnipeg sample have also been delineated elsewhere (Distasio, Sareen, & Isaak, 2014; see also Chapter 1). In brief, 513 participants were recruited for a two-year longitudinal study and were interviewed at three-month intervals. At recruitment, participants provided their personal health information number (PHIN) and consent for the

<sup>&</sup>lt;sup>3</sup> The authors acknowledge the Manitoba Centre for Health Policy for use of data contained in the Manitoba Population Research Data Repository under project # 2015-035 (HIPC# 2015/2016 – 14). The results and conclusions are those of the authors and no official endorsement by the Manitoba Centre for Health Policy, Manitoba Health, or other data providers is intended or should be inferred. Data used in this study are from the Manitoba Population Research Data Repository housed at the Manitoba Centre for Health Policy, University of Manitoba and were derived from data provided by Manitoba Health, Manitoba Families and Winnipeg Regional Health Authority.

researchers to link survey responses to the administrative health data using their PHIN. For the present study, data were successfully linked for 483 out of the 513 participants.

**Measures.** The present study uses a subset of the site's collected data. Baseline data included self-reported demographics (age, gender, ethnicity, education, familial residential school history and lifetime homelessness), self-reported diagnosed chronic medical conditions (CMCs), and psychiatric diagnoses (as measured by the Mini Neuropsychiatric Interview [MINI]; Lecrubrier et al., 1997). The MINI has demonstrated good reliability ( $\kappa > .75$ ), sensitivity and specificity. The modules used for the present study include major depressive episodes, suicidality, manic and hypomanic episodes, post-traumatic stress disorder, alcohol dependence/abuse, substance dependence/abuse, psychotic disorders, and generalised anxiety disorders.

Longitudinal self-report data included self-reported daily housing status, total income, instances of victimization, and number of case management appointments. Income, instances of victimization and number of case management appointments were entered into analyses as totals per interval, while daily housing status was indexed in the model by the percentage of days spent stably housed during the interval.

Longitudinal survey data used included self-report measures of substance use problems, food security, and physical and mental health. Substance use problems were measured using the Global Assessment of Individual Need – Substance Problem Scale (GAIN-SPS; Dennis, Chan, & Funk, 2006). The GAIN-SPS has previously demonstrated good reliability ( $\alpha$  = .92; Dennis, Chan & Funk, 2006) and suitable applicability to a homeless population in the At Home/Chez Soi project (Adair et al., 2012). Internal consistency of the GAIN-SPS at the Winnipeg site was good, with an average of  $\alpha$  = .88. Food security was measured using a 10-item scale developed

by the At Home research team (O'Campo et al., 2017). Items were adapted from the 2008 version of the USDA's Adult Food Security Survey Module (Bickel, Nord, Price, Hamilton & Cook, 2000). The scale produces a total score, ranging from 0-10, with higher scores reflecting greater food insecurity. At the Winnipeg site the instrument demonstrated adequate reliability, with an average of  $\alpha$  = .73. Participants' current health was measured using the Short Form – 12 (SF-12) health survey (Ware, Kosinski, & Keller, 1996). The SF-12 is a shortened version of the SF-36, and includes two summary scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The PCS incorporates 6 items assessing physical health and physical limitations, while the MCS incorporates 6 items assessing mental health and limitations as a result of emotional problems. The SF-12 has been used effectively with homeless samples in previous research and demonstrated suitable reliability ( $\alpha_{pcs}$  = .82,  $\alpha_{mcs}$  = .79) and validity (Chambers et al., 2013; Larson, 2002).

Administrative covariates were also utilized in the present study, including documented in-office physician visits from the *Medical Services* repository, monthly receipt of social allowance from the *Social Assistance Management Information Network*, and the rate of ED visits over the two years prior to enrolment in the study from the *ADT-E-Triage* and *Emergency Department Information System (EDIS)* databases (MCHP, 2014). The outcome variable in the current study was the number of ED visits occurring between each study interview, as captured by the *ADT-E-Triage* and *EDIS* databases.

Analysis. Hypotheses were tested using negative binomial longitudinal mixed modelling (LMM) for the count outcome. Models were fit using maximum likelihood to allow comparisons among non-nested models. Continuous variables were transformed into units of standard deviation to ensure model convergence and allow direct comparison between parameter

estimates. Variables were entered into the model in three steps: 1) The unconditional growth model; 2) Baseline, time-invariant covariates; and 3) Time-variant covariates, removing collinear covariates. Analyses were conducted using *SAS 9.4*, with the mixed models being created using *PROC GLIMMIX*.

Missing Data. Due to the transient nature of the population the sample is drawn from, high levels of attrition or inconsistency was an anticipated concern. The nature of the missing data in the final dataset followed a nonmonotonic missing data pattern – that is, although some participants were lost to follow-up, most missing data was the result of missed interviews followed by a return to later follow-up – assumed to be considered Missing at Random. Analysis using LMM allows for the inclusion of all available data without deletion of participants due to missing data. Estimation of effects and their associated variances using LMM has been found to be robust to the effects of missing data (Twisk, de Boer, de Vente, & Heymans, 2013). As a result, the following results are assumed to be a reasonable estimate of effects in the population.

### **Results**

Descriptive statistics are presented in Table 1. Interpretation is intuitive (i.e., higher values indicating a greater level of the variable in question), with the exception of the food security measure, which, as noted, ranges from 0 to 10 with lower scores indicating greater food security (O'Campo et al., 2017). A high degree of variability was observed in housing stability, victimizations, and case management visits. Reported homelessness history was also highly variable, though most participants were homeless for two years or more. ED visits and use of primary care physicians was also highly variable among participants. Regarding self-reported income, a small number of participants (n < 5) displayed atypical income patterns. When these participants were excluded, the numbers more clearly showed that the vast majority of

Table 1. Sample Characteristics

Variable		
Baseline	n (%)	
Gender		
Male	309 (64)	
Female	174 (36)	
Need Level		
High	187 (39)	
Moderate	296 (61)	
Indigenous		
No	139 (29)	
Yes	344 (71)	
Family History of		
Residential School Attendance	e	
Yes	287 (59)	
No	196 (41)	
	M (SD)	Min-Max
Age (Years)	38.98 (10.89)	18-71
Years of School	9.96 (2.57)	1-25
Months of Lifetime Homelessness	59.40(65.11)	1-420
ED Visits 2 Years Pre-Baseline	10.04 (21.04)	0-283
# CMCs	5.66 (3.57)	0-19
# MINI Diagnoses	3.80 (2.03)	0-10
Time-Varying		
ED Visits (Outcome)	7.71 (15.4)	0-154
Months on Social Assistance	18.82 (8.87)	0-39
Stable Housing	41.9% (46%)	0-100
GAIN-SPS	2.03 (1.97)	0-5
Primary Care Visits	21.40 (19.27)	0-157
Food Security	6.70 (3.13)	0-12
SF12 PCS T-Score	43.38 (11.25)	13.37-70.96
SF12 MCS T-Score	38.51 (11.92)	6.39-72.61
Case Management Visits	14.77 (21.06)	0-152
Victimizations	43.94 (121.21)	0-1318
Average Annual Income*	\$7791.70 (7673.75)	\$150-\$126,167

*Note:* \*When a small number of participants (n < 5) are excluded due to atypical income patterns, these statistics change as follows: M=7298.83, SD=3457.66, Min=150, Max=28,182.50.

participants remained below the most recently published low-income cut-offs (Statistics Canada, 2015). The inclusion of these participants did not affect the results of longitudinal modelling; therefore, they were included in the remaining analyses.

The mixed modelling results are presented in Table 2. Continuous variables can be directly compared amongst each other and are sorted in descending order of effect size.

Bivariate categorical variables can be compared amongst each other and are similarly sorted.

However, the continuous and bivariate variables are not on the same scale and cannot be directly compared. Due to differences in days between data collection points among participants, an offset exposure variable was included in the unconditional growth model and remained in subsequent steps. Time variables predicted ED visits in the first two model steps, indicating that ED visits tended to reduce over time and tended to be higher in longer observation windows.

These time variables became non-significant when time-varying covariates were added in the third step, indicating the reduction in ED visits over time is accounted for by the time-varying covariates entered into the model. A random intercept was also included and found to remain reliable across the models, indicating that significant variability in initial ED usage existed among participants and was not accounted for by the included covariates. Finally, two baseline variables were excluded from the final model – number of MINI diagnoses and CMCs – due to observed collinearity with the SF-12 Mental Component Summary and Physical Component Summary, respectively. Visual inspection of studentized residual plots and predicted versus observed distributions indicated good model fit.

When controlling for other variables, self-identified Indigenous ethnicity was a predictor of higher ED visits. When considering continuously measured covariates, historical ED use patterns had the greatest effect, with higher numbers of ED visits pre-baseline predicting higher

*Note:* \*When a small number of participants (n < 5) are excluded due to atypical income patterns, these statistics change as follows: M=7298.83, SD=3457.66, Min=150, Max=28,182.50.

Table 2. Results of Longitudinal Modelling for Number of ED Visits

	Model 1	Model 2	Model 3
N Obs =	3613	3481	2194
-2LL	8203.5	7721.14	4645.87
AIC	8213.5	7751.14	4691.87
BIC	8234.43	7813.30	4784.90
Fixed Effects	b(se)	b(se)	b(se)
Time Variables			
Time	19*** (.03)	17***(.03)	06 (.04)
Exposure Offset	.25*** (.02)	.24*** (.02)	02 (.05)
Categorical Baseline Covariates			
Indigenous (Ref. = Yes)		29^ (.15)	36* (.16)
Need Level (Ref. = Mod.)		.27* (.13)	.24* (.12)
Res. School History (Ref. = Yes)		15 (.13)	06 (.13)
Gender (Ref. = Male)		.07 (.13)	.01 (.13)
Continuous Baseline Covariates			
Past ED Use		.64*** (.05)	.56*** (.05)
Past Homelessness		08 (.06)	12^ (.06)
Education		.09 (.06)	.07 (.06)
Age		08 (.07)	07 (.06)
CMCs		.22*** (.07)	
MINI Diagnoses		.05 (.07)	
Continuous Time-Varying Covariates			
Months on Social Assistance			.37*** (.06)
Primary Care Visits			.26*** (.04)
SF12 PCS			20*** (.05)
Substance Use Problems			.17*** (.05)
Stable Housing			16^ (.09)
SF12 MCS			09^ (.05)
Food Security			.08^ (.04)
Case Management Visits			.07* (.04)
Victimizations			.04 (.03)
Income			.01 (.03)
Random Effects			
Intercept	90*** (.07)	81*** (.11)	77*** (.12)
Variance Components			
Intercept (-2LL)	9254.42***	8257.69***	4855.46***

*Note:* AIC = Akaike information criterion, BIC = Bayesian information criterion,  $-2LL = -2 \log 1$  likelihood. Each is used to compare the relative fit of nested models. In all three cases, comparatively lower values indicate better fit.  $^{\land}p < .10, ^{*}p < .05, ^{**}p < .01, ^{***}p < .001$ 

numbers of ED visits over the study period. Contrary to hypothesized predictions, participants receiving social assistance and case management were more likely to attend the ED. As well, participants with higher numbers of primary care visits were more likely to attend the ED. Measures of physical health (i.e., CMCs, SF12 PCS) significantly predicted ED visits, with poorer health predicting higher ED visits. The effect of mental health measures was smaller and less reliable, with the exception that being identified as 'High Needs' (primarily based on the presence of psychosis or bipolar disorder; see Goering et al., 2011) reliably predicted higher numbers of ED visits. However, the relative size of this effect cannot be inferred from the model. Regarding measures of housing stability and homelessness, most effects were in the predicted direction – with the exception that higher lifetime homelessness tended to predict lower ED use over the course of the study – but also tended to be smaller and less reliable than measures of physical health, though greater than measures of mental health. Increasing food security predicted reduced ED visits, but the effect reliability was relatively low. Age, gender, education, family history of residential school attendance, self-reported victimizations and income had no demonstrable effect on ED attendance.

### **Discussion**

The present study recruited homeless participants and tracked various baseline and time-varying measures of health and its social determinants to predict ED use over time. The inclusion of time-varying covariates accounted for the observed reduction in ED visits over the two years, with Indigenous ethnicity, high needs mental illness (see Goering et al., 2011), and higher levels of health service use (i.e., pre-baseline ED visits, concurrent primary care visits), case management, social assistance and substance use problems reliably predicting ED visits

over the study period. Concurrent housing and food security effects tended to be smaller and less reliable, but in the predicted directions.

Except for months on social assistance, measures of physical health and health service utilization were the strongest predictors of ED visits. These findings suggest that ill-health factors, which are of higher prevalence among homeless populations, are the largest drivers of ED use among people who are or were homeless. Consistent with a recent cost-analysis which found that costs associated with ED visits and ambulance use were a fraction of the cost of primary care among five Canadian samples of people who are homeless (Latimer et al., 2017), the present findings, instead, support growing evidence that the use of ED by homeless participants should not be categorized as inappropriate (Doran, 2016). Their ill-health predisposes them towards a greater need for medical care in general, rather than their lifestyle predisposing them towards misuse of medical services. This is contrary to hypotheses (Wang et al., 2015) and findings (O'Toole et al., 2010) in other research that has suggested homeless participants underutilize primary care and use ED services instead.

Health service use patterns and measures of physical health also had a greater impact on ED use patterns than measures of housing and homelessness history. This replicates findings from previous Canadian research (e.g., Chambers et al., 2013), but contradicts research in American settings (e.g., Moore & Rosenheck, 2017). It may be that the context of universal health coverage resulted in the observed differences. However, Moore and Rosenheck's moderation analysis did not outline the relative strength of housing and health variables in a multinomial model, only claiming that housing was the primary mediator of decreased ED use in a Housing First sample (2017) without assessing whether health remained a greater predictor of ED use.

The present study, particularly when considering its replications of previous analyses (i.e., Chambers et al., 2013) may also help explain why housing didn't have as substantial an effect as anticipated across the various analyses of the At Home/Chez Soi sites (e.g., Aubry et al., 2016; Kerman et al., 2018; Stergiopoulos et al., 2015). Health and health service use consistently and reliably predict ED use, but the effect of housing may be more variable among subgroups of participants.

Beyond only housing, findings from the present study support the notion that factors predicting ED use among people who are homeless is not fully understood. For example, the variable with the largest effect on ongoing ED use was past ED use, even when controlling for measures of health and its social determinants. As well, the variance of the model's random intercept remained significant after the addition of baseline and time-varying covariates. This indicates that the variability in initial status was not accounted for by the included measures. In summary, the various measures of the Behavioral Model for Vulnerable Populations (Gelberg et al., 2000) included in the present study do not completely explain ED use.

Finally, Indigenous ancestry remained a significant, strong predictor of ED use, even when controlling for measures of physical health, health service use and so on. However, a family history of attendance in the Indian Residential School system (TRCC, 2015) did not predict ED use when controlling for baseline covariates, and the strength even decreased when adding time-varying covariates in the model. Reasons for this can only be speculated. It is possible that the postulated effects of Residential School attendance are captured in the included measures (e.g., lower physical health, high levels of mental illness, etc.). It may also be speculated that damage done through such colonial practices extends beyond individual families

to the entire community of First Nations peoples and, as such, is captured in the strong and reliable ethnicity effect included in the model.

# Strengths, Limitations & Future Research Directions

The present study is one of few available studies to utilize a longitudinal design that combines administrative health and social service data with multiple measurement points of survey data. This is particularly true in the context of universal health insurance. The inclusion of a large proportion of Indigenous participants is also a study strength, given their overrepresentation in the homeless population of Canada (Gaetz, Donaldson, Richter, & Gulliver, 2013). However, the context of universal health insurance may limit generalizability to other settings and populations, as the access the participants had to primary care within a system of universal healthcare may result in different patterns of healthcare system utilization compared to contexts in which such individuals have limited access to primary care.

Generalizability may also be limited by the ethnic make-up of the sample. It may be worthwhile to replicate this analysis at other At Home/Chez Soi sites to see if the relative weighting of variable effects is altered when Indigenous ancestry, the largest categorical predictor of ED use in the present study, is less extensively represented. It is still anticipated that measures of health and health service use would remain among the largest of predictors, but relative weighting may change and other social determinants of health may demonstrate a more substantial effect within the model. In the national and local context of the present study, however, the strengths of emphasizing Indigenous representation outweighed this minor cost.

Although the present study did not find an association between income and ED use, inferences that can be drawn from this are limited. The vast majority of participants experienced poverty throughout the duration of the study, with self-reported income being independent of

their housing and health. As such, the range of incomes captured in the present study is narrow and very few incomes climbed high enough to expect there to be a significant impact on ED visits. Income source is another potential consideration, with the present study including all potential sources of garnering income, not just employment or social allowance. Further to income from social allowance, this variable is potentially confounded by the fact that participants with an identified disability can receive social allowance in Manitoba without a time-limited expectation of seeking stable employment. As a result, identified illness may be somewhat conflated in that measure.

Considering housing, the current sample had a high degree of chronicity in their past lifetime homelessness, with most participants having been homeless for two years or more preceding enrolment. With the retrospective ED use extending back only two years, it is possible that the influence of homelessness chronicity on ED use is not fully captured in the present study. With this high level of past lifetime homelessness, it is also possible that a longer follow-up is needed to increase the observed reliability in the effect of current housing stability on ED use. As well, with such a high degree of homelessness chronicity, future research should evaluate the impact of early intervention and prevention on ED utilization rates.

Finally, the role of recall bias cannot be ruled out as a potential contributor to the present findings. This may have influenced the accuracy of self-reported income, victimizations, substance use, food security, housing stability and case management visits over the study follow-up period.

Additional aims for future research should be towards clarifying the remaining variability that was observed in the present study, in addition to the broader research literature. There is more to be learned about why people who are homeless choose to use the ED to manage their

health, which is unlikely to result in their best possible health outcomes. Longitudinal studies utilizing latent class analysis to identify subgroups of ED and primary care users may be helpful in clarifying these factors, allowing us to tailor interventions appropriately.

# **Conclusions**

The present study supports a growing body of literature that challenges misconceptions about the appropriateness of ED use among people who are homeless. Not only is physical illness one of the largest predictors in the longitudinal modelling results, but those participants who managed their health through ED visits also did so through visits to primary care physicians. These physical health measures also had a larger effect than measures of mental health among a sample of individuals with a diagnosed mental illness. Intervention studies may wish to change their focus from reducing health service use to improving health among people who are homeless. As well, physical health management should be incorporated into homelessness intervention studies, above and beyond the mental health interventions that are often incorporated. Further, homelessness prevention and early intervention studies may also better promote health, reducing ED visits over time.

# **Chapter 3: Qualitative Study**

# **Fixed Nodes of Transience:**

# Narratives of Homelessness and Emergency Department Use<sup>4</sup>

#### **Abstract**

Some scholars suggest ED use among people who are homeless is inappropriate, and others indicate that such claims are inaccurate. Although research has investigated the ED experiences of people who are homeless, scholarship has not addressed how people who are homeless understand the role of the ED in their healthcare and day-to-day lives. Sixteen participants were recruited for semi-structured interviews regarding their ED stories and experiences. Interviews were analyzed using narrative analysis. Set within the context of narratives of disempowerment and discrimination, participants storied the ED in differing ways. The findings indicate that participants understand the ED to be a public, accessible space where they could exert agency. ED narratives were also paradoxical, storying it as a fixed place of transient care in their transient lives; as a result, they were isolated, and yet belonged. Implications for policy and practice are discussed.

### Introduction

Physical and mental health are notably worse among people who are homeless when compared to the general population (Hwang, 2001; Hwang, Wilkins, Tjepkema, O'Campo, & Dunn, 2009; Kushel, Vittinghoff, & Haas, 2001). Research has also found that individuals who are homeless tend to seek care at the emergency department (ED) at a commensurately higher rate than those who have housing (Hwang et al., 2013; Ku et al., 2014; Kushel et al., 2001; Mandelberg, Kuhn, & Kohn, 2000). Some researchers suggest that people who are homeless access the ED more frequently because factors associated with the homeless lifestyle (e.g.,

<sup>&</sup>lt;sup>4</sup> An abbreviated version of this chapter is currently under review with *Qualitative Health Research*.

having acute needs for food and shelter) prevent them from seeking preventative forms of healthcare (Gelberg, Gallagher, Andersen, & Koegel, 1997) and some have found that increased physical illness contributes to their increased ED use (e.g., Chambers et al., 2013). Others have suggested that the ED use pattern of people who are homeless is 'inappropriate', concluding that their increased usage rates are due to people who are homeless choosing to access the ED for concerns that are more aptly suited to primary care appointments (Ku et al., 2014; Wang et al., 2015), despite growing evidence that claims of inappropriateness are inaccurate (Doran, 2016).

In addition to evaluating healthcare usage patterns, researchers have recently turned their attention to characteristics of the healthcare encounter itself as potentially contributing to how people who are homeless choose to engage with the healthcare system. For instance, feeling unwelcome in healthcare interactions has been found to negatively influence the willingness of those who are homeless to seek healthcare in the future (Wen, Hudak, & Hwang, 2007). Qualitative inquiry regarding healthcare encounters of people who are homeless has consistently found that perceptions of stigma characterize the stories and experiences that they voice. Some studies have noted that participants feel as though their homelessness affected the quality of the healthcare they received and that they had to wait longer for care than the general public (Wen et al., 2007; Woith, Kerber, Astroth & Jenkins, 2017). People who are homeless feel dehumanized in these interactions (Biederman & Nichols, 2014; Munoz, Aragon, & Fox, 2015), judged or disrespected because of their social position (Martins, 2008; McCabe, Macnee & Anderson, 2001; Rae & Rees, 2015; Woith et al., 2017), and invisible to healthcare providers (Martins, 2008). The interactions they reported evidenced examples of both 'enacted' and 'felt' stigma (Jacoby, 1994). According to Jacoby, enacted stigma refers to "episodes of discrimination", while felt stigma refers to the shame associated with social labelling and fear that enacted stigma will occur.

Themes of marginalization and stigma also appear in the ED stories of Indigenous populations. Regarding their experience in the ED, Browne and colleagues (2011) conducted an ethnographic investigation of Indigenous Canadians attending an urban ED who had been triaged as 'non-urgent' and found that a prevailing theme in participant reports was anticipating providers' perceptions of them based on their race. Such findings echo those of previous qualitative studies where Indigenous participants report perceiving significant stigma within the healthcare system (Benoit, Carroll, & Chaudry, 2003; Levin & Herbert, 2004), and report feeling a sense of freedom from that stigma when accessing services in Indigenous-led environments (Van Herk, Smith & Gold, 2012). This experience is likely to be a reflection of the history of Canada's Indigenous peoples. Today's Indigenous children are born into a culture shaped by a history of colonialism and paternalism (Smith, 2012), as well as the fallout of related policies such as the Indian Residential School system. These historical factors are hypothesized to be among the largest contributors to the current social and health inequities for Indigenous peoples in Canada (Lavallee & Poole, 2010). One such inequality is over-representation of Indigenous peoples in Canada's homeless population (Belanger, Weasel Head, & Awosoga, 2012). Findings from at least two Canadian studies (Chambers et al., 2013; see also, Chapter 2) indicate that Indigenous status predicts increased ED utilization among homeless participants.

Research into the healthcare encounters of people in marginalized groups, then, has consistently found that the experience of being marginalized influences their lived experience of healthcare encounters. Despite the increased attention to their voice, however, little is known about how those who are homeless understand their experience of the ED and its role in their day-to-day lives. With stereotypes in the existing research literature, and among the general

public as well, that the ED usage of people who are homeless is often 'inappropriate' – that they use the ED for treatment of non-urgent illness, for supporting addictions, or for food and shelter – further research is needed that sheds light on how people who are homeless understand the ED.

Narratives of the ED. The present study addresses this topic from the perspective of narrative, seeking to evaluate how participants tell the stories of their ED experiences. The way they narrate their experiences is the entry point into assessing how they make meaning out of the ED encounter. Through an analysis of their stories, we are able to see how people who are homeless understand the role of the ED in their day-to-day lives. Narrative is commonly understood as the practice of storying our lives and the lives of others. These stories constitute the building blocks of cognition (Bruner, 1990), as we narratively structure our understanding of our experiences, our identities, and our world (Atkins, 2004; Bruner; Salmon & Riessman, 2008). Narrative constructions are not framed in the isolation of a particular individual; rather, "...identities and selves are shaped by the larger socio-cultural matrix of our being-in-the-world" (Smith & Sparkes, 2008, p. 6). In order to formulate these narratives, then, we must draw on the storylines which are available to us within the society in which we live (Gergen, 1994; Miller, 2011; Smith & Sparkes, 2008). This is an active process, whereby an individual's understanding of identities, experiences, and culture is both allotted by society, and resisted, disputed, or claimed for themselves (Taylor & Littleton, 2006). We adopt a storied resource perspective of narrative, whereby, "...narrative selves and identities are socio-cultural phenomena, realized within active relationships, and...are taken up, modified and individualized" (Smith & Sparkes, p. 20).

As this process implies, not all storylines in any given culture hold equal sway. Some narratives are more hegemonic than others, representing what society deems 'normative' or how

life 'should' be and proceed. Andrews (2004) refers to these as the master narratives of a given culture. "Trouble" (Bruner, 1990; Taylor & Littleton, 2006) arises when one's experiences fall outside the master narrative. When this occurs he or she is forced to reconcile their experiences with what should have been. To do this, counter-narratives are formed that are no longer in-line with the master narrative, but neither are they always directly opposed to it. Alternative cultural resources may be drawn upon, while aspects of the master narrative remain or are reinterpreted, comprising the process of actively 'taking up, modifying and individualizing.'

Homelessness and Healthcare – An Intersection. Cultural representations and understandings of healthcare and homelessness are embedded in the narrative and discursive constructions of the participants. There are, then, two broad sources from which the participants garner their narrative resources. The first is how the ED is understood by the general population. The second, how people who are homeless understand their social position in the community at large, of which the ED is a part.

Themes of ED Research. In 2010, a literature review on the public's experience of the ED was summarized by Gordon, Sheppard, and Anaf. They observed several notable themes across the available studies. First, despite the medical-technical setting, participants articulated expectations that their emotional needs would be met through empathic and respectful care. However, all of the studies reviewed articulated that participants often did not feel these expectations were met, with their emotional needs given low priority in this setting. Second, the amount of communication and information available to patients significantly influenced their perception of care. Patients desired more communication regarding all aspects of the ED encounter, including triage, wait and diagnostic processes, their condition, and their treatment plan. Their fears and anxieties tended to be ameliorated when this information was provided.

The experience of waiting in the ED factored greatly into participant stories of ED care, but time spent waiting seemed less important to patients than the amount of information provided as to why they were waiting. Third, the emergency room environment tended to contribute to a sense of disempowerment. For instance, the presence of marginalized populations (e.g., people who are homeless or abuse substances) was largely perceived by the general population as contributing to a broadly negative perception of visiting the ED, consistent with the observation in the homelessness literature that, "Homeless bodies might infect, spoil or taint [public] spaces" (Hodgetts, Radley, Chamberlain, & Hodgetts, 2007, p. 722). This is something that participants who are homeless might need to contend with in their own narrations of the ED encounter. In addition to the ED environment, patient-staff interactions were disempowering if the patient was deemed to be an inappropriate attendee (i.e., non-urgent symptoms or a repeat ED user), contributing to a sensed need to behave in such a fashion as to be labelled a 'good patient' (e.g., by joking with nurses, displaying compliance, and so forth).

Homelessness and Stigma. As cited earlier, people who are homeless have consistently voiced experiences of discrimination in medical settings. Rejection and stigma have also been described in day-to-day encounters among those who are homeless (e.g., Williams & Stickley, 2011) with many people who are homeless internalizing this discriminated identity (Martins, 2008). Along the lines of negative internalizations, Persaud, McIntyre, and Milaney (2010) found that participants in their study had adopted society's opinion that their homeless status was a result of their personal responsibility and moral failings.

In an interesting contrast, however, research has also found that some homeless participants demonstrate an external locus of control, with participants voicing the perception that the life they are in is because of circumstances beyond their control (Nickasch & Marnocha,

2009). Various studies have highlighted similar instances of homeless participants reframing their standing relative to disparaging conceptions of homelessness. For instance, many participants have been observed to stress their differences from the type of homeless individual which is derogated and rejected by society (e.g., Trimingham, 2015). Others have found that people who are homeless conceal being homeless in an effort to resist exclusion from public places (e.g., Casey, Goudie, & Reeve, 2008).

Farrugia (2010), in his discussion of power relations and the "symbolic burden" associated with the structural inequality of homelessness, comments on the contrast between the rejection and stigma internalized by people who are homeless and their observable and internal acts of resistance against imposed power differentials. He observed in the participants of his study that, "The power relations that are inherent in the experience of homelessness...act to close down spaces [that allow them] to experience selves which they, and others, recognize as valuable" (p. 82). On the other hand, the participants, "...subvert the meanings which create feelings [of suffering] by drawing on a heterogeneous array of practices and symbols as part of their active efforts to construct identities which do not carry the symbolic burden of homelessness" (p. 85). This research suggests that those who are homeless respond to power differentials by trying to counteract the scorn imposed by social discourses of homelessness.

Research Question. As stated, being homeless appears to have a strong influence on how people interpret their experiences of healthcare encounters. In fact, it is inseparable, as homelessness both constructs and reflects the positionality of one's sense of self relative to powerful others. Although this is the case, there has been little research that has directed attention to how these social discourses are intertwined in narratives about ED experiences among people who are homeless. The nature of this narration is important to understand, as how

one understands themselves relative to the 'other' of the healthcare system will inform how they engage with it. With this in mind, the findings outlined herein will answer the question: How do people who are homeless narrate their experiences of the ED? Answering this question will provide insights into how scholars and healthcare professionals can work to create a healthcare system that meets the needs of a group of people in need of empowerment.

### Methods

### Procedure.

Participant Recruitment and Characteristics. Interviewees were recruited from among a sample of participants who participated in the Winnipeg site of the At Home/Chez Soi Housing First demonstration project (Distasio, Sareen, & Isaak, 2014) and had given consent to participate in related studies. At the time of recruitment a four-year follow-up study was under way, facilitating access to up-to-date contact information for many participants.

Prior to contacting the participants, their self-reported ED use over the course of the Housing First study was reviewed and ranked by decile. Participants were selected to reflect a range of ED use, sampled from upper deciles (Number of ED visits between 8 and 114 over two years), middle deciles (4-7 visits over two years) and lower deciles (1-3 visits over two years). Participants needed to have a minimum of one visit to the ED over the course of the Housing First study to be considered eligible to be contacted. Sample selection was also intentionally tailored to reflect similar representation of males and females.

Participants were contacted through the Winnipeg site's research office using phone, letter mail and written contact through social media (i.e., Facebook). Participants who opted to participate were also asked if they had contact with anyone else from At Home/Chez Soi who may be interested in participation.

Due to the context of the Winnipeg site, the study is influenced by Canada's ethnic makeup, particularly regarding the aforementioned over-representation of Indigenous peoples in the homeless community. In Winnipeg, approximately 1 in 10 individuals self-identifies as having Indigenous ancestry (Statistics Canada, 2017). In contrast, over 60% of the homeless population in Winnipeg reports Indigenous ancestry (Belanger et al., 2012). The Winnipeg context is also notable for local media and political attention directed towards ED wait times, with the average wait to see a physician being consistently higher than the national average (Manitoba Health, Seniors and Active Living, 2017). Further, a local ED came under severe local and national scrutiny in 2008 when Mr. Brian Sinclair, an Indigenous man, died in the ED from a treatable infection after 34 hours of waiting without being seen. His death has been attributed to problems of racial profiling, with several hospital staff believing him to be inebriated and/or homeless, despite the fact that he was neither (Browne et al., 2017).

Sixteen participants were recruited via letter mail, telephone calls, or electronic messages (see Appendix A). Participants ranged in age from 29 to 60 years, with a mean age of 45 years. Regarding self-reported ethnicity, 12 participants identified as 'Native', 'Aboriginal', 'First Nations', or by a particular First Nation (e.g., Cree, Ojibway), 2 identified as Métis, and 2 identified as White. Nine participants were female and seven were male. Participants reported ages of first homelessness ranging from 7 to 49 years of age, with half experiencing their first period of homelessness in childhood. The longest reported period of homelessness they had experienced in their lifetime ranged from 4 months to 10 years, with one participant (age 45 years) declining to specify due to reportedly spending most of his life without a home. At the time of this study, 13 participants had obtained some form of housing, but most noted that their current living situation was poor or unstable. Two participants had obtained employment (one

full-time, one part-time), but the remainder garnered income from social assistance (12 participants) or panhandling (2 participants).

Interview and transcription. Interviews were arranged to take place in private office space in either a local mental health hospital or downtown university. Participants were provided with honouraria consistent with that of interviews of similar length in the earlier study. Following the consent process (see Appendix B) and completion of a background demographic questionnaire (see Appendix C), they participated in open-ended, semi-structured discussions regarding their use of hospital emergency departments, with special effort made to elicit stories of past visits and the circumstances surrounding their visit. Interviews ranged in length from 60 to 90 minutes and included prompts and questions such as: "What is it like when you visit an ED?" "Tell me about a memorable time. What happened?" "Why were you there?" or, "Tell me about a positive/negative experience in the ED" (see Appendix D). The interviews were audio-recorded, professionally transcribed for content and, later, transcription conventions were added (e.g., speed, volume, pauses; see Appendix E). Pseudonyms replaced identifying information to protect confidentiality.

Analysis. The transcribed interviews were analyzed using principles of narrative analysis. The analysis of the transcripts took place at three levels: thematic, structural, and performative (Riessman, 2008). The thematic level attends to the content or themes of the participants' stories; what they are trying to communicate. Thematic analysis is directed towards understanding the intended message of the story, or perhaps the moral, if there is one. The structural level of analysis seeks to identify the way the participants organize or arrange the stories, or different storytelling techniques used to convey the message, evaluating how the structuring facilitates the communication of the message. In short, the structural level looks at

how they tell their stories. The performative level of analysis considers who the teller is, their audience, and the cultural resources or pressures which shape their narrative. Analysis followed an idiographic, stepwise approach. Each level of analysis was considered separately within each interview, followed by the evaluation of within-interview similarities and differences across the various analytic levels. Observations across the interviews were then made, comparing and contrasting similarities and differences across participant narratives.

Qualitative Rigor. To ensure the quality of the research, qualitative rigor was attended to according to the criteria proposed by Tracy (2010), such as rich rigor, credibility, and ethics. The strategies adopted for ensuring rigor were consistent with recent APA task force guidelines for methodological integrity, both in regard to fidelity and utility (see Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017).

Beginning with rich rigor, descriptions have already been made regarding the study context, the sampling, data collection, and analysis processes, and the sufficiency and relevance of the theoretical constructs implicated in the current study. Time in the field was ensured through the researchers' involvement in the six years of data collection for the Housing First demonstration project, as well as focused consultation with local health care practitioners who have a portion of their job dedicated to working with people who are homeless. Further, the initial study question and design were submitted for review to a local advisory body comprised of Indigenous representatives and of individuals with lived experience with homelessness and mental illness. Their input helped frame the research and interview questions and approach.

Consultation with the advisory board also constituted a crucial component of the study's ethical process, helping to ensure that this project was conducted in a culturally sensitive manner. Ethical approval of the study was obtained from a university health research ethics board.

Sincerity and credibility were ensured through a reflexive approach to the research, with multiple team members directly reviewing the data. As much as possible, thick quotes from the interviews are provided to the reader to allow the reader to interrogate the data for themselves and form their own opinions. As well, the data shared is multivocal, outlining differences within and between participants, rather than sharing a one-dimensional over-simplification of the participants' narratives.

# **Findings**

Although the vast majority of stories that were narrated were about physical and mental health complaints, the focus of the healthcare stories was rarely about illness. On the contrary, receiving treatment for the illness or injury was only a minor plot point, if mentioned at all. Treatment was taken for granted in their stories, suggesting that treatment was presumed to be a part of the story and thus not worth mentioning. Instead, participant narratives were centered on the ED encounter, particularly the environment or the interactions surrounding it. Participants incorporated elements of narratives that are found among the general population regarding how the ED is constructed and positioned, but the dominant storylines centered on experiences negotiating the complex dynamics of power differentials in EDs, and the precariousness of (not) assuming personal moral responsibility for agency in their healthcare. The tension between powerlessness and agency introduces a paradoxical way of understanding the ED.

**Power in the Emergency Department.** Participants anticipated, at best, a cold, clinical encounter, in line with the medical-technical setting in which the encounter took place. Such coldness did not constitute 'good' healthcare, however. Just like the general population (Gordon et al., 2010), participants perceived good care to be empathic, respectful socioemotional care, rather than medical treatment. Empathic 'care' is differentiated from treatment in this sense;

recall, treatment was rarely discussed in the participants' stories. Beyond respectful care, good encounters occurred when physicians or hospital staff stepped out of the hierarchical position afforded to them and chose to use their authority for the sake of the patient. These atypical positive experiences were often characterized by unexpected warmth, compassion, or pausing amidst busyness. Consider the following excerpt from the interview with Paula, a 35-year-old woman who self-identifies as Native. She first became homeless in her mid-twenties, having become addicted to prescribed pain medications. She reported frequently using the ED to obtain prescription painkillers. At the time of the interview she had been living independently on social assistance for two years and she no longer used addictive substances.

**Paula:** Every time I've needed <u>real</u><sup>5</sup> help, I've *gotten it*.

**Int.:** Is there a time that jumps out to you, "I needed real help at that time"?

Paula: There's been a couple. (2) I was in here not too long ago... These doctors were taking forever. I was sitting in the emergency room and I was watching my leg turn red, like I'm sitting in the emergency room and I kept looking at my leg and it started going all the way up my leg... I kept telling them, "Something's going on. Something bad is happening. I can see it like I'm watching my leg turn red." They kept saying wait, they kept saying wait, and I kept saying, "No, I can't wait. Something's happening. I know...Something bad is happening." ... I still ended up waiting... The nurses were <ignoring me>. <Everyone was busy>. This one lady doctor walked by and I said, "Excuse me." I said, "I know you guys are really busy, but something's really wrong. Can you come here?" She walked to the room and she looked at my leg and she was, "Holy shit," and she called and like in two minutes, ten doctors were there, like it was just crazy. But yeah, I couldn't believe like how much I was getting sloughed off.

Paula starts her care story by performing a sense of urgency and panic, emphasizing it by repeating the symptoms and frequently raising the pitch of her voice (the italicized words). In particular, she portrays her powerlessness in this situation, being told to wait by people "in the emergency room," thus emphasizing this is the one place someone in her condition should not be expected to wait. Consistent with findings among the general population (Gordon et al., 2010), the wait at the ED was disempowering and she felt like she needed to advocate for the care that

<sup>&</sup>lt;sup>5</sup> Transcription Conventions: <u>Emphasis</u>; *Higher Pitch*; <Faster>; >Slower<; (Pause, in seconds), LOUDER

she thought she required. The majority of the participants spoke of the wait for medical care in the ED as a problem.

The difference between the participants and the general population, however, is that the participants often attributed the wait – and indirectly, this disempowerment – to their homelessness and disenfranchised social status. Most told stories where the wait exacerbated their chronic feelings of powerlessness or discrimination, of people who were supposed to care ignoring their unbearable pain, even if they were desperate for help. Gordon is a 60-year-old male who self-identifies as Métis. While homeless, he found himself using the ED due to suicidal ideation and depressed mood on a few occasions. In the following excerpt he was asked how being housed influenced the care he received in the ER:

Gordon: I really can't see any difference, it comes down to the waiting game...Like I said, that one time, they took me right away because of my *blood pressure*. Couldn't get it down. (2) Or else you're not really an *emergency*. They figured, you know, you're at the bottom of the list, cause you're not really- they don't consider you an *emergency*. They know you're there for <u>help</u>, but you can <u>wait</u>.

**Int.:** And at the time, did you agree with that?

**Gordon:** Yes and no, in a way...I can see their point <u>now</u>, I'm thinking clearly now, I can see their <u>point</u>.

**Int.:** ... What do you mean, I'm thinking clearly now, but not then?

**Gordon:** I was just thinking it's the same old bullshit game. I'm homeless, (2) I'm automatically put on the bottom of the list. (2) That's what I thought. Homeless people are put on the bottom of the list, (.) unless they're <u>dying</u>, or almost <u>dying</u>. (2) I think that's basically <u>true</u>, because you look at the inquiry about [a local ED], in the past, how they treat homeless and that, you know, and that's come out, you know (1) they're *kind of forgotten*. They're <u>left</u> there for <u>hours</u>.

Two cultural narratives are at play across this portion of his interview. On the one hand, the wait is narrated as a product of the medical environment and the priority of emergent over non-emergent symptoms. However, the lens of homelessness has a powerful effect as he then reframes the wait as someone "at the bottom of the list" due to his homeless status.

Viewing their experiences through the prism of powerlessness related to their

homelessness seemed to be why the participants do not expect good care. In fact, they fully expected to be discriminated against. Stories of actual racism were rare, but perceived discrimination – felt stigma (Jacoby, 1994) – based on homelessness was nearly ubiquitous. Even though Paula (above) critiques this perspective, she also recognizes that she, too, had a similar expectation to most other participants when approaching the ED. They also anticipated that their concerns would not be taken seriously. Consider the comments of Charles, a 34-year-old male who identifies as Aboriginal:

**Charles:** Being judged is <u>one thing</u>. (3) I <u>seen</u> a lot of people get discriminated on, because they're, like somebody that's <u>homeless</u>, and *maybe that guy* really <u>does</u> have a broken arm or a broken leg, and he really <u>is</u> there for real reasons. But because of his <u>appearance</u>, and >maybe hasn't< changed his *clothes in a month*, I seen that happen a lot.

Charles stresses both "homeless" and "does" in the same sentence, as if being homeless and a genuine need for – in fact deserving of – medical care would normally be considered contradictory. In his understanding, medical professionals expect that the person who is homeless *really doesn't* need the care they say they do. Somehow their appearance equates to an abuse of the medical system. To him, the powerlessness experienced in the ED has a logical conclusion that medical personnel naturally discriminate against those who are homeless.

At the same time the conclusion that medical personnel are unjust and unempathic is also contested in their stories, because there is also an expectation that they are caring, compassionate professionals who have the best interests of the patient in mind. There is a tension, then, between the ideal of hospital staff who are supposed to care, and the encounters where the participants perceive that they don't. Edward, a 54-year-old man who identifies as Métis, articulates it this way:

**Int.:** Yeah you said kind of (2) the hospital is kind of the same way in that they just don't seem to care.

Edward: Well they do (1) and then they don't. I don't know. It depends on your situation.

**Int.:** It seems like both, kind of depends.

**Edward:** Yeah. Well it's their <u>job</u> to care (1) and *then they don't*. ((laughs)) I don't know what they're thinking but I can tell you the impression of what they're thinking

(1) or what they might be thinking.

**Int.:** Do any of the interactions that you had kind of jump to mind as far as that would just gave you the impression they didn't care or they didn't- (1)

would just gave you the impression they didn't care or they didn't- (1) **Edward:** Well the comment about *frequent flyer* was one. (1) I thought, because I've

been to ((the ED)) before and then she seemed <u>nice</u>, but then she *made that comment*...when she said *that*...she thought I was there just for the

prescriptions.

Edward is somewhat reluctant to voice his opinion that healthcare staff do not care, as indicated by the pauses in his speech and the uncomfortable laughter; he is saying something that he doesn't feel completely comfortable saying. He, along with several other participants, give the impression that there is a debt that is created by the receipt of healthcare in that the person with more power – the medical professional – has given them something they should be grateful for. To express an expectation of good socioemotional care is to express an ungrateful entitlement.

Personal Responsibility. The power differential was only one undercurrent of how participants made sense of situations they thought exemplified poor care. When asked why she had been "sloughed off" in her story about waiting while her leg turned red, Paula reported, "It would be probably because of like my <a href="history">history</a> here...I don't deny not being here and not fucking being an asshole. I've done a lot of shit here." In other words, she referred to her past morally questionable behaviour, as if it justifies poor care. In the context of the broader narratives of homelessness, this falls in line with the social story that they are culpable for their current circumstances. The participants frequently equated homelessness with lowliness, dirtiness, and hopelessness and they had internalized the narrative of homelessness as the result of their moral failure and lack of personal responsibility. If morally questionable behaviour justifies poor care, then the identity and social role they inhabit justifies their poor care. They feel pressure to

accept this set of circumstances as it is.

When the participants began to voice their experiences of discrimination, then, they are counter-narrating against the master narrative. One could view this as a form of resistance. There is another compelling narrative thread that appeared repeatedly among the participants that asserts that the medical spaces are supposed to be a haven of compassion and care. The compassionate care narrative says all patients, regardless of class, race, or gender should be treated with dignity and respect. The contrast between personal responsibility and unjust discrimination creates 'trouble' (Bruner, 1990) regarding the right to receive care in the emergency room. Participants believed themselves to be unfairly treated, on the one hand, but powerless to influence the staff and systems of the ED that dictate the terms of the care available. This reflected their experience of life on the streets. Their stories of homelessness were devoid of understanding themselves as able to alter the monotony of their day-to-day lives. The services available to them and routes out of homelessness were circumscribed, unchangeable, and insurmountable. The ED was epitomical of their daily lives. And yet they voiced a pressure to perform agency, if possible, within the inalterable system that is in place. The personal responsibility narrative required action on their part.

How the participants storied their agentic actions tended to fall into one of five storylines. For the sake of parsing these storylines apart, they are grouped according to whether they were predominate in a particular participant's interview; that is, participants tended to rely on one of these narrative types in their interview, with some notable exceptions. In actuality, however, although most participants' stories are described as falling into a particular grouping, each often interweaved the other storylines into their narratives in subtle ways.

One participant re-storied her life to align with the narrative of personal responsibility.

Paula was the sole participant to respond by fully 'siding' with the healthcare system.

**Int.:** So are there complaints that you hear from -- because you mentioned people complain about the ER, [what do they have to say about it?

Paula: Yeah, but] a lot of that is bullshit. Yeah, a lot of the fucking, the <u>rubbies</u> come in here, a lot of the fucking sniffers come in, they fucking <u>use</u> this place up and then they fucking wonder why they're sitting there for 10 hours. You know? *That's why*. I don't fucking <u>blame</u> the staff here. I fucking <u>see it downtown all the time</u>. Fuck, <u>I</u> wouldn't <u>rush</u> to them. Look, they do it <u>to themselves</u>... And >I'm <u>Native</u>< (1) you know? <u>I</u> see Natives and I tell them the same thing. Well, if you're going to be all <u>fucked</u> up, why am I going to give you my change? ((laughs)) YOU KNOW, like <u>REALLY</u> though ((laughing))... Who <u>wants</u> to help somebody like that, you know? *I understand* it, and I'm <u>sober</u> and I've taken a step back from a whole bunch of shit.

Paula interrupts the interviewer to begin to make this point and performs her anger and disgust through repeated expletives, raising her voice, and emphasizing the moral failures of 'that' type of person who is homeless. As someone who is now housed and sober, she accentuates her distance from them. Though she formerly interpreted medical encounters through the lens of discrimination, she now critiques her past behaviour through the lens of immoral behaviour in that she used supposedly erroneous claims of discrimination to justify the immoral behaviour of trying to obtain pills. She resoundingly condemns a people group that she used to belong to – the people who "use this place up." This is not an easy position to occupy, however. She becomes loud and laughs as she begins to notice her own discomfort with what she is saying. The interpretation she has adopted holds a degree of taboo. To be permitted to hold that opinion and minimize criticism, she feels pressure to emphasize her Indigenous descent in-group status, conflating homelessness and substance abuse with ethnicity. Despite the interviewer not holding in-group status, she is still compelled to justify her criticism of her people by underscoring this identity. It may be that Paula feels like a "token" (Gent, 2017; Kanter, 1977) in the prevailing group – she emphasizes her visible minority self-identity as a Native person, carrying with it the social stereotypes she is conflating. The cost of joining the dominant is that she must derogate

her own identity in order to belong.

Another storyline was to avoid the ED altogether. Four participants broadly narrated their lives in this way. They narrated their choice not to go. They would only go, then, when they absolutely had to. On the one hand, this was said in the context of being considered a responsible user of health services, articulating their awareness that the predominate view in culture says that only certain injuries and illnesses are appropriate to seek care for in the ED. For this group in particular, however, the avoidance of ED went beyond responsible health service use to include perceived problems in ED care – helplessness, anonymity, frequent mistreatment, and chaos. If they did need to attend, they portrayed choosing to be a good patient to minimize the potential of ED problems occurring. This often meant making extra-special efforts to be courteous and respectful to hospital staff. The only agency they could exercise was to control their own behaviour, fully aware that they were at a disadvantage and needed to ensure no complaint could be levelled against them.

A third plotline was told by three of the participants, portraying helplessness across all of life, of which healthcare encounters were a small part. The meaning they assigned to the ED was as a place to survive, but in a posture of fear. The ED's permanent fixture as a place open to the public, combined with its role as a centre of authority, made it a place that they sought for safety while, simultaneously, being scared of what might happen to them while there. Jill, a 51-year-old woman who identifies as Aboriginal, experienced this when she took her friend to the ED.

**Jill:** Well my friend (1) my friend, just recently, my best friend, one of my buddies, she went into the hospital for a (1) *pneumonia* (1) and they put her on an oxygen...This just happened like a couple of weeks ago...<When she got up she was ((rapid, deep breathing))>. She pushed that ><u>buzzer</u>< right away they came and said, "What's wrong?" and her oxygen was completely <u>shut off.</u> ... They looked behind the curtain at this >native guy that <u>was there</u>< ...I said... "He could have killed you in your <u>sleep</u>." (1) Like stuff like <u>that</u> it's kind of, its scary... If I ever to go in for something like that I said *I don't know*.

Although Jill's desire to avoid the ED is present, her primary stance is that the ED is a fearsome, imposing place to which she must yield in times of need. This is consistent with how she narrated her day-to-day life, trapped in substandard housing that she was helpless to change.

Other participants resisted societal tropes of how the ED 'should' be used. They counternarrated appropriate ED use, portraying themselves as protagonists beating the system. They used the ED to survive in savvy ways, exerting subversive power in a place of imposed rules, regulations and discrimination. It was in this minority of participants that the stereotypical 'abuses' of the system by people who are homeless appeared, such as obtaining unnecessary prescriptions or feigning illness to avoid sub-zero temperatures. For example, Brad, a 50-year-old man who self-identifies as Aboriginal, discusses obtaining medications to sell. Early in the interview he denies selling medications, but then makes this disclosure late in the sitting:

**Brad:** I have no problems sleeping there you know, but [the doctor] gives me Restorals anyway. My <u>back</u> isn't really all <u>that bad</u> there to take >T3's< all the time, but he still gives me... I end up <u>selling</u> them, I SELL them. I need <u>money</u>, you know...

**Int.:** You said my back's not that bad, my sleep's okay, I don't really need them. How do you convince the doctor?

**Brad:** Well *some* <u>doctors</u> are- they <u>really</u> don't they're not really (1) that pry- they're not gonna pry right into- they just want to give you something... they get <u>paid</u>...they must get good money for handing out prescriptions anyways.

**Int.**: So it kind of feels like a win-win?

**Brad**: Yeah.... *They pretty much* every doctor knows you're trying to get something off them so they know, they think- you know there's- there's (1) a need for something that you're there for and you're (2) trying to (.) get off him. (1) Most doctors there they (2) they just fill out the prescriptions right away.

Brad is initially uncomfortable, as the interviewer has introduced the narrative pressure of appropriate care – a narrative Brad evidences familiarity with earlier in the interview when he conceals selling medications. He settles on justifying his actions in the context of a mutually agreeable business transaction between patient and physician. Such, 'inappropriate' use, however, was not the participants' only way of resisting the requirements put upon them by the

healthcare professionals. James, a 29-year-old man who self-identifies as Aboriginal, was homeless at the time of our interview. He described a recent encounter at the ED.

James: There's one nurse who I told her I was okay, and she was just, I don't know, ignoring me. "Nurse? I'm all right." "You gotta wait to see a doctor." I was like, "Come on, nurse, I'm okay." <And, I don't know>, I just got mad at her... So I put on my clothes, I ripped the needle out, and I walked out the door. Surprising they didn't see me though, 'cause I was sneaky.

James refuses to comply with the instructions given to him by the nurse. Leaving the ED due to displeasure with the rules and procedures of the ED, either before or after receiving their care, was common tool for resisting the authority of the doctors and nurses.

Three other participants threaded the avoiding, yielding, and resisting narratives together to story their ED encounters. Sometimes this involved concealing homelessness, such as by carefully choosing how they dressed or by choosing not to disclose their lack of fixed address. For example, in the following quote Peter, a 45-year-old male who identifies as First Nations, displays his awareness of the ED staff's prerogatives, but portrays his choice to yield to the power differential while simultaneously resisting the logistical structures in place.

**Peter:** Well, when you're <u>homeless</u>, you (1) you're in the back of the bus, way in the back of the line. And someone else will come that <u>has</u> an address, and it's like they're *cutting you*. We'll be right with you, sir, we'll be, we'll be right with you. And you're just seeing all these other people going <u>in</u> right <u>away</u>. When you don't have an address, how are they going to help you?

• • •

**Int.:** And did you find that that changed at all, when you did show up to the ER when you had an address?

**Peter:** Yeah. Come in, just wrote down my paper, (1) and you're there, you're in the waiting room. Yeah, we'll be right with you. Just a minute we'll be right with you. What about now? I wanna see a doctor, help me out here. (2) 'Where do you live?' 'mmmmmm'. (3) So that's when you start coming up with bullshit addresses.

Peter both submits to the ED system in the way he falls in line with their processes, and avoids unjust discrimination through subtle subversion.

Finally, a pair of participants advocated that the ED was the best place for them to receive the healthcare they needed. Like Peter, they resisted the claim that homelessness precluded them from legitimate ED care. Unlike Peter, they understood the ED as a place where they belonged, whether it was due to a particular medical condition or feeling that the ED was a place of acceptance. Michelle, a 60-year-old woman who identifies as Cree Indian, spent the majority of her interview advocating for the right to occupy and use a particular ED in the city for her frequent anxiety and panic attacks. To do so, she contrasted her experiences there against a particularly dehumanizing experience at a different local hospital.

**Michelle:** I went to ((one hospital)) one time and I stayed there for five days. I didn't like the treatment at all.

**Int.:** How come?

**Michelle:** That's when blood was coming out and um, you were *farting all the time* and all that *old blood*. (1) And I stunk and I asked, "Can I have-<Is there any way I can have *a shower*?"> And they didn't want to take the >IV< out. And then that morning, they woke me up early and they got me into the wash room and *they stripped me* and <u>left</u> me there. I'd never to go back there. I just want to go to ((the other hospital)) cause- they *seem to know*. I think they <u>deal</u> more with, like >the <u>drunk</u> people<. (1) You know, you can go there and they don't look <u>down</u> at you for being all hungover and <u>stunk</u>, you know? (1) That's how <u>I</u> see it over there.

Notice her emphasis and changes in intonation (as indicated by the underlining and italics, respectively) both when describing being stripped and left alone and when telling the story of her attendance at the ED for a second time in a week's span. She felt she was treated inhumanely in both cases. Regarding the first, they left her naked and alone in the bathroom in a vulnerable state. She is incredulous at the vulnerability and shame she was subjected to. She opines that the first hospital is a horrible place and emphasizes this belief as a juxtaposition against the sense of belonging she feels at the second hospital. At her hospital-of-choice she belongs because she is one of the people who are "all hungover and stunk." Those are her people and that is her place.

The Paradox of the ED. Michelle's comparison between the two hospitals introduced a paradox in how she portrayed the ED. Despite her attempts to convey the acceptance and belonging she feels in one ED, the place where she feels that she belongs was also a place of loneliness and isolation. At one point in her interview she said, "I get lonely sitting in the ER cause I'm by myself all the time. I look around, everybody's got somebody else, one of their family members." This was an extension of how she portrayed her homeless lifestyle in that she was independent and alone while she was homeless, and she continued to perceive herself to be so now that she was housed. Many participants portrayed the homeless lifestyle in a similar way, adrift and isolated. For her in particular, the paradox was that the loneliness was painful, but familiar. Her favoured ED was a place of comfort and acceptance, warm and welcoming to her. However, it was also lonely and painful. She felt she was accepted because she was one of social outcasts. She found it comforting because it was a place where her loneliness — and the pain that went with it — was allowed and she was compassionately cared for. Indeed, she felt welcomed and belonging there because she was, in fact, alone and outcast.

Michelle was not the only participant to view the ED in a paradoxical way. There was an underlying understanding of the ED that was paradoxical for all of the participants. Much like the other fixtures of homelessness, such as shelters or soup kitchens, the ED was always there, a fixed node in lifestyles of transience. What allowed Michelle to be welcomed in her loneliness was that the ED was a fixed place *of* transience. Even though some participants felt under surveillance based on their history or fear of being found out as homeless, they were never truly known. They were depersonalized within the 'system'. At the ED, the crowd was always different, unless they recognized other people who were homeless. Rare reports of repeat associations with staff members were warmly recalled in the context of cold busyness of clinical

stays in waiting rooms and behind curtains. We can see this in another excerpt from Paula's interview as she discussed being able to obtain pain medication for her addiction. Her ability to get what she wanted was tied to the anonymity that the ED provided.

Int.: One of the things you said earlier was you'd say anything. You'd push, you'd get mad, because you didn't care. You just want your <u>pills</u>. How would you have reacted if somebody did stop and say, you're using a lot or how would they have helped you?

**Paula:** I *don't know*. I think about it now (2). I don't know if I <would've gotten mad>. Maybe I wasn't ready too, right?... But if somebody would've said like, (2) "You're taking 60 T3s in one day, that's a lot of fucking pills, right?" Then maybe I would've said. "Well, <u>maybe</u> it <u>is</u> a lot of pills," you know? Like, "wow", but I didn't at that time, it was just- it didn't occur to me.

**Int.:** They just pass you through kind of thing.

**Paula:** Yeah, like because it's *emergency room*. They <u>have</u> to. They have so many other things going on and I understand that too. That's why sometimes you slip by too, right? Because they have so many things going on here. Sometimes how I got my pills too was they were ><u>so</u> <u>fucking busy</u><. It was just like, "<Here take your pills and get out>," right?

In the social services net that they accessed in the broader community, the participants were identified and outed as needy. In the ED, every patient is in need without being outed as homeless. But being in a space that was public, transient, and anonymous had both benefits and a cost. Benefits included the ability to hide one's disenfranchised identity, the possibility to blend in free of judgment, and being safe from harm because of witnesses in a public place; costs included continued loneliness, the ability to hide without being known or helped, and the potential judgment from the public if they were identified.

Those few participants who spoke of having a consistent family physician, nurse practitioner or medical specialist voiced a place in the medical system where the costs of the ED were avoided. One participant, referring to this regular care, reported, "My family doctor is pretty good. I see him and talk to a diabetic nurse occasionally, like regularly. They're actually helping me and it's not like E[D]." They could be known and, through being known, could be

helped and receive the type of medical care they desired. However, participants who described interactions with medical professionals outside of the ED understood that the benefits of the ED were the costs of being known – the inability to hide their disenfranchisement and being vulnerable to judgment. As in other areas of their life, the participants believed themselves powerless to control this. Just as in the ED, the participants were at the mercy of the medical professionals who offered the help they needed.

Mental Illness Identity. The findings that have been outlined thus far were applicable whether the participants presented for physical or mental health concerns. Despite an inclusion criterion of the broader study being the presence of a diagnosable mental illness, a minority of participants mentioned seeking care for depression, anxiety or serious mental illness. For most of this minority (four out of six), they either shared a single story of seeking care for such a mental health concern or mentioned anxiety in passing. The fifth identified the ED as the place that best suited the treatment of her panic attacks. For the sixth, diagnosed with Bipolar Disorder, the city EDs were fixed places she sought shelter and assistance in periods of manic chaos. In all cases, the same discourses, dynamics and paradoxes that have been shared regarding the participants' physical health care-seeking stories permeated their mental illness care-seeking stories. In the vast majority of cases, their mental health care-seeking stories were indistinguishable from physical health care-seeking stories.

One subtle difference appeared in three of these participants' narratives. Recall that some participants shared stories where substance abuse was a notable part of their ED experience, whether seeking to obtain substances themselves or feeling fearful that, should their homelessness be revealed, they would be unjustly assumed to be seeking substances and, therefore, abusing the healthcare system. Similarly, in the case of mental health treatment-

seeking, there were times when these three participants felt as though they were judged for using the ED in this way and, again, abusing the healthcare system. What was different, however, was this identity (having a mental illness) was not conflated with their homeless status or marginalization. Consider the following from Amilia, a 53-year-old woman who self-identified as White.

**Int.:** How do you make that decision of I need to go to the ER or no I'm going to stay home? (2) When does it become time to go?

**Amilia:** (3) Um (2) I <u>know</u> there's probably been a time or two that I did go to ER when I should have went to my family doctor, but (1)

**Int.:** Like what?

**Amilia:** I don't remember what it was for, but I know I <u>should have</u> because it was like, (1) it was for a prescription but (1).

**Int.:** Why do you say you should have gone to your family doctor?

Amilia: Because I remember the ER doctor wasn't too happy with me, ((laughs)) you know, he was just like (2) it seemed like it was a waste of his time, you know what I mean? Which it was probably a waste of his time. With me I just thought it was time for me to see a doctor and I was very depressed so I just figured that was the best time for me to >go in<. I got myself out of where I was and made myself go you know (.) to see a doctor

Notice that, although Amilia references the power held by the physician and the cultural narrative of inappropriate ED use, she doesn't reference any of her other marginalized identities. Across those few participants where mental illness stories appeared, then, mentally ill identities did not appear to intersect with their homeless identities within the space of the ED.

In sum, the ED, then, is seen in multiple ways by the participants, constrained by its role as a stable, fixed point of transience in a transient life and a public, accessible extension of an impenetrable, overwhelming healthcare system.

# **Discussion**

This study sought to address the question of how people who are or were formerly homeless understand their care experiences in the ED and its role in their day-to-day lives. The findings reveal that the ED's role is multi-faceted and variable. A minority see it as a resource

for survival, with some of the participants admitting to using the ED for avoiding the cold or obtaining medications for addictions or money. On the other hand, all see it as a healthcare facility that they should be entitled to access. Regardless of the role it occupies in their narratives, discrimination and powerlessness are anticipated and incorporated into all of the participants' stories as they navigate their reasons for accessing the healthcare space. Even though stories of enacted stigma (Jacoby, 1994) were rare, complaints about the ED that are common among the general population were interpreted through presumed or felt stigma, colouring participants' understandings of the ED setting or the actions of the medical staff. Participants' lack of alternative explanations left them to conclude that the felt stigma was the driving force behind the wait, the busyness, the isolation, and other ED characteristics.

The ED also had a paradoxical part to play in participant narratives. It was a transient space that matched their transient lifestyle, yet a fixed, public, accessible space; a place where they were isolated, but belonged. And yet, this paradox was what allowed participants to believe that they could begin to exert some control over their healthcare experience. The participants couldn't change how or when they received meals or beds in homeless shelters. In other medical encounters, the physician and administrative staff had the authority to turn them away, make insensitive comments regarding the trappings of homelessness, or, as the participants hoped, provide them with the care they needed. As long as such power was used in their favour, some participants appreciated this. But, in general, most of the participants found that the ED was a place where they could exert a little more control than in the rest of their lives.

Overall, the participants understood themselves to be infiltrating a discriminatory space, watched by a system which they are not welcome in as healthcare professionals try to screen them out. Some responded by avoiding it, others by advocating for a right to use it, others by

acquiescing to those in authority in order to be allowed to stay, and still others by using the ED for their survival, hoping not to get caught. One participant came to narrate her story from the perspective of the powerful other, allying herself against her disenfranchised past. Little was said by the participants regarding their Indigenous identity, but, when it was discussed, it was conflated with derogated images of disempowerment and discrimination. Other marginalized roles were also conspicuous by their absence from the narratives. Despite occupying the intersection of other marginalized identities related to mental health, poverty, and, in some cases, gender, the homeless identity was primary in the participants' narratives.

Implications for Practice. With negative healthcare interactions being found to influence later willingness to engage in the healthcare system (Wen et al., 2007), and episodic emergency care being ill-suited to the chronic physical and mental health problems that people who are homeless often experience, healthcare providers need to be aware of how the setting, hierarchy, and overall system are perceived by those who are homeless. To those who are homeless, the healthcare encounter can be seen as one microcosm of their homeless life. The internalized master narratives of society – those of lowliness, powerlessness, hopelessness and so on – come with them into hospitals and primary care facilities. These settings are only unique in that they provide healthcare, and are likely to have an increased power differential relative to the social services they access due to the size of the healthcare system and the relative social standing of medical professionals. As a result, the felt stigma will colour how those who are homeless perceive healthcare encounters.

With this awareness in mind, professionals must communicate their acceptance of these patients' life circumstances and their deservedness of care regardless of the situations, actions, or behaviours that have brought them to be in need. Second, consideration needs to be directed to

the authority the care provider has over the patient. The participants entered the interaction with a narrative understanding of the hospital as an imposing, discriminatory place where healthcare professionals are the gatekeepers to information and access to care. The information and expertise they hold regarding the wait, medical decision-making, and logistical processes of the ED should be shared openly and transparently, translated into the worldview of all patients when possible. Health professionals should seek to empower their patients through freely disclosing why and how they do what they do (e.g., how the patient is categorized in triage, how they are prioritizing the patients in any given moment, or the availability of physicians). Further, they should seek to understand the unique perspective of the patient with whom they are interacting, tailoring their care to the patient's worldview. To do this, time will need to be spent with the patient that goes beyond assessment, diagnosis, and treatment, developing understanding and empathy for what the patient is thinking and experiencing in that moment.

Implications for Policy. Professionals' ability to adopt the above-stated stance will be influenced by the healthcare policies that currently exist. Participants understood many logistical aspects of a standard healthcare encounter at the ED to be a barrier to them receiving high-quality, non-discriminatory care, such as rules around patient registration and security. Nevertheless, the participants perceived the healthcare system to be intimidating and impenetrable. Although many members of the general population may also be unaware of how and why the ED operates the way it does (Stuart et al., 2003), the participants in the present study, representing the disenfranchised, found it threatening to their own personal power.

The participants were also clearly aware of the narrative of 'appropriate' use of the ED and resisted the idea that their use was inappropriate. Individual education and public awareness campaigns are unlikely to be effective in altering their health-seeking behaviours. In fact, any

system-driven goals aimed at reducing the ED attendance of people who are homeless, even if altruistically driven, are likely to be interpreted as imposed by a faceless system with ulterior motives. Taking the findings from this study as a jumping off point, efforts should be made to engage representatives of the homeless community in designing care that is empowering and appropriate for their needs. The participants viewed the ED as a place in the healthcare system where they could exert a small amount of their own agency. Participatory-action approaches could be implemented that recruit representatives with lived experience of homelessness to provide input systems and models of healthcare that empower them in all of the healthcare decisions and are compatible with their lifestyle and their understanding of their own needs.

**Limitations.** Although the participant diversity in age, gender, and housing history allowed for the identification of commonalities across a broad range of life backgrounds, exploring the viewpoints of various subgroups of people who are homeless would also be valuable, such as homeless youth or people who are homeless and have HIV/AIDS and/or brain injuries. Further research with other subpopulations is warranted.

Replication may also elucidate the observation in the present study that, despite occupying the intersection of multiple marginalized positions, the homeless identity was primary in the participants' narratives. It cannot be ruled out that the lack of emphasis on other identities is an artefact of the focus of the research question and subsequent approach of the writer. In my role, my approach to the interview invited the opportunity to discuss mental illness, substance use and Indigenous ethnicity in the context of their healthcare, but the primacy of the research question in my own mind may have narrowed my focus to homelessness, subsequently impacting how the participants and I co-constructed their narratives. Future projects with similar and varying subpopulations of people who are homeless could clarify if this was related to the focus

of the researcher and research question, the participants' narrative understanding of their experience, or perhaps both. Other researchers engaging in similar projects are advised to carefully word their questions and interviews to allow for other potential identities to emerge.

Additionally, the present research study limited its focus to people who were homeless who had used the ED. This allowed for a focused analysis with relevant implications for hospital EDs that would influence how participants who present to the ED are treated and how healthcare policy-makers can engage the community of people who are homeless. This focus also results in the limitation that people who are homeless who do not present to the ED may understand and narrate their perceptions of the ED differently. For example, it would seem unlikely that those who do not use the ED would view it as a stable place of transience in a transient life; it is unlikely to be a node in their stories at all. Although they may not have first-person accounts of ED stories to share, there may be findings that could inform either why such a population would avoid the ED if they needed such care or, perhaps, discover if they have found ways of navigating the healthcare system that have resulted in them finding empowering care in other places. Recruiting participants who choose not to access the ED for their healthcare could provide insight to healthcare policy-makers on how to provide adequate, empowering healthcare to people who are homeless.

Concluding Remarks. Researchers and policy makers cannot hope to facilitate the empowerment and agency of people who are homeless without a better understanding of how they understand and interpret their healthcare experiences within their storied lives. Among this sample, the participants found the healthcare system imposing and paradoxical. There were multiple motives for using the ED and multiple ways of engaging the healthcare system.

Improving health and healthcare access will need to be as complex as the patient population that

is accessing it. The findings from this study support engaging users in the development of empowering healthcare.

### **Chapter 4: General Discussion**

The final research question of the present thesis was: what implications for theory and practice emerge from a synthesis of the quantitative and qualitative inquiry into ED use among people who are homeless? The final chapter summarizes the findings from each study and then answers this question through a synthesis of the findings and a discussion of the implications for theory and future research directions.

### **Summary**

Each of the two reported studies added novel and important information to our understanding of the role of the ED in the lives of people who are homeless. The results of the longitudinal quantitative study showed that several variables predict ED utilization. These included previously established social determinants of health, including Indigenous ethnicity and high needs mental illness both predicting higher levels of ED use. Consistent with hypothesized relationships, concurrent ratings of physical health problems and substance use problems predicted higher ED use, as did pre-baseline ED utilization. Contrary to hypothesized predictions, concurrent receipt of case management and social assistance also predicted increased ED utilization. Further, contrary to the hypothesis that accessing primary care reduces ED utilization, primary care access was associated with an increased number of ED visits. Relationships between ED use and concurrent food security and past and concurrent housing stability were in predicted directions (i.e., higher levels of each predicting lower ED utilization), with housing displaying a similar effect size as substance use problems. However, the effect reliability of these variables was lower when controlling for other predictors in the model. Selfreported income and victimizations did not reliably predict ED utilization. Another notable finding from the quantitative results was a significant variance in the random intercept of the

final model, indicating that a great deal of variability in participant ED utilization remained to be explained. This conclusion is also supported by the fact that pre-baseline ED use had the largest effect size when controlling for all other concurrent and baseline predictors.

The qualitative investigation found, as previous studies had before it (Hodgetts, Radley, Chamberlain, & Hodgetts, 2007; Persaud, McIntyre, & Milaney, 2010) that the participants had internalized the conservative master narrative (Krumer-Nevo & Benjamin, 2010), that homelessness was a personal or moral failing which had put them in a position of lowliness, rejected and outcast by society. This was simultaneously counter-narrated as a drift into homelessness that was beyond their control, powerless to influence the trajectory of their lives. These narrative elements, common in the findings of previous research, framed their understanding of the ED. Experiences that are ubiquitous to all who enter the ED (e.g., the wait, interactions with healthcare professionals, lack of control, and so forth; Gordon, Sheppard, & Anaf, 2010) were interpreted through the lens of their social position and the cultural narratives that come with it. They waited longer because they were homeless, they perceived felt discrimination (Jacoby, 1994) because of their homelessness, and were at risk of being exposed as homeless. They believed their presence to be unwelcome, with healthcare professionals on the look-out for abusers of healthcare services and the participants afraid that they would be accused of such if their homelessness was exposed. Although these findings overlap with the frequently cited study by Wen, Hudak, and Hwang (2007), who found that welcomeness and unwelcomeness in healthcare interactions had a profound influence on willingness to seek later care, participants' use of ED services is not only influenced by the one-on-one interactions they engage in during their ED visit. The qualitative study showed that participants will then interpret the encounter through their homeless identity. Even though participants may avoid the ED

because of interactions that made them feel discriminated against and 'unwelcome', use of the ED is framed by a broader context of societal power dynamics and social discourses of homelessness. The meaning-making process influences every aspect of the visit, including noninteractive components such as the wait to see a physician. Participants narrated different approaches to handling their powerlessness in the ED that went beyond avoiding care because of unwelcomeness. Although some avoided the ED, others yielded to perceived authority, others individually resisting perceived impositions – such as providing an address or waiting for a physician to discharge them – and others advocating to the researcher their right to belong and receive the healthcare they believed themselves entitled to. Whether they believed they belonged or not, the ED, because of its unique characteristics (e.g., open 24 hours a day, available to the public, occasionally crowded, etc.), was one of very few public places, much less healthcare spaces, that they thought themselves able to enter. The characteristics of the ED allowed them greater personal agency than other healthcare or social services organizations that they could access and gave them room to exert power to access the health services they needed in their illness or injury.

#### **Synthesis**

Each study provides a distinctive, but complementary, perspective on the use of the ED by people who are homeless. In the quantitative study, the primary finding was that ED attendance was driven by health-related concerns. Concurrent physician visits and ratings of physical health, in addition to the highly colinear baseline chronic medical conditions, had the largest effect sizes, next to the number of ED visits over the previous two years and concurrent receipt of social assistance. This is consistent with the self-reported stories of the participants from the qualitative investigation. Participants' ED narratives most often centered around illness

and injury, rather than stereotypical abuses of the healthcare system such as substance use or using the facility and system to stay warm or survive. Participants were clearly aware of such discriminatory societal discourse as they narrated and counter-narrated their ED stories. The concurrent findings of the quantitative study challenge claims that the participants were engaged in the practice of "fictive storytelling" (Snow & Anderson, 1987) – an identity-work practice observed among people who are homeless such that there were "narrative contradictions" in their stories that resulted in "embellishment of the past and present [and/or] fantasizing about the future" (p.1359). Rather, taken together, the findings of the quantitative study corroborate the narratives of the participants that, in the majority of cases, they used the ED for health-related concerns. This is consistent with the repeated observation from previous research that people who are homeless have poorer physical and mental health (Fazel, Khosla, Doll & Gedes, 2008; Kuhn & Culhane, 1998; Hwang, 2001; Hwang, Wilkins, Tjepkema, O'Campo, & Dunn, 2009), and provides further support for the position which advocates that people who are homeless do not misuse the healthcare system but, instead, use it for legitimate health concerns (Doran, 2016).

With that said, the two studies identified that substance abuse was a contributing factor to participants using the ED. As observed in the qualitative project, a small subset of the participants reacted to the power dynamics of the ED by using the ED as a place to exert power, obtaining medications to either use or sell. The remainder of the participants were, at minimum, subtly aware of this in the way they counter-narrated their approach to the ED (e.g., being a good patient, a subject of unjust discrimination). The quantitative study found a reliable association between substance use problems and attendance at the ED, with higher visits being predicted by higher levels of substance use problems. This effect size was smaller than the measures of physical health, but higher and/or more reliable than measures of housing stability, food security,

or victimization. What is not clear, however, is the actual prevalence of using the ED for facilitating substance abuse. It is plausible that participants who attended the ED with higher substance use problems did so due to health crises related to abuse of a substance (e.g., overdose, acute illness), due to acute concerns associated with chronic abuse of substances, or due to being brought in under the influence of substances. This was not differentiated in the study and may have raised the effect size. It should not be assumed that this finding only represents abuses of the healthcare system. The prevalence of using the ED for facilitating substance use cannot be inferred from the combined research findings.

In contrast to the consistent finding that substance use played a role ED care for the participants, the importance of ratings and stories of mental health and illness as potential influencers of ED care among people who are homeless was variable. In the quantitative study, mixed findings emerged. High-needs mental illness predicted ED use over the course of the study, but the effect size of self-report ratings of mental illness was relatively small and unreliable when compared to the other time-varying covariates. The same is true for the number of diagnosable mental health conditions when compared to other baseline covariates. Two factors may contribute to this observation. First, self-report ratings of mental health were entered while controlling for high needs mental illness. Second, the inclusion criteria of a diagnosable mental health condition may have limited the variability of the sample and, by extension, decreased the power of the study to find an effect of self-report mental health ratings in ED careseeking behaviours. In contrast, the qualitative study found that participants' mentally ill identities did not appear to intersect with other marginalized identities in their stories of careseeking for mental health concerns. The narratives of the participants support the conclusion that the presence of mental illness among people who are homeless is of lesser relative importance

than the cultural pressure of other marginalized identities or stereotypes (e.g., homeless, substance user, etc.). However, it seems reasonable to expect that the inclusion criteria of a diagnosable mental illness in the qualitative study would be more likely to facilitate its emergence as a notable influence on the participants' narratives. Taken together, these findings imply that increased ED access is more highly related to health-related variables, over housing status. This hypothesis is supported by the finding that housing status was not a significant predictor of ED use when controlling for ratings of physical and mental health.

Another consistent finding across both studies was in the variability each contained regarding ED use. The largest predictor of ED visits over the two-year period encompassed by the quantitative investigation was rate of ED use over the two years prior. Further, the random intercept remained significant after controlling for the plethora of factors from the Behavioural Model for Vulnerable Populations that were included. Each of these statistical findings indicate that baseline variability in ED use was not fully explained. The qualitative findings reflect this result in that there were varying ways in which participants understood the role of the ED in their healthcare and daily lives. Some saw it as a place to avoid, others as a place where they could exert control over their healthcare and their lives (for a small minority, this included stereotypical abuses of emergency care), and others still saw it as a place they belonged. The combined findings inform us that people who are homeless have varying reasons for using the ED. It is possible that the varying ways of understanding the role of the ED may account for some of the unexplained variance in the quantitative investigation.

One contributing influence that was not directly measured in the quantitative study may be related to participants' locus of control. Nickasch and Marnocha (2009) conducted semi-structured interviews with nine people who were homeless at the time of the interview and asked

them about their healthcare experiences and barriers to good health. Using a grounded theory methodology, they found that the participants discussed unmet physical needs, lack of affordable healthcare and resources, and uncompassionate care from healthcare providers were all related to an overarching belief that life circumstances were beyond their control. Chambers and colleagues (2013) conducted an analysis of self-report and administrative health data among 1165 Canadian people who were homeless and found frequent ED users were more likely to have a higher level of perceived external health locus of control.

The present qualitative study observed that the participants' narratives often referenced power dynamics within the healthcare system, with such dynamics set within the context of the social services agencies that either serve those who are homeless or frame the culture within which homelessness occurs (e.g., soup kitchens, shelters, case managers, housing supports, and so on). It may be reasonable to hypothesize a connection between the participants' sense of their own power and agency and their tendency to access the ED and various types of social services, such as case management or social assistance. That is, a high external locus of control – and concomitantly low belief in one's own personal agency – may drive the tendency to access case management services, social assistance, and emergency medical services. This may account for the observation that accessing case management services and months on social assistance predicted higher ED use. It is possible that those who rely on social assistance for longer, or who seek case management services, see themselves as less able to influence their own circumstances directly and effectively. Individuals with a lower locus of control, then, may also be more likely to access transient forms of healthcare, such as the ED. Just as the participants in the qualitative study saw the ED as one of the few places in the healthcare system where they could exercise what power they had, they may view case management services and social assistance in a similar

way. Such formulations are tentative and speculative, as the quantitative measures also capture other elements. It has already been observed, for instance, that the social assistance variable may incorporate a measure of physical and/or mental health in that disability in either area can facilitate access to long-term receipt of social assistance in the province of Manitoba. It is also possible, however, that locus of control may predict a tendency towards accessing healthcare services in general. The quantitative study found that accessing the ED was predicted by primary care visits, in addition to accessing social assistance and – to a lesser extent – case management visits. Such findings may indicate an type of individual who is more inclined to access public supports systems in general, potentially resulting from an external locus of control. In any case, further evaluation of the role of locus of control is warranted, particularly with purer measures of locus of control.

Finally, the specific role of homelessness and housing stability can be commented on by the present research, though firm conclusions cannot be made. Based on the qualitative findings, homelessness framed narratives of powerlessness and transience. This powerlessness was approached in different ways, but many participants – apart from a small minority who had connected with specialist health providers or a general practitioner – saw the ED as a place where their powerlessness was ameliorated by such things as public witness (i.e., safety from harm), public access (i.e., a space that everyone should be free to use), and a certain degree of anonymity that being in a public space permitted (i.e., the ability to hide their homeless status and reduce the likelihood of related discrimination). According to the quantitative study, transitioning into stable housing had a smaller, less reliable effect on ED utilization, though in the expected direction of decreasing ED visits. Ongoing interpretations of their own powerlessness may explain why this finding was not as reliable as predicted, as participants

continued to occupy disempowered positions, living in poverty and relying on housing support services to obtain shelter. However, there remain a variety of competing explanations, not the least of which include continued chronic mental health conditions and the ongoing presence of other social determinants of health post-housing, such as high needs mental illness and Indigenous ethnicity.

## **Implications for Theory**

The findings from the combined research findings have implications for the leading theory of health behaviours among vulnerable populations. Previous research into the Behavioural Model (Gelberg Andersen, & Leake, 2000), as it applies to people who are homeless, has found that increased housing stability and food security are related to lower ED visits (Parashar et al., 2014; Kushel, Gupta, Gee, & Haas, 2006), along with gender, such that females are more likely to use hospital services (Chambers et al., 2013; Linton & Shafer, 2014). Among a sample of low-income female heads of household, both housed and homeless, those with higher ED use had lower scores across measures of social, physical and mental functioning, and had more comorbid health conditions at baseline and follow-up assessments (Weinreb, Perloff, Goldberg, Lessard, & Hosmer, 2006). Similar findings were also obtained in a study of non-sheltered homeless individuals (Linton & Shafer, 2014). Much of the research, however, has occurred in the US context, where the availability of health insurance, an enabling factor, consistently predicts higher numbers of ED visits (Linton & Shafer, 2014; Kushel, Perry, Bangsberg, Clark, & Moss, 2002).

In the context of universal health insurance, Chambers and colleagues (2013) found that the most reliable predictors of higher ED use, when entered into a multivariate model with other hypothesized predictors, included being a single female, presence of a past month drug problem,

being a current smoker, birth in Canada, unmet mental health needs, and lower self-report ratings of physical health. When differentiating between frequent users and non-frequent users of ED services, these researchers also found that higher ratings of perceived external control from powerful others predicted greater likelihood of being categorized as a frequent user of ED services, as did lower levels of monthly income.

The findings from the quantitative study, with a different design and study population, provided a replication of some of these findings. This included the influence of self-report physical health ratings, concurrent drug use, and high needs mental health concerns. As well, both studies found that homelessness history, housing stability and food security did not yield as reliable an effect (or any effect at all in the study by Chambers et al., 2013), as would be anticipated by the Behavioural Model. Some findings were not consistent, including the present study finding that Indigenous ethnicity continued to make a unique contribution in multivariate analyses, while lower income and being female did not. The qualitative study findings provide indirect support for the finding by Chambers and colleagues that participant views of external power influence ED use.

When considering the two studies in tandem, one of the implications for the Behavioural Model for Vulnerable Populations is that, certainly within the Canadian context of universal health insurance, the various predisposing, enabling and need factors exert a different magnitude of effect on subsequent health behaviours. For instance, the enabling factors of competing needs (e.g., shelter, food security) do not appear to have as great an effect on tendency to access the ED as the need factors, and do not appear to be as reliable as the predisposing factors of ethnicity, high needs mental illness and substance abuse. When considering that the ED is intended to be a facility for emergent care – that is, life-threatening illness or injury – and that patients who are

homeless understand it as such, this makes sense. The findings from the present research lead one to conclude that people who are homeless use the ED for reasons that are consistent with the overall purpose of EDs. This would mean that certain variables in the model are less pertinent to understanding how people who are homeless choose to use the ED.

Not only do different factors carry a different influence on ED use, there does not appear to be reason to believe that the weighted importance of factors should remain consistent across contexts, or, perhaps, even within a single sample. This is reflected in the variability observed within the present qualitative and quantitative studies and their differences in findings compared to the other Canadian study. This does not imply that the theoretical model needs revision.

Instead, researchers should use it thoughtfully, being mindfully aware of the plethora of health-related behaviours that can be investigated under its scope. It is a broad tool that covers a wide range of human behavior. Not all factors in the model need be related to all potential health behaviours. Researchers should give careful to consideration to the hypotheses of their research, rather than include variables simply based on their notation in the Behavioural Model of Vulnerable Populations; in other words, one should have a logical rationale for why any predisposing, enabling or need factor should be meaningfully connected to the health behaviour or outcome in question.

Although the relative weighting may vary based on context, population and so on, the model's predicted directional influence of enabling factors affecting need factors, thereby predicting health behaviours, may be supported by the present study. By way of a specific example, consider the relationship between housing (an enabling factor), evaluated mental health (a need factor) and visiting the ED (a health behaviour). As mentioned previously, the concurrent findings of the quantitative and qualitative projects in this thesis, along with the

findings from Chambers and colleagues (2013), suggest that increased ED use among people who are homeless is primarily related to health variables, including high needs mental health, to a far greater extent than housing status. Hwang and colleagues (2013) found that, when compared to low-income controls matched on age and gender, participants who were homeless used the healthcare system, including the ED, at much higher rates. However, the participants who were homeless had a significantly higher number of participants with chronic physical health conditions and mental health problems. Taken together, these three quantitative analyses, conducted in the context of universal health insurance, may suggest that the previously observed relationship between homelessness and higher rates of ED use is mediated by the presence of ill-health. This would be consistent with the directional nature of the Behavioral Model.

Finally, the role of health beliefs in the Behavioural Model is supported by the present research. Varying health beliefs were observed across the participants in the qualitative study, influencing how they understood their engagement with ED services. For example, participants who feared the ED in their narratives indicated they were less likely to use it. This is similar to the finding by Wen, Hudak and Hwang (2007) that unwelcomeness in past healthcare encounters deterred future engagement in health services. As well, similar to the Chambers and colleagues (2013) study, perceptions of power, control and agency also appear to affect how the ED is used. The present research also underscores that participants were aware of a master narrative of ED use that said there are appropriate and inappropriate ways to use the ED. Taken together, health beliefs – though a single, seemingly diminutive characteristic of the model – is worthy of expansion and further inquiry.

### **Indigenous Health and Homelessness**

As mentioned, the results from the quantitative analysis of longitudinal self-report and administrative data found that Indigenous ethnicity continued to reliably predict increased ED use in this sample. This means that, given equally poor health, substance use concerns, social services use, and so on, people of Indigenous descent who are homeless are more likely to use the ED. The reasons for this are not entirely certain. The findings are inconsistent with the study from Chambers and colleagues (2013), which found that Indigenous ethnicity predicted any ED use over other ED use, but not when controlling for other variables. Indigenous ethnicity also did not differentiate ED users from frequent users in their study. It is possible that the Chambers study lacked the statistical power to find an effect of Indigenous ancestry, with only 9% of their sample being of Indigenous descent compared to 71% of the current sample. Another possibility is the differing contexts of the two studies. Although both took place in the context of universal, Canadian health insurance, Winnipeg has the highest concentration of Indigenous peoples in Canada per capita. Indigenous people's relative social disadvantage may be more in public awareness as a result, increasing the pressure of negative social discourses regarding homelessness and Indigenous ancestry. The narrative practices observed in the qualitative study (e.g., the ED being a public place that reduces powerlessness relative to other health and social services) may contribute to a greater likelihood of accessing the ED for healthcare.

Relative disadvantage has been observed in previous research on stigma towards

Indigenous peoples in the healthcare system (Benoit Carroll, & Chaudry, 2003; Levin & Herbert,
2004), which has also found that there is a related avoidance of preventative health services

(Kurtz, Nyberg, Van Den Tillart, Mills, & OUAHRC, 2008). Such avoidance could result in
increased reliance on emergency services as preventative care is not pursued and health

complications arise to an acute level of need. On the other hand, research experts are divided on the importance of traditional forms of healing for Canada's indigenous people (Patrick, 2014). On the one hand, some advocate for incorporating Indigenous healing practices as a crucial component of 'culturally relevant' treatment, even to the point of advocating that health access must look beyond changes within currently available services to changing how services are provided altogether (Van Herk, Smith, & Gold, 2012). On the other hand, some lobby that non-Indigenous approaches still have an important role to play, arguing that "...there is no singular Indigenous experience, and that many Indigenous patients find current biomedical services and approaches to be 'culturally appropriate' and preferable to so-called traditional services" (Waldram, Herring, & Young, 2006, p. 296). This latter point – that culturally appropriate care is relative due to the absence of a singular Indigenous experience – can be observed both across and within individuals. For example, in a qualitative investigation involving Indigenous women with a history of heart problems (Medved, Brockmeier, Morach, & Chartier-Courchene, 2013), participants readily affirmed the use of pharmaceuticals for managing their heart health, despite behavioural 'heart healthy' practices being perceived, "as an assault on their autonomy and, more than that, as a part of an ongoing colonial process" (p. 1620). The authors also noted that the participants expressed limited desire for access to traditional healing alternatives.

The results from the qualitative study, unfortunately, do not provide a great deal of data that lends itself to firm conclusions in this regard. The participants rarely spoke of race as it pertained to the healthcare system; if they did, it was usually in response to direct questioning, with most participants saying that they found it made little difference. One participant noted having a positive experience with an Indigenous service provider, but made little reference otherwise. Overall, however, there were no notable differences between the narratives of the 14

participants who made a declaration of Indigenous ancestry and the 2 who did not. As mentioned in Chapter 3, the infrequent times Indigenous ethnicity was spoken of it was in the context of conflation with homelessness and substance abuse. Racism, in this sense, was present but subtle in that it was primarily in derogated association with disempowered identities, occasionally self-directed by someone who identified as Native, Aboriginal or by a specific First Nations band. It is possible that it wasn't discussed because of my identity, as the interviewer, as a white settler, in that the participants were reticent to complain of racism in colonial healthcare to an audience they interpreted to embody colonialism; however, there was very little evidence of othering language along ethnic lines in the interviews. It could also be that the participants did not have any concerns with accessing westernized medicine. The sample could be selfselecting because the inclusion criteria required that participants must have visited the ED on at least one occasion. People who are homeless and Indigenous who do not access the ED at all may have differing narrative constructions of what it means to access an ED, some of which may incorporate considerations related to racism and ethnicity, as other researchers have observed among Indigenous participants across a variety of healthcare settings (e.g., Benoit Carroll, & Chaudry, 2003; Browne et al., 2011; Levin & Herbert, 2004; Kurtz et al., 2008; Van Herk, Smith, & Gold, 2012). However, among those in the sample of At Home/Chez Soi participants who self-identified as being of Indigenous ancestry, fewer than 10% failed to access the ED over the two-year follow-up. If narratives that include elements of racism and ethnicity are prevalent among those who don't access the ED, it may represent a small minority of those Indigenous peoples who are homeless.

It may also be that the absence of the narratives of Indigenous ancestry is what is most notable. When considered in the context of synthesizing the quantitative and qualitative studies,

the quantitative findings indicate Indigenous ethnicity is a contributing factor to increased ED utilization, but it was almost unmentioned in the semi-structured interviews of the qualitative study. As noted, most narratives mentioning Indigenous identity conflated it with substance abuse, homelessness or abusing the healthcare system. Perhaps the participants didn't demonstrate much identity work regarding their ethnic identity because it was so closely associated with their homeless identity. Because one can be Indigenous and not homeless, and thereby have a relatively higher level of social power, the participants did not need to discuss Indigenous ethnicity in the context of discussions of the ED. However, in Winnipeg, it is far more infrequent that one would be homeless but not Indigenous. When the two are equated, it is of no narrative purpose to discuss the higher status perspective of Indigenous and non-homeless when one occupies the lower position in the dichotomy: Indigenous and homeless. When faced with the power dynamics in the healthcare system and, specifically, the ED, the identity work is in the powerless position of homeless. Such suggestions, however, are merely speculation. It would be useful to pursue this topic in other samples of Indigenous people who are homeless to clarify which of the proffered suggestions, if not other possible hypotheses, account for the relative lack of narrative work regarding Indigenous self-identity in the ED.

#### **Future Research Directions**

In addition to further qualitative inquiry into the experience of Indigenous peoples who are homeless in the ED, there are potentially beneficial avenues of future research. The present qualitative study, in addition to the cursory findings from Chambers and colleagues (2013), suggests that beliefs related to power and locus of control may be health beliefs worth further exploration in understanding how people who are homeless choose to use health services. Hypotheses in line with the conservative master-narrative of personal responsibility (Krumer-

Nevo & Benjamin, 2010) would be that an external locus of control leads to increased health services utilization. Hypotheses that account for the counter-narratives of poverty would consider the context (e.g., structure of healthcare, increased burden of illness) and agency of participants within that context. For example, understandings of external power and agency may mediate or moderate the relationship between ill-health and treatment-seeking behaviours.

Beyond power, other specific beliefs regarding specific health conditions or relationships with healthcare providers may also be important avenues of investigation. For example, those few participants in the qualitative study who had connected with a consistent health specialist or primary practitioner had found a safer place in the healthcare system. Qualitative inquiry would be well-suited to exploring how participants form these relationships and what characteristics of the relationship are important to people who are homeless.

Research into health beliefs is not the only area in which further study is warranted. The quantitative results showed a high degree of variability in ED usage patterns across participants. The qualitative study echoed this finding, observing that participants tended to fall into different groupings on how they saw themselves responding to the power dynamics in the ED. As suggested when discussing the quantitative analysis, projects utilizing latent class analysis may be a fruitful course of study to help identify different clusters of ED use patterns, identifying appropriately tailored ways to help participants achieve better health. The reader is encouraged to review the recommendations for further research in the respective investigations, including replication of findings from both studies in other subgroups of people who are homeless, and, due to the high chronicity of homelessness in the samples, conducting investigations with longer baseline and follow-up windows. Beyond the quantitative study, a longitudinal program of qualitative inquiry could also help to identify changes in participant understandings over time.

This could help researchers and policy makers identify which aspects of the participants' life experiences had the greatest influence on their understanding of their healthcare needs.

Based on the high degree of homelessness chronicity in the sample, one of the recommendations coming out of the quantitative study was an emphasis on the importance of early intervention and prevention of homelessness. As mentioned previously, the present research program was not able to conclusively comment on the role of housing in altering views of the ED or changing behaviour related to ED utilization. In part, this is likely because the present research findings support the view that participants use the ED because of health-related concerns rather than because of lifestyle factors associated with homelessness. However, further insight may be gained if participants are followed over longer periods of stability or if the research is conducted in the context of early intervention or prevention.

Regarding mental illness, when triangulating the findings from the two current research studies with the findings of two previous research projects (Chambers et al., 2013; Hwang et al., 2013), the present project hypothesized that mental illness (along with physical illness), may mediate the previously observed relationship between homelessness and ED use. That is, homelessness worsens health, thereby increasing use of the ED. One of the implications of this hypothesis has been the presentation of the findings of the enclosed research studies as more broadly generalized to the population of people who are homeless, despite the inclusion criterion of a diagnosable mental illness. This was done because the role of mental illness did not emerge as a significant contributor to ED care in the qualitative study, and only appeared to be a significant factor for participants with high-needs mental illness in the quantitative analysis. As such, it seems reasonable to posit that the conclusions drawn regarding ED care among people who are homeless with moderate-needs mental illness would hold in the absence of such a

diagnosis. Concerning high needs mental illness, there is still the matter that having a mental illness did not appear to influence homeless identity work in ED stories. Future research could aim to support the generalizability of the present findings, and the approach to their presentation, through recruiting samples of participants who are homeless both with and without a diagnosable mental illness and directly comparing their rates and experiences of ED use.

Finally, replication of these studies in other contexts and with other samples is warranted. In addition to the inclusion criterion of the presence of a diagnosable mental illness, the transferability of these findings may be limited due to such factors as the high representation of Indigenous peoples in both the quantitative and qualitative projects – and related context of Winnipeg, which has more Indigenous peoples, per capita, in both the general population and population of people who are homeless – and the context of universal health insurance. Although both of these factors are strengths of the studies given the relative lack of emphasis of each in the literature, future research should confirm the transferability of the findings to other settings and populations. Further, the findings of each project have been used to infer information regarding people who are homeless with associated deductions regarding differences between the sample and the general population. Future research could replicate these studies with suitable comparison groups to confirm if these inferences hold. For example, quantitative research could compare ED use of members of a sample of people who are homeless with a control group matched on gender, age, geographic location, community poverty level and so on to see if the inference that physical illness drives health service use is warranted. Regarding the qualitative study, it may be worth replicating with a sample of participants recruited from homeless shelters or ensuring the inclusion of participants who have not used the ED to see if the present findings are generalizable to other samples or are an artefact of the sampling method.

#### **Homelessness Intervention**

The combined research project outlined in this thesis also has implications for service provision for people who are homeless. The finding that physical health is a primary driver of ED usage implies that homelessness service teams (e.g., Housing First teams, shelters, etc.) should seek to improve the physical health of their patrons. Reflecting on the At Home/Chez Soi project in Canada, ACT and ICM service teams both provided case management to the participants, and the ACT team also provided psychiatric follow-up care. The physical health needs of this population are still high and would benefit from targeted support and intervention. Housing First teams, and other service providers to people who are homeless, should incorporate physical health services into their service models. This could include access to a family physician, as well as other physical health therapists (e.g., physiotherapy, occupational therapy, etc.). The finding from the qualitative study that participants are in need of empowering care may be ideally met through the Housing First teams; that is, those participants who had been assigned to the Housing First condition tended to view the service teams as empowering places already and bringing healthcare into such a setting may extend this empowerment to the perceptions they hold of physical healthcare.

Providing case managers with an in-house option for referring their clients for medical care needs may ameliorate the finding from the quantitative study that the receipt of case management services increased ED visits among the participants in the At Home/Chez Soi Winnipeg site. In a qualitative study of frequent users of the ED, Wise-Harris and colleagues (2016) found that participants often felt as though professionals in their life were encouraging them to go to the ED, even if they themselves hadn't thought that it was necessary at the time. Although this did not arise in the data of the enclosed qualitative study, this may help account for

the findings in the quantitative analysis. If case managers feel they have a viable, familiar physical health service for their participants they may be inclined to refer the participants there rather than the ED.

Turning to early intervention and prevention, intervention studies may help to forestall the increased burden of physical and mental illness that people who are homeless develop and which puts them in greater need of health services. Unfortunately, homelessness prevention is in its infancy at this time, in large part because of the broad diversity of pathways into homelessness and the composition of the population of people who are homeless (Henwood et al., 2015). As O'Connell (2004) observes, "The often-romanticized hobos and skid-row denizens of past lore have been joined by families with children, run-away and "throwaway" adolescents, struggling minimum-wage workers and fragile elderly people" (p. 1251). Pathways into homelessness, then, are complex, influenced by social determinants of health and aspects of public policy, such as regarding the availability of affordable housing, a satisfactory living wage, disability benefits and so on (Henwood et al., 2015). A potentially promising start point for prevention research could include evaluating health-care utilization before, during, and after Critical Time Intervention (CTI; Herman et al., 2011), a case-management-based transitional intervention that aims to intentionally connect clients and families at risk of homelessness with ongoing community support services with the hopes of extending the intervention time horizon beyond the discontinuation of CTI. Broader population-based research with groups at-risk of homelessness (e.g., youth in foster care) may also help in identifying preventative solutions for reducing the need for health service utilization.

### **Chapter 5: Reflections and Conclusion**

The death of Mr. Brian Sinclair and the subsequent publicity have had a lasting impact on the local conversations and mythos surrounding Winnipeg EDs. This was no different from the participants in the qualitative study, who repeatedly referenced the tragedy. He appears on the narrative tapestry as an icon of their powerlessness and vulnerability in the healthcare system. This thesis is submitted in the sunset of the 10<sup>th</sup> anniversary of his death. A decade later, they adopted his story as a representation of their story. A decade feels like a substantial portion of time, one where at least the beginning of change should have been allowed to take place, even in the ponderously slow movement of bureaucracies and systems that govern such change.

Some change has been suggested, and some has even been made. The final report of the inquest into Mr. Sinclair's death made 63 recommendations for improving care to vulnerable populations (Preston, 2014). A handful of the participants also noted the procedural changes made in the ED where Mr. Sinclair died, presumably for their benefit. One, for example, complained about the wristband system that has since been put in place to track patients. As observed in the qualitative study, the participants understood themselves to be observed and screened based on their disenfranchised status. The new systems and changes in place have only exacerbated that for him.

#### **Personal Reflections**

In light of the research I conducted for this dissertation, the way changes are currently being made in our healthcare system is my biggest concern: people in positions of power and influence altering the system in ways that they think are best for a community of people to which they do not belong. The inquest report, for example, did not interview a single person who was homeless, yet mentioned homelessness and medical professionals who frequently work with

them on multiple occasions (Preston, 2014). And yet, the recommendations made were not condemning or harsh towards people in vulnerable positions and appeared to be aimed at trying to ensure that vulnerable people in our healthcare system would be less vulnerable than when they entered. In fact, I am convinced that the professionals, administrators and decision-makers in the process are intelligent, well-meaning, kind, compassionate, nonjudgmental people. That we have such wonderful people in power, however, is a necessary but not sufficient condition to implementing change that empowers the people we set out to help. Compassion and sympathy will only carry us so far along the journey towards helping without hurting.

When I undertook this research project, I did so with such motivations. I had compassion for people in poverty and had a strong desire to use my training to help implement change, birthed through exposure I had had to previous research on the social determinants of health from some of my other courses and graduate education. I began the projects with a combination of enthusiastic interest and pragmatic determination, writing proposals, completing ethics applications, recruiting participants, and beginning statistical analyses. I then started interviewing the 16 people who you have heard from in these pages, followed by months studying what they had said to me. I didn't realise it at the time, but it was these stories that impacted me the most in this research. I knew *about* how economic inequality and relative deprivation disempowered and compromised the health of the community, particularly those in the lower echelons. I knew *about* how people who were homeless came to understand their world because of the social and material worlds they occupy. I knew *about* how an emancipatory approach should seek to empower the populations it recruits for study. But those interviews made it real, putting a face, story and soul to their stories.

The interviews exposed me to a tension that I will carry with me as I move into the next phase of my personal and professional life, continuing to implement change and help people in disenfranchised social positions. On the one side of the tension, I learned that the people I interviewed are just like me. They have dreams, desires, pains, imperfections, flaws, and strengths. They live their lives in the best way that they know how, making meaning out of the experiences and circumstances life throws their way. In their healthcare stories they hate the wait at the ED (like me), resent judgmental providers (like me), and want compassionate, respectful care (like me). And they deserve it, just like me. On the other side of the tension, they are very different from me. The cares and stresses they experience eclipse my own. I have no idea what it means to stand in the soup line or freeze in a parkade stairwell. I will never know what it is like to enter an ED and fear judgment simply because of where I live. It never would have crossed my mind before I met them. I am both ashamed of that, and simultaneously resigned to the fact that I can't change the experiences I've had that have made me who I am.

But what I can change is the experiences and people I expose myself to. Getting to know the participants and their stories, even though I cannot fully internalize and comprehend their stories the way they do, changed how I understood the way society views homelessness. It changed how I see the provision of their care. As I enter my own career in healthcare, as I acquire more and more power to implement changes in systems in which I provide services to disenfranchised populations and communities, I have learned that I need to include them in the process. There is nothing wrong with having ideas. There is nothing wrong with using the strengths and abilities I have been blessed with for the benefit of those who are disempowered. It is about how I use these ideas and abilities. If I truly want to help without hurting, I must try to enter the world of the people I wish to help and include them in the process. To have their

story infiltrate my own, instead of only expecting that my story should infiltrate theirs. They must be a part of building the systems and processes that are for their benefit.

It is the tension between the two poles that create the necessary and sufficient conditions for helping without hurting. We are alike, but different. Our worlds are divergent, yet the same. Holding both helps us to develop the compassion required to help, while simultaneously including them in the process because we realize both that we cannot know how they experience whatever changes are introduced and that we would want the same level of control over our own lives. These are the changes that are needed in our healthcare system. There is nothing wrong with inquests, recommendations, and expert opinion. There is nothing wrong with statistical analyses of administrative data. There is nothing wrong with academics in ivory towers defending their dissertations and peer-reviewing research. But it is so terribly wrong to take all of that and impose it on those who already feel as though they have no power at all.

I believe the reason that this is wrong is because it results in the perpetuation of the myth of the other. It will only continue to reinforce the conservative master narrative (Krumer-Nevo & Benjamin, 2010) that disenfranchises the powerless. Stereotypes of homelessness will continue to infiltrate the ED and compromise the care they receive. The lesson that I have learned through this project is I cannot hope to help the powerless only by using my power for them. I also have to give up my power to them so that they may use it to change the story. As I share this, I do not mean to reach for the speck in my brother's eye while I ignore the log in my own – that is, I do not intend to criticize the decision-makers in the healthcare system while ignoring the fact that my receipt of a doctorate stands on the shoulders of the wonderful men and women who graciously shared their stories with me. As I close this thesis, the lesson troubles me. I can only hope that I have conducted the research in a way that I gave them power to share

their stories. That I communicated the findings in a way that did not further separate 'them' from 'us' but, instead, narrowed the distance between the audience and the participants.

It is with hesitancy and humility that I imagine what a better ED experience would look like. In retrospect, it is a question I wish I would have asked the participants. I share my thoughts under the condition that the audience does not take it as prescriptive, but as a contribution or starting point to an ongoing discussion with people who are homeless and have been recruited to help heal our healthcare system.

This is what I imagine. I imagine an ED filled with professionals who remember that the people that enter are looking for warmth and friendliness, not only medical treatment. The staff would try and view the patient as the same as them and yet different in perspective and experience. As a result, they would view them with inherent worth while simultaneously holding in mind that the patients who are homeless do not understand the ED the same way they, as staff, do. The staff would by mindful that these patients don't feel welcome and would attempt to go above and beyond to communicate that they, in fact, are welcome. Attempts to push through the barrier of perspective would mean patients who are homeless would feel accepted, welcome, and like they were treated equitably by the hospital staff.

Changes in the staff-patient interaction would need to be supported by broader changes in healthcare policy. The emphasis would shift from directing people to the 'appropriate' place for their healthcare, to ensuring the patient gets the healthcare that is appropriate to their needs. The emphasis on homelessness in healthcare would change from the burden of homelessness on the healthcare system to the burden of homelessness on the health of the individual.

Changes in healthcare policy would be supported by changes to societal views on homelessness. The influence of the conservative master narrative would weaken. People who

are homeless would feel welcome in all healthcare interactions because they would never feel as though they were lesser than other people in the waiting room. They would never feel lesser than people in the waiting room because their social worth would never be tied to their address. This is what I imagine.

#### **Concluding Remarks**

It is true that a minority of people who are homeless use the healthcare system for survival and substance abuse. However, perpetuating the societal narrative that people who are homeless abuse the healthcare system is, at best, misguided. Research into input, throughput and output shows that the input factors have little to no impact on the burden of ED wait times. Pursuing answers to ED 'abuses' will solve nothing in our healthcare system. The present research has two major findings. First, people who are homeless access the ED because they are ill and in need of healthcare. Second, they also access the ED, in part, due to the power dynamics that frame their life and the healthcare system. It is a place where they have public access (exerting agency) with some believing there to be public witness (feeling safe) and public anonymity (avoiding stigma). But there is a cost. They believe that the powerful system screens for their presence, seeking out trespassers that don't belong because of their group membership; trespassers that, in actuality, do not exacerbate the wait time of anyone else attending. At worst – and what is far more likely to be the case – is any research, public policy, or media coverage that continues to story people who are homeless in a way that says they taint healthcare spaces will only serve to disempower them further. Regardless of how compassionate and wellintentioned such actions are, it will only result in harming those who, arguably, need access to quality medical care the most. As was the case with Mr. Brian Sinclair, such harm could be of the greatest kind.

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### Appendix A:

### **Qualitative Study Recruitment Letter**

Dear Participant,

I'm contacting you because you participated in the At Home/Chez Soi Housing First Demonstration project and said you would be willing to participate in related research projects. We are currently recruiting participants for a new study called, "Urban Homelessness and Emergency Department Usage: Participant Stories of Emergency Care." All participants will be given \$30 for participating in their interview, as well as tickets to cover the cost of city bus fare to the interview location.

This new study is being conducted to help understand how adults who were and are homeless choose health services, particularly emergency rooms, and what their experience has been like. That is, how do participants choose their healthcare services, why do they choose to seek care at the ER, and how do they feel about the services they receive? A total of 16 participants will be recruited for this study.

If you agree to participate, we will meet one time to hear your personal stories about your use of health services, such as what led to your need to use the ER or your interactions and experiences with healthcare providers. Examples of potential questions include: "What is it like when you visit and Emergency Department?" or "What has been a positive or negative experience in the Emergency Department? Tell me about it."

The interviews can take place at the PsycHealth building at Health Sciences Centre or at 599 Portage Ave. To facilitate the research the interview will be audio-recorded. The interview is likely to take between 60 and 90 minutes to complete.

If you would be willing to participate, please contact me by e-mail at *e-mail@address.com*, or at 204-555-0000. I will be happy to schedule your interview.

Best,

Ross McCallum, MA Principal Investigator

### Appendix B:

### **Qualitative Study Research Participant Information and Consent Form**

Title of Study: Urban Homelessness and Emergency Department Usage: Participant Stories of Emergency Care

#### **Principal Investigator:**

Ross McCallum, MA, PhD Candidate, Department of Psychology, University of Manitoba, Department of Psychology, P263 Duff Roblin Bldg, University of Manitoba, Winnipeg, MB, R3T 2N2

#### **Co-Investigators**

Maria Medved, Associate Professor, Department of Psychology, University of Manitoba, Phone: (204) 555-1234

Jitender Sareen, Professor, Department of Psychiatry and Community Health Sciences, University of Manitoba, Phone: (204) 555-5678

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

#### Why are we doing this research?

This study is being conducted to further our understanding of health service use among homeless and formerly homeless adults, particularly use of emergency rooms. We would like to know more about the perceptions of those who access them. That is, how do participants choose their healthcare services, why do they choose to seek care at the ER, and how do they feel about the services they receive? A total of 16 participants will be recruited for this study.

#### What are we asking you to do?

If you agree to participate, we will meet one time with you to share your personal stories about particular events regarding your use of health services, such as what led to your need to access the emergency department or your interactions and experiences with various healthcare providers. Examples of potential questions include: "What is it like when you visit and Emergency Department?" or "What has been a positive or negative experience in the Emergency Department? Tell me about it." The interview is likely to take between 60 and 90 minutes to complete. These interviews will be audio recorded.

In addition to the interview data, you are providing permission for the principal investigator to review the self-report interview data which you provided when you participated in the At Home/Chez Soi Housing First demonstration project between 2009 and 2013. This may include reviewing your self-reported health conditions, housing stability, food security, and other relevant information during that period of time.

#### What are the benefits and risks of participating?

All participants will get a cash honorarium of up to \$30 for their interview, proportionate to amount of the interview you complete. For example, participants who complete half of the interview will

receive \$15. As well, you will receive money to cover the cost of bus fare. In addition, your participation will help inform research, and hopefully services, aimed at improving the healthcare services received by homeless adults with mental illness.

A risk of participating is that some of the questions are personal and could make you feel uncomfortable, stressed, angry or upset. We will try to make the interview as comfortable as possible for you. You can refuse to answer any questions or end the interview at any time.

#### Costs

There is no cost to you for participating in this study.

#### **Confidentiality**

Information gathered in this research study may be published or presented in public forums; however, your name and other identifying information will not be used or revealed. Demographic information will be gathered from your former At Home records. At no time will your name, address, phone number or other personal information be associated with your health, education or social services data. This process is undertaken to ensure the highest level of privacy and confidentiality.

Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. All study documents related to you will bear only your assigned participant code. In all of the transcripts from the recorded interviews, any names used will be deleted and replaced with a pseudonym. The University of Manitoba Health Research Ethics Board may review research-related records for quality assurance purposes.

#### **Records and Recording devices**

The recorded sound files will be typed into transcripts so that your stories and explanations can be studied. The sound files will not be used for any other purpose and will be deleted/destroyed at the end of the study (August 2017). The transcripts may be stored up to seven years (August 2022).

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

We will tell you about the new information from this or other studies that may affect your health, welfare, or willingness to stay in this study.

By signing this consent form, you have not waived any of the legal rights that you have as a participant in a research study.

#### What if you want to stop participating in this research study?

Participation is completely voluntary. If, at any time during the study, you do not want to be involved, you can stop participating, but we encourage you to talk to the study staff and your regular doctor first. If you are getting supported housing, you will not lose your housing or support services even if you decide you do not want to participate in the research. The study staff may decide to take you off this study if it is in your best interest. We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

#### **Ouestions**

You are free to ask any questions that you may have about the study and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the study staff: Mr. Ross McCallum or Dr. Maria Medved (Ph: 204-555-1234), or Dr. Jitender Sareen (Ph: 204-555-5678). For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

#### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Ross McCallum and/or his study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

X		
Signature of Participant	Name (printed)	Date
X		
Signature of Interviewer & Role in the study	Name (printed)	Date
I would like to receive a sum	mary of the study results $\Box$ Ye	s   No (initial)
I would like to receive this su	mmary by the following means (c	check one):
In person. I can be co	ontacted for follow-up at the addr	ess/phone number below.
By phone. I can be c	ontacted at the phone number belo	ow.
In writing by mail/e-	mail (circle one). I can be contact	ed at the address below.
Mailing Address	Phone Number_	
	E-mail	

### ASSISTANCE WITH INFORMED CONSENT

☐ Yes ☐ No (initial)	less by having the consent form read to me.
was accurately explained to and apparently un	rmation in the Participant Information and Consent Form derstood by the participant or the participant's legally participate in this study was freely given by the participant ntative.
Witness signature	Date (day/month/year)
Witness printed name:	(day/month/year)
	ed the relevant details of this research study to the participant has understood and has knowingly given their
Printed Name:	Date (day/month/year)
Signature:	
Role in the study:	

## **Appendix C:**

### **Qualitative Study Demographic Information Form**

Participant Code #:
Age:
Gender:
Self-Identified Ethnicity:
Age of First period of Homelessness:
Longest amount of time spent homeless:
Education History:
Current Income Source:

Any other information you think is important for researchers to know:

### Appendix D:

#### **Qualitative Study Interview Protocol**

- Tell me how you became involved in the At Home project.
  - o How did you become homeless?
  - O Where do you stay now?
- How has your health been in the last year? Recently?
  - o Have there been any recent changes in your health?
- What places do you usually go to to get medical care?
  - Tell me about a time you were satisfied with your care. Tell me about a time you were unsatisfied with your care.
- How do you figure out whether you need medical care?
  - o Have there been times where others influenced this decision?
- Have you ever used the emergency room?
  - What is is like when you visit an ED?
  - o Tell me about a memorable time. What happened?
  - o What has been a positive/negative experience in the ED?
  - \*Prompts for particular stories\*
    - What lead you to use the ED? How did you choose the ED? How did you know you needed help?
    - What did you want them to do? Did you get the care you expected/wanted/needed?
    - How were the nurses/doctors? What did they tell you? How did they treat you?
    - How did you find their recommendations/prescriptions? How was discharge?
- How does the care of the ER compare to the:
  - Crisis Response Centre
  - o Crisis Stabilization Unit
  - Siloam/MSP/UGM
  - o Family Physician/Walk-in Clinic
- Tell me about a time when you were especially satisfied with your healthcare. Tell me about a time when you were especially unsatisfied with your healthcare.
  - o At a doctor's office?
  - o At the ED?
  - o Other?

- Tell me about one of your best interactions with a healthcare provider. Tell me about one of your worst.
- Has there ever been a time where you thought you needed healthcare but didn't go?
  - o What stopped you?
  - o How did you address your health concern?
- What has been the most helpful in dealing with your health?
- What people help your health the most?
  - o Medical professionals? Which ones? Tell me about them.
  - o Case managers/therapists/spiritual care? Tell me about them.
  - o Friends/family/acquaintances? Tell me about them.
- (If Indigenous)
  - Do you think your cultural background plays a role in your healthcare?
     How/Why/Why not?

# **Appendix E:**

## **Transcription Conventions**

<>	Speed up talk
><	Slow down talk
[]	Start and end of overlapping speech
(2)	Pauses in seconds (here: 2 seconds)
(.)	Micropause
(:)	Prolongation of preceding vowel
((Text))	Transcriber's comment
Underlining	Emphasis
CAPITALS	Speech that is louder than surrounding speech
subscripts	Speech that is quieter than surrounding speech
_	Utterance interrupted
Italics	Increase in pitch