A First Voice Perspective on Homelessness and End-of-life Care:

A Vicious Cycle of Deteriorating Circumstances

by

Cait Vihvelin

Submitted in partial fulfilment of the requirements

for the degree of Master of Science

at

Dalhousie University

Halifax, Nova Scotia

December 2020

TABLE OF CONTENTS

LIST OF FIGURES

ABSTRACT

Despite an increased risk of progressive illness(es) and mortality, there are limited resources available to serve the multifaceted end-of-life care (EOLC) needs for those experiencing homelessness. This population faces many barriers in accessing EOLC services due to systemic and structural injustices. Utilizing an interpretive phenomenological methodology and the theoretical lens of critical social theory, this study set out to explore *how* and *in what way*, individuals who are experiencing homelessness and living with progressive illness(es), experience EOLC. Through in-depth semi-structured interviews, the meaning that each individual gave to death and dying was uncovered and the perceived, and/or real, barriers that participants faced in accessing health/EOLC services were discussed. Resulting in themes surrounding the perception of discrimination and COVID-19 as barriers in access, late access and/or being unsure of their diagnoses/prognosis, experience of existential struggle, wishing to die at 'home' (wherever that may be), and fear of dying alone/in pain.

LIST OF ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
CAMP	Calgary Allied Mobile Palliative Program
COPD	chronic obstructive pulmonary disease
COVID-19	coronavirus disease of 2019
EOL	end-of-life
EOLC	end-of-life care
HIFIS	The Homeless Individuals and Families Information System
HIV	human immunodeficiency virus
HRM	Halifax Regional Municipality
ICU	Intensive Care Unit
PEACH	Palliative Education and Care for the Homeless
PiT	Point-in-Time
PORT	Palliative Outreach Resource Team
PTSD	post-traumatic stress disorder
REB	Research Ethics Board
TCPS 2	Tri-Council Policy Statement
TB	tuberculosis

ACKNOWLEDGEMENTS

First, I wish to thank my thesis supervisor, Dr. Lori Weeks, who immediately became my person of first contact from the very beginning of this journey. She guided me through each step and encouraged me to aim higher, believing in me and the purpose of this study. Your late-night responses and unwavering support did not go unnoticed. I would also like to thank Dr. Brenda Sabo who acted as a co-supervisor prior to her retirement from Dalhousie, for her experience, creativeness and unique ability to make one want to find their purpose. Your passion for the palliative experience strengthened my courage. To my thesis committee members, Dr Jean Hughes and Dr. Jeff Karabanow, your work with those experiencing homelessness, has been an inspiration. Jean, taking your marginalized populations course, lit a fire in me that I didn`t even know existed. Jeff, your work both locally and globally, make this world a better place. I would also like to acknowledge The Nursing Research and Development Fund, who provided financial support for this project. Next and most importantly, I would like to thank my family. To my husband Hugo, I could not have done this without your unwavering support and encouragement. Thank you for believing in me and being my rock. To my daughter, born during my thesis writing process and amidst a global pandemic. You my sweet girl are everything; my patience, my passion, my love. You will move mountains. To my parents and siblings, who pushed me to be stronger, braver and to reach for the stars. And to our heavenly sister, Carol Ann, who gave our family strength and continues to keep us safe. Lastly, and most critically, I would like to thank the participants in this study. Sharing your stories took utmost bravery. Thank you for trusting me, being kind and showing me unforgettable emotion. This project is for you.

CHAPTER I: INTRODUCTION

Homelessness is defined as "the situation of an individual or family without stable, permanent, appropriate housing, or the immediate prospect, means and ability of acquiring it. It is the result of systemic or societal barriers, a lack of affordable and appropriate housing, the individual/household's financial, mental, cognitive, behavioral or physical challenges, and/or racism and discrimination" (Canadian Observatory on Homelessness, 2017). The Canadian Observatory on Homelessness (2017) estimated that there were 1,508 individuals living in shelters, 48 living on the streets, 32 staying in non-profit organizations and 21 staying in public health systems in the Halifax Regional Municipality (HRM) as of 2015. In addition, 19,565 households in the Halifax region were considered to be living in deep housing poverty, defined as 50%+ of gross income going towards housing costs (Canadian Observatory on Homelessness, 2017). Most people do not choose to be homeless, and the experience is generally negative, unpleasant, stressful and distressing (Gaetz et al, 2012).

In much of the literature, people experiencing homelessness are often described as being on the margins of society or 'outsiders' (Burt et al., 2001; Melnitzer, 2007). Health Canada defines those living on the margins of society as having:

> An increased likelihood to experience difficulties in obtaining needed care, receive less care or a lower standard of care, experience different treatment by healthcare providers, receive treatment that does not adequately meet their needs, or be less satisfied with healthcare services than the general population (Health Canada, 2001, p. 7).

The marginalization of individuals who are experiencing homelessness, or the deficiencies in which this population is associated, go beyond the fact that this population is experiencing homelessness or are 'without shelter' (Melnitzer, 2007).

The reason behind homelessness is very individualized and therefore each individual may experience further marginalization depending on race, gender, and mental health status. People who are precariously housed experience marginalization in a very profound sense; not only are these individuals stigmatized by society, but the dehumanizing factor of isolation can lead to poor self-esteem and victimization, leading to poor health outcomes and a lost sense of dignity (Melnitzer, 2007). According to Bunds and colleagues (2015) lawmakers, law enforcers and public citizens have created a society where those who live on the margins are actually punished; the viral videos of “bum fighting” where people who are experiencing homelessness are being exploited through extreme violence, the criminalization of “begging”, “scrub downs” in San Francisco in which high pressured hoses are used to “clean” the streets where people experiencing homelessness are sleeping, and the physical removal of those appearing to be homeless from the city center are all extreme and very real examples of human discrimination and punishment (Bunds et al., 2015). By nature, structural causes of homelessness are economic and often outside the control of the individual (Burt et al. 2001). Housing policies, unemployment and wider policy developments such as the closure of psychiatric hospitals are all examples of this.

When looking at the marginalization of individuals experiencing homelessness within the context of the Canadian healthcare setting, there are few studies focused on this issue. In Canada, one Toronto-based study looked at 1,169 individuals who were experiencing homelessness and asked if their healthcare needs were being met (Khandor et al, 2011). Results indicated that 1 in 6 of these individuals who needed health care were unable to get it. Results also indicated that mothers with children who were living in shelters, youth experiencing homelessness, and people who had been victims of physical assault were more likely to have unmet health care needs. The study concluded that a lack of family physicians, lacking proof of healthcare coverage (i.e. ownership of a health card), lack of transportation, and the reluctance to seek medical care based on stigmatization or negative prior experiences are all contributing factors of unmet healthcare needs (Hwang, 2001; Khandor et al, 2011). People who are experiencing homelessness with concurrent disorders, such as mental health issues and substance abuse, are even more vulnerable given the greater barriers to healthcare services, and access to shelter, housing and food (Burt et al., 2001; Street Health, 2007). According to the Toronto based study conducted by Street Health (2007), individuals experiencing homelessness with concurrent mental health/substance misuse disorders were more likely to report higher rates of hospitalization and emergency room visits, difficulty following healthcare providers' advice and feelings of discrimination from health care providers (Street Health, 2007).

People experiencing homelessness are at an increased risk of mortality compared to the housed population. The mean age of death is between 34-47 years. In a study completed by Dr. Stephen Hwang at St. Michael`s Hospital in Toronto, Canada, it was identified that 8 out of 10 people who are precariously housed experience chronic and/or progressive health conditions (Hwang, 2011). Chronic obstructive pulmonary disease (COPD), diabetes, tuberculosis (TB), cancer, HIV/AIDS, as well as unintentional injuries, hypothermia, heatstroke, alcohol and drug overdose are of high prevalence (Canadian Observatory on Homelessness, 2017; Hwang, 2011).

Although little research has been done regarding end-of-life care (EOLC) services for individuals experiencing homelessness, research suggests that people experiencing homelessness are interested in advanced care planning as well as choosing where they want to die (Canadian Observatory on Homelessness, 2017; Song et al., 2007). Palliative care services are underused among this population and many obstacles exist for accessing these services (Davis-Berman, 2016; Webb et al., 2017). Furthermore, healthcare providers are inexperienced when it comes to working with this patient population and do not receive sufficient training or education (McNeil & Guirguis-Younger, 2011; Webb, 2015). Lack of education may lead to negative attitudes and create a relationship of mistrust between healthcare professionals and individuals experiencing homelessness (Hwang, 2001). Throughout the literature, individuals experiencing homelessness describe their healthcare experiences as poor, often relating this to discrimination and disrespect; therefore, individuals experiencing homelessness may avoid seeking palliative care services because of the perceived negative relationship with healthcare professionals (Hudson et al., 2016; Song et al, 2007). At many palliative care institutions, zero tolerance policies exist (Mcneil & Guirguis-Younger, 2012). Due to the high prevalence of substance use, prohibiting the use of alcohol and other substances makes these institutions inaccessible to many people who are experiencing homelessness (Doran et al., 2018; Hudson et al., 2016). Moreover, it has been suggested by healthcare professionals that prohibiting the use of alcohol or other substances during the end-of-life (EOL) phase may lead to extreme discomfort due to withdrawal symptoms such as confusion, nausea, vomiting and agitation as well as inadequate pain management related to higher opioid tolerance and lower thresholds for pain (McNeil et al., 2012).

Identifying the Problem

Individuals experiencing homelessness have complex needs, and this frequently leaves them on the margins of healthcare. From chronic conditions, such as cancer and mental illness, to sporadic care needs based on living conditions, individuals who are experiencing homelessness often go unseen by healthcare professionals or are only seen after a medical emergency occurs (Argintaru, 2013; Håkanson & Öhlén, 2016). Due to the overwhelming burden of these illnesses, poverty, and inadequate access to healthcare, the life expectancy of an individual experiencing homelessness is half that of the average housed Canadian (Argintaru, 2013; Håkanson & Öhlén, 2016), creating an identifiable need for EOLC services. Canadian palliative care services are designed with the needs of mainstream society in mind (Collier, 2011) and do not reflect the needs of individuals who are experiencing homelessness. Because of the scarcity of resources and barriers to access, these individuals are dying on the street, in shelters and in acute hospital beds without proper, dignified, person-centered EOLC.

People who have experienced, or currently are experiencing, homelessness have the best understanding of the issues surrounding homelessness and what needs to be done to address these issues. Understanding the EOL experience of individuals experiencing homelessness with progressive, life-limiting illness will provide vital information that can inform care for community-based services and contribute to the limited body of knowledge on this topic. For the purposes of this paper, a progressive, or progressive life-limiting illness will refer to an illness that affects a person's health and quality of life, that gets worse over time, and that can lead to death in the near future (e.g., cancer, heart failure, chronic obstructive pulmonary disease and cirrhosis of the liver) (Ontario Palliative Care Network, 2018). This paper will also use non-stigmatizing, person-first language such as 'individuals experiencing homelessness' and 'individuals who are precariously housed' interchangeably throughout.

Locating Myself in the Research

Growing up, having a stable roof over our heads was not without its challenges for my family. Now, as a Registered Nurse, who has previously worked in Intensive Care Unit (ICU) in Halifax, I have had the privilege of caring for people from a mosaic of cultures from many different communities. On one particular shift, I cared for an individual who would be considered marginalized by society. My patient assignment for this night was a "John Doe" (name unknown), found on the street with a bottle of "Drano" in hand. After drinking this very caustic chemical, not only had John Doe been severely poisoned but also experienced an extreme corrosion injury of the gastrointestinal tract. With an injury this severe, palliation was the only option. With limited resources and a patient who was actively dying, we were unable to track down any family members, friends or acquaintances. With the exception of staff working that night, John Doe died alone, without an identifiable name.

As I walked home down Spring Garden Road (a street in Halifax, Nova Scotia in which many individuals experiencing homelessness reside) and looked around, I reflected on my experience with "John Doe" and was deeply saddened. Maybe that man knew him? Maybe they were friends. I then began to observe human interaction, interactions that present themselves every time I walk down the street, interactions in which I have been involved in myself. As people walked by those who were sitting on the street or panhandling for change, I couldn`t help but notice most people awkwardly looking down at their phones, looking straight ahead or the rarity of a shy smile. Why the discomfort? The portrayal of those experiencing homelessness throughout history as *crazy* or those who are unable to take care of themselves, parents grabbing their children in close when a man asks for change, or the assumption that all individuals experiencing homelessness are *lazy* or *nomadic hoboes* is the stem of these uncomfortable encounters.

Providing EOLC for "John Doe" was a very intimate and profound experience for me. This experience, in conjunction with completing Dr. Jean Hughes' marginalized populations class at Dalhousie University led me down a rabbit hole, with a thirst to know more. I discovered that the unfortunate reality of this story is a common fear for individuals experiencing homelessness, that is to die anonymous or alone. How can we, as a society, do better? How can I, as a healthcare professional, do better? Everyone has the right to die with dignity, free from distress and suffering. Everyone deserves equitable access to palliative and end-of-life care services. All people are entitled to universal healthcare, no matter what their housing situation looks like. My mission, aims, and approach focuses on advancing health and social justice for those living in disadvantaged environments while informing care and practice change and centering the voice of those experiencing homelessness.

Research Purpose and Questions

The purpose of this study was to gain insight into how, and in what way, individuals who are experiencing homelessness and living with progressive illness, experience palliative and EOLC. More specifically, I focused on the perceptions and meaning individuals give to: a) their experience of end-of-life care; b) concerns and preferences for end-of-life care; and, c) accessibility to end-of-life care services. In this study, I sought to answer the following questions:

1) What is the experience of palliative and EOLC among individuals living with progressive life limiting illness who are also experiencing homelessness?
2) What meaning do individuals - living with progressive life-limiting illness who are also experiencing homelessness - give to death, dying and EOLC?
3) What concerns do individuals - living with progressive life-limiting illness who are also experiencing homelessness - have with respect to their EOLC or potential EOLC experience?
4) What preferences do individuals - with progressive life-limiting illness who are also experiencing homelessness - have in regard to EOLC needs?

5) What perceived and/or real barriers do individuals face in accessing EOLC services when living with progressive life-limiting illness and also experiencing homelessness?

Summary

By nature, the causes of homelessness are due to structural factors, system failures and individual circumstances, all of which are outside the control of the individual (Burt et al., 2001). Poor housing conditions and poor health are directly linked. People who are structurally precariously housed are experiencing chronic and progressive illness earlier and are at an increased risk of mortality compared to the housed population (Argintaru, 2013; Håkanson & Öhlén, 2016). Individuals who are precariously housed experience many barriers of access to end-of-life care services, this is due to the marginalization of those who are vulnerable, our healthcare system's rigid guidelines, inexperience or lack of education for healthcare workers, and mistrust between healthcare professionals and individuals experiencing homelessness (Argintaru, 2013; Håkanson & Öhlén, 2016; Hudson et al., 2016; McNeil & Guirguis-Younger, 2011; Webb, 2015). There are limited resources available that serve the multifaceted end-of-life care needs for individuals who are experiencing homelessness (Corfu, 2018; McNeil et al., 2012). Few studies have been conducted from the perspective of those who are experiencing homelessness and living with progressive life limiting illness. In order to provide adequate and equitable access to EOLC services, a first-voice perspective must be obtained.

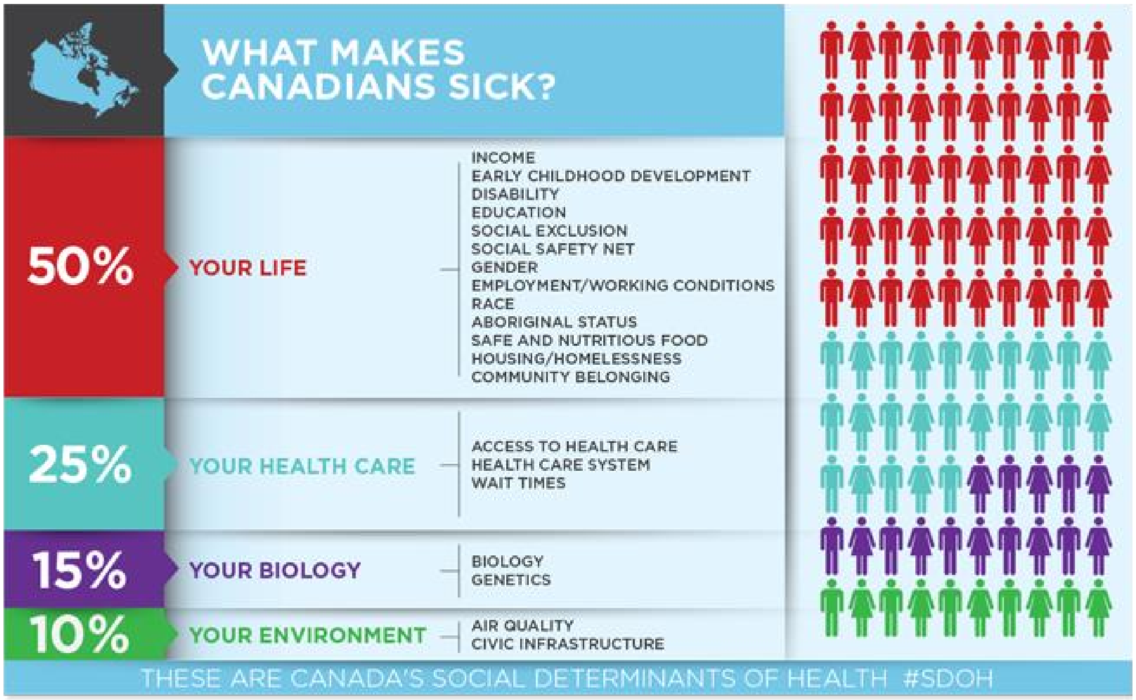
CHAPTER II: LITERATURE REVIEW

In this chapter, I will present a review of the literature describing research on the perceptions and experiences people who are precariously housed have surrounding EOL/EOLC and the barriers that are faced in accessing these services. There is limited scholarly literature based on the perspective from people who are experiencing homelessness themselves, therefore support workers and clinician's perspectives on homelessness and EOLC will be included. The social determinants of health, the incidence and prevalence of homelessness, the impact of being homeless and harm reduction services were also explored to further identify the need for equitable EOLC services for this population. To conduct this literature review, standard search strategies were used including the use of two online databases (CINAHL & PubMed), a wide scope of keywords (*end of life care, palliative care, homelessness, homeless people)* and the evaluation of relevant articles, organization websites and other forms of grey literature. The search was limited to publications from 2000 to present. Older publications referenced in this paper are of relevance as they aid in the description of pertinent terms and definitions, how far we have come in understanding the incidence and prevalence of homelessness and for building upon knowledge surrounding the need for adequate access to EOL services for those considered marginalized.

The Social Determinants of Health

The social determinants of health are defined as "the conditions in which people are born, grow, live, work and age" (World Health Organization, 2014, p. 1). The World Health Organization describes poverty as the single largest determinant of health. From limited resources for basic care to food insecurity and unemployment, individuals experiencing homelessness are at increased risk of poor health outcomes and mortality. In fact, this population often die of conditions such as pneumonia, influenza, HIV/AIDS, liver disease, and renal disease, which are often more easily treated in the housed population (Health Care for the Homeless Clinicians` Network, 2018; Hwang et al., 2001). Within the homeless population, there is much interplay across the social determinants of health, further exacerbating existing problems (Sekharan, 2014). According to the Canadian Medical Association, 10% of illness is related to environmental factors such as poor air quality, 15% to biology or genetics, 25% to lack of access to healthcare and 50% to "your life" or the day to day aspects such as income, education, social exclusion, safety, gender, race, aboriginal status, access to nutritious food and homelessness. Those who are experiencing homelessness are at increased risk of experiencing all the factors mentioned above, suggesting an increased risk of physical and mental health problems which in turn, lead to higher mortality rates.

Figure 1: Canadian Medical Association: The Social Determinants of Health



Incidence and Prevalence of Homelessness in Canada and Halifax

Many challenges exist in how we calculate the scope of homelessness. Many individuals experiencing homelessness live transient lifestyles, making them inaccessible or hard to reach especially through general population census data collection methods such as addressed mail and email. Some individuals are unwilling to engage with service providers or researchers, also creating a barrier in data collection (Frankish et al., 2005). Another notable challenge for counting the homeless population is the lack of a clear or agreed upon definition of homelessness across time and space (Frankish et al., 2005). The Homeless Individuals and Families Information System (HIFIS) was later introduced which focuses on data collection and analysis related to the use of emergency shelters in Canada. This system provides information on the size and characteristics of Canada`s homeless population (Frankish et al., 2005; Government of Canada, 2020).

Many communities in Canada have initiated local homelessness Point-in-Time (PiT) counts to measure population demographics and involvement in the homeless system through a federally funded data collection initiative that utilizes consistent methodology (Affordable Housing Association of Nova Scotia, 2015; Frankish et al., 2005). In Nova Scotia, the most recent PiT count provided a one-day snapshot of homelessness which captured numbers and basic demographics of those staying in emergency shelters in the urban core of the Halifax Peninsula, two non-shelter service providers, the Central Library, and on the streets (Affordable Housing Association of Nova Scotia, 2018). It was noted that on April 24th, 2018, there were 220 visibly homeless individuals with 197 of them sheltered, 18 unsheltered and 5 in cells with police. 67% of this population was male-identifying, 32% were female-identifying and 1% trans-identifying. The ages of these individuals ranged from 16-80, with 20% being under the age of

24, 72% being in 25-59 years of age category and 8% being 60 years and older. While these numbers are alarming enough, not all individuals who are experiencing homelessness or vulnerably housed were captured that day. It is clear from these numbers that homelessness is a human rights issue that needs to be addressed.

Who is at Risk and what are the Contributing Factors of Becoming Homeless?

The population of people who are experiencing homelessness is diverse, including individuals of all gender identities, ages and ethno-racial backgrounds (Segaert, 2012). From children to elders, homelessness can happen to anyone. At a local level, according to the PiT count completed on April 24th 2018 in HRM, 25% of participants said the main reason they left their last permanent address was due to eviction for a variety of reasons, 18% said it was due to illness or medical conditions, 18% also said it was due to "other" individualized and complex reasons not already listed, 17% of participants said it was due to addictions, 17% also said it was due to family conflict (spouse or partner), 13% said family conflict (parent), 13% said incarceration, 13% also said job loss, 10% said domestic abuse (spouse or partner), 9% said unsafe housing conditions and 5% said hospitalization or treatment (Affordable Housing Association of Nova Scotia, 2018). In the following section, I will discuss pathways into homelessness further and for the following subgroups: adult men, women, youth, indigenous peoples and seniors. It is important to note that the following section only touches the surface on some of the reasoning behind homelessness for each subgroup, homelessness is multi-factorial and encompasses both individual and systemic components.

Adult Men

According to the Segaert National Shelter Study (2012), single adult men between the ages of 25-55 account for just under half of the homeless population in Canada. Throughout the literature, pathways into homelessness for adult men include systemic issues often beginning with a financial crisis that precipitates a homelessness state (Chamberlain & Johnson, 2011). Examples include loss of a job or collapse of a small business, inadequate social housing and unaffordable rent. Another pathway into homelessness is surrounding problematic substance abuse and inability to maintain employment because of it (Chamberlain & Johnson, 2011). It is suggested that this group has a higher incidence of mental illness, addictions and disability with limited supports available (Gaetz et al., 2013). At a local level, according to the PiT count completed on April 24th 2018 in HRM, 22% of men compared to 9% of women voiced their reasons for losing housing was due to family “conflict” (spouse or partner) and 15% of men compared to 9% of women said it was due to incarceration (Affordable Housing Association of Nova Scotia, 2018)

Adult Women

Women make up a lower percentage of individuals using emergency homeless shelters (males: 73%, female: 26%) (Segaert National Shelter Study, 2012). Pathways into homelessness for adult women commonly include family violence, separation, and divorce. It has also been reported that limited options for employment and lack of education contribute to the pathways into homelessness for women (Segaert National Shelter Study, 2012). At a local level, according to the PiT count completed on April 24th 2018 in HRM, 24% of women compared to 3% of men said that their reason for losing housing was due to domestic abuse with a spouse or partner, 22% of women compared to 8% of men said it was due to family conflict with a parent, and 16% of women compared to 4% of men said it was due to unsafe housing conditions (Affordable Housing Association of Nova Scotia, 2018). Moreover, single women caring for children are at an increased risk of experiencing poverty and enter shelters at twice the rate of two parent families (Segaert National Shelter Study, 2012). Single women with children are often unable to work or choose part-time or temporary jobs due to domestic responsibilities. Childcare in Canada is often unaffordable for even two-parent families (Segaert National Shelter Study, 2012; Yeo et al., 2015). Another major issue of homelessness for women is that it is often hidden. Women often avoid the shelter system due to sexual exploitation and assault (Segaert National Shelter Study, 2012). In fact, in a report completed by Khandor and Mason (2007) 35% of women experiencing homelessness reported being physically assaulted in the last year while 1 in 5 women reported being sexually assaulted or raped in the last year.

Youth

Youth aged 16-24 make up approximately 20% of the homeless population (Segaert National Shelter Study, 2012). The pathways into homelessness for this population tend to be different from the older adult population and for the most part, youth experiencing homelessness are running away from traumatic environments (Karabanow, 2003). Factors associated with homelessness for youth are often due to family violence (including physical, sexual and emotional abuse), parental drug addiction, discrimination and homophobia (Chamberlain & Johnson, 2011; Gaetz & O'Grady, 2002; Karabanow, 2003; Saewyc et al., 2006). Youth experiencing homelessness and identifying as LGBQT+ are vastly overrepresented. According to Gaetz et al. (2013) 25-40% of youth experiencing homelessness identify with the LGBQT+ community and were more often abused at home and victimized on the streets. It is also important to note that the needs of a 16-year-old are different from those of someone who is older; youth often lack the skills and supports to live independently and have trouble securing employment and housing.

People who are Indigenous

Men, women and youth who are Indigenous make up a significant percentage of individuals who are moving through homelessness in urban centers in Canada. A study completed by Belanger et al. (2013) suggests that 1 in 15 people who are Indigenous are experiencing homelessness in urban centers. Much of the research on people who are Indigenous and homeless suggests that historical trauma, oppression and discrimination, often through reserve systems and residential schooling, are the major factors contributing to homelessness and poverty amongst this population (Belanger et al., 2013; Oelke et al., 2016). Research has also shown that structural factors - such as high levels of unemployment, low levels of education, racism and landlord discrimination - are directly linked to homelessness and low income (Belanger et al., 2013). Furthermore, research also has linked historical trauma to the high incarceration rates and high suicide rates experienced amongst youth who are Indigenous (Belanger et al., 2013). This is a huge issue in Canada for people who are Indigenous living on and off reserve.

Seniors

Current research indicates that the number of older adults (aged 50+) becoming homeless is growing, largely due to the increased population at risk of becoming homeless or vulnerably housed in general. In 2013, there were four times as many seniors experiencing homelessness in Toronto as there were in years prior (Woolley, 2015). The pathways into homelessness for older adults are similar when compared to other sub-groups (e.g., a mix of structural, systemic and individual factors) but other challenges also exist. The literature highlights financial difficulties following retirement, declining mental or physical health, social marginalization/lack of social support, unaffordable housing and loss of family and friend caregivers who provided support physically or financially (Crane & Warnes, 2010; McNeil et al., 2012; National Coalition for the Homeless, 2009; Woolley, 2015).

Impact of Experiencing Homelessness on Health

Homelessness impacts both physical and mental health. Individuals experiencing homelessness are at increased risk of mortality and are dying at a rate that is 2.3-4 times more than the general population (Hwang et al., 2017). The mean age of death for this population is 34-47 years versus 82 years for the average Canadian (Hudson et al., 2016; Statistics Canada, 2018; Thomas, 2012). It is suggested that progressive illness such as cancer, liver disease and HIV, as well as co-occurring disorders such as substance abuse and mental illness, are experienced earlier among this population (Thomas, 2012). Marshall and colleagues suggest that those who are experiencing homelessness are the most vulnerable with regard to HIV transmission due to unprotected sex and intravenous drug use (Marshall et al., 2008; Nyamathi et al., 2013). The overcrowded conditions of some shelters throughout Canada also raise concern. Over-crowdedness can lead to a higher likelihood of being exposed to tuberculosis and physical assault (Frankish et al., 2005). Locally, the HRM 2015 PiT count concluded that 42% of participants said that they had medical conditions such as high blood pressure, asthma and diabetes, and 18% said they had physical disabilities (Affordable Housing Association of Nova Scotia, 2015). The 2018 PiT count concluded that 71% of participants used an ER in the past year and 39% were hospitalized in the past year (Affordable Housing Association of Nova Scotia, 2018).

Much of the literature focuses on mental health disorders and harmful use of substances among people who are experiencing homelessness. Hulchanski (2009) reported that 67% of shelter users in Toronto, Ontario report severe mental health disorders such as schizophrenia and personality disorders, post-traumatic stress disorder, substance abuse/concurrent disorders, and major depressive disorder. The 2015 HRM PiT count concluded that 54% of participants indicated they had mental health issues and 52% said they were struggling with addictions. McNaughton (2008) conducted a longitudinal qualitative study in which 28 individuals experiencing homelessness took part and described their transition through homelessness. Substance use was a key factor in precipitating participants' homelessness; participants identified that substance use was a way to escape the daily reality of their current living environment, cope with past trauma and feelings of isolation. Social isolation and violence are a daily reality for some individuals who are experiencing homelessness, as well as contributing factors of compromised mental health and substance use.

Inaccessibility and Discrimination within the Healthcare System

Primary and Community-Based Services

Throughout the literature, it is made evident that many barriers exist in accessing healthcare services for individuals experiencing homelessness. One of the most prominent issues is the lack of family physicians available. Currently in the province of Nova Scotia, approximately 5.7% of the province's general population do not have a family physician (Whiffen & King, 2019). As of January 1st, 2019, this was approximately 52,680 individuals (Quon, 2018). In comparison, according to O'Leary (2016), it is estimated that 50% of people who are experiencing homelessness do not have access to a family physician. Often individuals experiencing homelessness lack proof of healthcare coverage through ownership of a heath card which makes accessing any type of healthcare service challenging (Hwang et al., 2010; O`Leary, 2016). Other barriers include the inability to afford prescriptions, a lack of transportation to healthcare services, and mistrust between healthcare providers and people who are experiencing homelessness (Hwang, 2001; Khandor et al., 2011).

Individuals experiencing homelessness with mental illness are admitted to hospital five times more than the general population with mental illness, and people who are experiencing homelessness account for 52% of emergency department visits (Trypuc & Robinson, 2009). Examples of barriers that exist in accessing primary and mental health services are: not knowing what services exist or where they are located; feelings of embarrassment due to the stigmatization of mental illness and substance use; fear that the service provider would contact a social worker or the police; and the lack of collaboration between mental health, social welfare and homeless services (Ali, 2016; Canavan et al., 2012).

Acute Care Settings

With the emergency department open all the time, it is the most frequented service that people who are experiencing homelessness utilize for their healthcare needs (Kushel et al., 2002). Hwang and Henderson (2010) conducted a one-year study with 1,190 participants, all of whom were experiencing homelessness. It was concluded that 77.3% of participants had utilized an emergency department. Participants had a total of 8,898 emergency department encounters with a mean annual rate of 2.1 visits per person (SD 5.2) for one year. Based on the mean weighted cost estimates, the total emergency department cost was $6,118,087 USD or $5,252 per person. It was also noted, as previously mentioned, in the PiT count survey conducted on April 24th, 2018 in the HRM that 71% of participants had been in a hospital ER in the past year with 82% of that number being female compared to 66% being male (Affordable Housing Association of Nova Scotia, 2018). Not only is the emergency department the most frequented service utilized by those who are experiencing homelessness, the literature indicates that most people experiencing homelessness die in acute care settings (Hwang, 2000). From my own personal experience as a Registered Nurse working in acute care, by the time these individuals seek medical attention, their disease has progressed far beyond what is treatable.

Health Professionals Perspectives

Common themes exist throughout the literature regarding health professionals and shelter workers perspectives of caring for people who are experiencing homelessness. According to a study completed by Hakanson et al. (2015), healthcare professionals believed that individuals who are moving through homelessness are difficult to care for because of mental illness, drug and alcohol use, a lack of family support, their homeless state, and the inability to adhere to treatment recommendations. There is a gap in our knowledge about those caring for individuals who are experiencing homelessness and that training programs are needed to incorporate further education to address this knowledge gap. Although in recent years there has been heightened awareness and focus on marginalized populations for those completing health professional training. In professional post-secondary education programs, such as the Bachelor of Science in Nursing program that I completed in 2012, the focus was mainly on the health of the general public and very little time was spent adequately addressing the needs of those considered marginalized in our community. Moreover, there is a lack of understanding of addictions and palliative medicine in general making it hard for care workers to provide adequate pain and symptom management (McNeil & Guirguis-Younger, 2011; Webb, 2015). Campbell et al. (2015) completed a qualitative study in Calgary, Alberta, in which healthcare workers described the experience of caring for people who were precariously housed. One individual stated:

> I heard about an individual who was at [urgent care] getting help with some of kind problem that he has that involves a lot of pain. The moment they heard he was from a

> shelter, all they prescribed for him was Tylenol. They avoided the ones with codeine because they figured ‘oh, either he or somebody else in the shelter will abuse it.’ The moment you go and mention it, bang! Somehow the treatment level gets discounted down (Campbell, O`Neill, Gibson, & Thurston, 2015, p. 7).

It is clear from that participant’s response that not only does a lack of education exist surrounding addictions, but also that discrimination can lead to unmet healthcare needs for people who are experiencing homelessness. In my own personal practice, I have witnessed how the healthcare system further marginalizes and stigmatizes through labeling individuals as “frequent flyers” and “drug seeking”, especially in the emergency room setting.

In a study conducted by Shulman et al. (2017) it was found that there was also a lack of knowledge, or uncertainty around the prognoses of common illnesses resulting in difficulty in predicting illness trajectories. De Veer et al. (2018) also found that individuals experiencing homelessness have unpredictable disease progression; often, once the individual was sheltered in a stable environment with access to food, their physical symptoms improved. The results from this study also indicated that once individuals experiencing homelessness began to feel better, the individual would often want to get back to their usual way of life which sometimes meant accessing drugs or alcohol which also resulted in difficulty for healthcare providers to predict disease progression (De Veer et al., 2018). Palliative education addressing the needs of those who are marginalized has been non-existent in most settings, a practice that needs to change in order to serve our local communities equitability and holistically.

Inaccessibility and Palliative Care

Access to high quality palliative and EOLC services are a basic human right. Palliative care is often misunderstood as focusing solely on the end of life. However, palliative care should be provided throughout the trajectory of one’s illness. The National Consensus Project for Quality Palliative Care (2013) identified 8 domains of quality palliative care: 1) structure and processes of care; 2) physical aspects of care; 3) psychological and psychiatric aspects of care; 4) social aspects of care; 5) spiritual, religious, and existential aspects of care; 6) cultural aspects of care; 7) care of patients at the end-of-life; and 8) ethical and legal aspects of care.

Receiving care and dying where you want are also an important domain of quality care. A survey conducted by the Canadian Hospice Palliative Care Association (2013) showed that 75% of Canadians who had a preference would choose to die in their home. In a report conducted by the Canadian Institute for Health Information (2018), statistics based on the Home Care Reporting System showed that of the adults who died in 2016-2017, 66% received home care services in the last year of life but only 15% received palliative home care services. In 2014, the Nova Scotia Health Authority and Health PEI both launched a paramedic program for palliative care similar to a program initiated in Alberta (Canadian Partnership Against Cancer, 2019). The paramedics were trained to deliver care such as pain and symptom relief as well as psychological support. The aims of this program were to improve access to palliative care support at home, reduce emergency room visits and to provide care aligned with the patient’s wishes and goals of dying at home. Analysis of this project in Nova Scotia found that paramedics were able to keep palliative patients at home and prevent avoidable emergency room visits by 55% (Canadian Institute for Health Information, 2018). However, there is not much commented on in the literature regarding the effectiveness of psychological support provided by paramedics which is an important aspect of palliative care. Unfortunately, geography is a key factor in dictating quality of palliative care. Collier (2011) suggests that people who live in remote areas have a difficult time accessing high quality palliative care as urban centers tend to offer the most diverse palliative services. The work of Maddison et al. (2012) in Nova Scotia highlighted that geographic location of residence significantly influenced individual EOLC outcomes for cancer patients and that there is a lower rate of palliative care program access among older individuals over the age of 65. Burge et al. (2005) also identified that individuals living in long term care facilities have significantly less access to palliative care programs compared to the general population. After touching on the current issues surrounding access to quality palliative care for the generalized population and those living in rural communities, I next turn to those without a home.

Throughout the literature, many researchers have examined how homelessness affects access to palliative care services. Although there has been an increased interest in palliative care for those who are vulnerable or marginalized, such as individuals experiencing homelessness, only a small body of literature exists on this topic. Homelessness reduces a person's life expectancy by 50%, suggesting a high demand for palliative and end-of-life care services for this population. Unfortunately, there are limited resources available that serve the multifaceted end-of-life care needs for individuals who are experiencing homelessness (Corfu, 2018; McNeil et al., 2012). According to the literature, palliative care services are wildly underused among individuals experiencing homelessness. Many obstacles exist for accessing palliative and EOLC services which will be identified in the following paragraphs (Davis-Berman, 2016; Webb et al., 2017).

A systematic review was conducted by Parkinson (2009) on the attitude's nurses have towards people who are experiencing homelessness. The results indicated that throughout the literature, themes regarding the existence of negative attitudes were apparent, that people who are experiencing homelessness are often dehumanised and that nurses` prejudice acted as a barrier for people experiencing homelessness to access healthcare (Parkinson, 2009). Often health care providers are inexperienced when it comes to working with this patient population and do not receive sufficient training or education especially surrounding addictions (Hwang, 2001). This perceived lack of education or inexperience may lead to negative attitudes and create a relationship of mistrust between healthcare professionals and those who are experiencing homelessness. Throughout the literature, individuals who are experiencing homelessness describe their healthcare experiences as being poor, often relating this to discrimination and disrespect (Hudson et al., 2016; Song et al., 2007). Individuals who are experiencing homelessness may avoid seeking palliative care services because of this perceived negative relationship. In order to change this relationship, healthcare professionals need further education and more exposure in working with people who are experiencing homelessness.

Current end-of-life care programs do not reflect the complex circumstances of individuals experiencing homelessness. For example, there is much emphasis on family as end-of-life caregivers and “dying-in-place” (i.e., the home), which creates a significant barrier of access to palliative services (McNeil et al., 2012). Most EOLC services are offered in hospitals and people who are experiencing homelessness are unlikely to access supports (Hudson et al., 2016). At many palliative care institutions, zero tolerance policies exist, prohibiting the use of alcohol and other substances which makes these institutions inaccessible to many individuals who are experiencing homelessness (Hudson et al., 2016). As Stajduhar et al. (2017) insightfully suggest, current palliative care institutions serve to re-institutionalize, re-traumatize and re-colonize individuals experiencing homelessness. Throughout the literature, people experiencing homelessness express the desire to stay at their current living space (i.e., hostels and shelters) to die instead of being transferred to the hospital (Hudson et al., 2016). This is based on comfort level with staff and distrust of the healthcare system (Hudson et al., 2016); unfortunately, it is also apparent in the literature that hostel and shelter staff do not have the required resources available to care for dying individuals (Hudson et al., 2016). In the following section I will discuss what is known about the perceptions and experiences of individuals who are precariously housed have toward death, dying and EOLC.

Perceptions of EOL/EOLC: Individuals Experiencing Homelessness

In a study completed by Ko et al. (2015), perceptions of what constitutes a “good” or “bad” death from the perspective of individuals who are experiencing homelessness were explored. Concerns of experiencing a “bad” death through violence and drug overdose were evident in the study. Many people who are precariously housed experience chaotic lifestyles in which the day-to-day fear of violence, exposure to illicit drugs, and undergoing cold and hunger are at the forefront of their experience (Hudson et al., 2016). When faced with these challenging social and living conditions, death informs all aspects of these individual’s lives (Song et al., 2007). Throughout the literature, individuals who are experiencing homelessness expressed concern with dying alone (Hudson et al., 2016; Ko et al., 2015). These individuals related dying alone, or dying on the streets, as being an “undignified” death (Ko et al., 2015). A similar finding by Song and colleagues (2007) suggested that dying anonymously was a very real fear for individuals experiencing homelessness. These individuals expressed a fear that their death would go unnoticed, that their bodies would not be found, that their bodies would be anonymously cremated or that they would die in a public place (Song et al., 2007).

Desires surrounding EOLC for people who are experiencing homelessness are also similar to those of the larger population. These include dying peacefully, without pain or suffering and experiencing a spiritual or religious connection (Ko et al., 2015; Song et al., 2007;

Tarzian et al., 2005). Ko and colleagues (2015) found that making amends with family and friends is an important aspect of EOLC for people who are experiencing homelessness. Participants expressed that seeking reconciliation, expressing affection, apologizing and taking care of inner conflicts would aid in a sense of closure in order to accept death peacefully (Ko et al., 2015).

Another theme within the literature is that many people who are precariously housed have had personal life-threatening experiences or have experienced the death of loved ones, friends and acquaintances on the streets (Hakanson et al., 2015; Hudson et al., 2016). According to a study completed by Song and colleagues (2007), witnessing death or having near-death experiences has led these individuals to live in “survival mode” and become more careful in their day-to-day lives; as expressed by one participant who stated “I just feel that now it’s different because of me having such a near-death experience. I find myself, when I get up in the morning now...I’m more careful, look around...” (Song et al., 2007, p. 431). Individuals experiencing homelessness use strategies such as managing health conditions, sticking together and staying sober or clean to stay safe (Song et al., 2007). It is also suggested that, for some, these experiences may increase risky behaviors. In a study completed by Street Health (2007), 87% of individuals experiencing homelessness who have co-current disorders, both substance use disorders as well as mental health disorders, tend to use alcohol or drugs to self-medicate in order to relieve stress, pain or escape reality. Often persons living on the streets witness death in very traumatic and undignified ways:

> Someone got the hell beat out of him last week and they left him there to rot. And when someone died in their sleep. They got no medical attendant or nothing like that. …and

> I’ve seen over a hundred people die. Basically a lot of it was for nothing. They were outside cold, alone, frozen, beat to death, hung, whatever (Song et al., 2007, p. 431).

It is important to note that throughout the literature, many themes regarding concerns at EOL are shared amongst the larger population such as dying in pain, prolonging life with life support and becoming dependent on others (Ko & Becker, 2013; Song et al., 2007; Tarzian et al., 2005).

So, what does a “good” death look like? Smith (2009) has defined 12 principles that articulate the premise of what constitutes a good death. The following principles can be incorporated into palliative and EOLC service planning as they represent many factors that people from all backgrounds look for at the EOL: 1) To know when death is coming and to understand what can be expected; 2) To be able to retain control of what happens; 3) To be afforded dignity and privacy; 4) To have control over pain relief and other symptom control; 5) To have choice and control over where death occurs (at home or elsewhere); 6) To have access to information and expertise of whatever kind is necessary; 7) To have access to any spiritual or emotional support required; 8) To have access to hospice care in any location, not only in hospital; 9) To have control over who is present and who shares the end; 10) To be able to issue advance directives that ensure wishes are respected; 11) To have time to say goodbye and control over other aspects of timing; 12) To be able to leave when it is time to go and not to have life prolonged pointlessly.

Harm Reduction Approach: Breaking Down Barriers

Harm reduction approaches are designed with social justice in mind. Not only are the strategies aimed at reducing negative consequences associated with legal and illegal psychoactive drug use, but the approach also illuminates the provision of dignified care and respecting the rights of those who use drugs. Examples of harm reduction strategies are opiate substitution therapy where a replacement drug such as methadone is prescribed to treat opioid dependence and needle/syringe programs where clients can drop off used supplies for safe disposal and replenish with sterile, single-use injection equipment in order to reduce transmission of HIV or other blood borne viruses (Normand et al., 2013; Wodak & Cooney, 2006). Services such as opiate substitution therapy and needle syringe programs value non-judgmental, person-centred and equitable approaches to care (Normand et al., 2013).

In order to mitigate the existing challenges and barriers to access for people who are experiencing homelessness requiring EOL services, some studies have looked at implementing low threshold policies and guidelines (McNeil, Guirguis-Younger & Dilley, 2012). Throughout the literature, harm reduction techniques such as clean needle exchange and prescribing alcohol, has shown to be an effective strategy in pain and symptom management for people who are dying (McNeil & Guirguis-Younger, 2012; McNeil, Guirguis-Younger & Dilley, 2012; Podymow et al., 2006). By changing polices to include harm-reduction strategies, individuals experiencing homelessness who use drugs and alcohol are better accommodated, removing one of the main barriers of access to end-of-life services (McNeil et al., 2012). It was also suggested in a study completed by Podymow et al. (2006) that integrating harm reduction approaches to hospice centers decreased health costs by reducing the need for emergency medical services. It was concluded that that when patients stayed in hospice care for an average of 120 days, there was a projected savings of $1.39 million compared to similar stays in alternate care locations.

In Canada, many cities are beginning to introduce harm-reduction models of care for EOLC services. An example of an EOLC service that practices harm-reduction and people-centered care is Palliative Education and Care for the Homeless (PEACH). PEACH is a mobile program in Toronto Canada that takes end-of-life care to those experiencing homelessness, wherever they are situated. PEACH gives individuals experiencing homelessness the dignity of choosing where they receive supportive and end-of-life care. According to the PEACH project lead, Dr. Naheed Dosani (2014, p. 1), "Good palliative care takes a holistic view of the person who is receiving that care… it's truly meeting all of the biological and psychosocial needs that a patient really requires along their disease journey”. A total of 64% of PEACH patients never had to go to the Emergency Department and more importantly, 80% of PEACH patients died where they wanted to (Ubelacker, 2014). Similar initiatives have been introduced in Calgary (Calgary Allied Mobile Palliative Program - CAMPP) and Victoria (Palliative Outreach Resource Team - PORT) (Aleman, 2017). CAMPP is composed of a team of trained professionals who help people experiencing homelessness manage pain and navigate the healthcare system while PORT is a group of community outreach workers who advocate for and connect people experiencing homelessness to homecare services. The Diane Morrison Hospice, a 24-hour palliative nursing care program located in Ottawa, Ontario, utilizes a harm-reduction approach, setting them apart from other mainstream palliative care services. Patients are able to use substances as long as they are not posing a risk to others at the facility (Aleman, 2017).

There is strong evidence throughout the literature that harm-reduction strategies are effective when implemented appropriately within their contextual settings (Normand et al., 2013; Woolley, 2015). Harm-reduction in a palliative context requires further research, especially from the perspective of those utilizing such services. Very little research has been done from the perspective of those who are experiencing homelessness or who are “hard to reach”. How do we provide person-centered, equitable care? One option is to invite those who have the lived experience to highlight what works and what does not.

Summary

People who are moving through homelessness with progressive illness experience many challenges in accessing primary healthcare and EOL services. In North America, the end-of-life care system is generally based on the premise that clients are housed and supported by family and friends (McNeil et al., 2012). As such, much emphasis is placed on individuals dying at home with loved ones by their side. This assumption does not reflect the experience of individuals who are experiencing homelessness. Transportation issues, lack of family physicians, distrustful attitudes toward healthcare professionals, rigid policies and guidelines at existing EOL services including abstinence-only policies for drug and alcohol use, inexperience and lack of education among care providers, and discrimination are at the forefront of existing barriers and concerns for this population (Davis-Berman, 2016; Hudson et al., 2016; Hwang, 2001; Hwang, 2010; Khandor et al., 2011; Song et al., 2007; Webb et al., 2017). Although many similar concerns and desires for EOL/EOLC exist between people who are experiencing homelessness and the housed population, people who are experiencing homelessness have their own unique concerns due to their homeless state, violence on the streets and drug/alcohol dependencies (Hudson et al., 2016; Ko et al., 2015; Song et al., 2007). It is made evident throughout the literature that low-threshold, harm reduction approaches to EOLC services can aid in providing appropriate EOLC for people who are experiencing homelessness (McNeil et al., 2012; McNeil & Guirguis-Younger et al., 2012; Podymow et al., 2006). Healthcare professionals are inexperienced in providing EOLC for individuals who are experiencing homelessness and require further education and training (McNeil & Guirguis-Younger, 2011; Webb, 2015). The literature review clearly shows that people who are experiencing homelessness are dying earlier and often without adequate EOLC. Only a small body of literature exists surrounding the

EOL/EOLC concerns/desires from the perspective of people who are experiencing homelessness and living with progressive disease, and a better understanding of their experience is needed.

CHAPTER III: RESEARCH PARADIGM AND METHODOLOGY

Historically, much of academic research utilizes deductive positivist and post positivist approaches to methodology. These empirical and quantitative research paradigms focus on what is observable and measurable, which are the dominant foundations of evidence-based practice. In my experience as an intensive care nurse, these paradigms and the biomedical model of care have been fundamental in shaping my knowledge and practice. However, when looking at my nursing practice in its entirety, my nursing care is shaped by my own personal experiences, the individuals' experience, and a holistic view of the person which is synonymous with an interpretive worldview. The topic of death, dying and end-of-life care is multifaceted by nature. To gain an in depth understanding of the perspectives individuals experiencing homelessness living with progressive illness have surrounding EOL/EOLC, a qualitative design incorporating the methodology of interpretive hermeneutic phenomenology has been used. To further influence my understanding of a group often deemed marginalized by society, I utilized the theoretical lens of critical social theory.

Hermeneutic Phenomenology: A Philosophy and a Methodology

"The purpose of hermeneutic phenomenological research is to bring to light and reflect upon the lived meaning of experience" (Goble & Yin, 2014, p. 1). Within this research, the phenomenon is EOL/EOLC and the experience is that of individuals experiencing homelessness with progressive disease. Hermeneutic methodology has brought to light an understanding of the perceptions that individuals experiencing homelessness have surrounding EOL/EOLC and the meaning behind these experiences. Through understanding these experience, care-workers can be better informed. "To be able to understand and, if necessary, to improve our own practice, we have to start with our lived experience. We have to express it to become aware of its meaning, and often this awareness itself leads to improvements" (Lindseth & Norberg, 2004, p. 4).

Martin Heidegger (1889-1976), a student of Edmund Husserl and the "founder of phenomenology", expanded on the ontological underpinnings of phenomenology. He studied the concept of being in the world rather than knowing the world (Reiners, 2012). Heidegger extended phenomenology to include hermeneutics; knowing arises from interpretation and understanding. Hans-Georg Gadamer, a student of Heidegger (1900-2002) saw himself united with Heideggar in a generalized way but put more emphasis on language. Gadamer is now referred to as the "father of hermeneutics" and introduced the concept of fusion of horizons. As a researcher, through the lens of hermeneutic phenomenology, I have positioned myself to go beyond description of the experience and instead interpret the meaning of the experience and perceptions that individuals experiencing homelessness have surrounding EOL/EOLC (Creswell, 2013). In congruence with Heidegger and Gadamer`s philosophy, I was able to continuously self-reflect throughout this research on my own personal experiences, values and beliefs surrounding EOL/EOLC and my prior experiences as a Registered Nurse caring for individuals who are experiencing homelessness at the end-of-life; personal awareness is intrinsic to phenomenological research.

Defining Features of Hermeneutic Phenomenology

Being-in-the-world (Dasein)

Heidegger`s ontological focus is apparent through the concept of "Dasein", which in philosophy translates to being-in-the-world. Dasein reflects what it is to be human in the world. While Husserl used bracketing or the setting aside of one's own personal experience, Heidegger and Gadamer argued that one`s own experience, or presuppositions, are integral to the researcher`s understanding, moving from a descriptive phenomenological view to an interpretive view (Miles et al., 2013). Heidegger states that as entities of the world, we alone do not contribute to our being-in-the-world (Dasein) as others contribute to the interaction of living, and as such, we are unable to separate ourselves from these interactions (Heidegger, 1927). He argues that Dasein helps us to make sense of being-in-the-world and to answer the questions of what lived experience is.

Individuals experiencing homelessness face multifaceted challenges every day and their ‘life-world’ often consists of struggling with progressive illness and the notion of death informing all aspects of their lives. The researcher enters the world of the participants and interprets the meaning that they assign to the experience (Carson, 2017). The experience that individuals who are precariously housed with progressive illness have surrounding EOL/EOLC and the meaning behind that experience will be evident in my research.

Time and Space

Heidegger saw time (temporality) and space (spatiality) as non-chronological and non-linear. He saw time and space as infinite. When reflecting on a phenomenon, it is not chronological time that matters, it is why the phenomena stands out against the chronological flow of time (Dreyfus & Wrathall, 2005). For example, with regard to space, it is not the physical space itself but rather the sense of being in that space. You can have the same event or experience happen, but once placed in a different context, the experience would mean something different. Your social surroundings, how you are feeling on a particular day, the people who you are working with and your background all influence an experience or feeling; this is how time and space are revealed.

Fusion of Horizons

Gadamer`s metaphorical concept of fusion of horizon in research, refers to the encounter of the researcher and the topic of inquiry and the coming togetherness of each “horizon”. Horizon refers to our history, the background of a person’s ideas, meanings and experiences (Carson, 2017). This implies putting forth our own opinions or pre-knowledge of an experience and re-examining them in light of what we learned (Wilcke, 2002). According to Miles et al. (2013) the viewpoint of both researcher and participant spiral into new understandings of the lived experience of the phenomena. The researcher provides openness for the participant to tell their story and interprets it based on a multitude of linguistic sources such as body language, the words that are heard, silences and emerging meaning. In a hermeneutic phenomenological study, this analysis takes place during all steps in the research process. The researcher must also consider their presuppositions by bringing forward their own assumptions and biases and truly analyze what led them to the topic of interest.

The Hermeneutic Circle

The hermeneutic circle refers to an ever-expanding circle of interpretation and understanding (Gadamer, 2004). During the research process, evaluating and re-evaluating continuously is vital. The topic of inquiry is understood by viewing “the whole in terms of the detail and the detail in terms of the whole” (Gadamer, 2004, p. 291). The hermeneutic circle was later referred to as the hermeneutic spiral as there is no real circularity in the process of understanding. With regard to the circle, the interaction between the researcher and the participants was limited to only those included in the direct interaction; the spiral provided an opportunity for interpretation of others.

Critical Social Theory

Drawing from Habermas` (1972) theory of knowledge, critical qualitative research critiques the social and cultural assumptions that limit our ways of thinking and being in the world (Habermas, 1972). The foundational principles of critical social theory emphasize a commitment to emancipatory goals and social change while focusing less on individuals than on context. Critical Social Theory addresses the oppressive sociopolitical conditions that influence healthcare (Browne, 2000). Critical Social Theory is not made of just one theory but instead a collection of theoretical perspectives that seek to explore phenomena by examining the contextual effects of power, knowledge, and values (Bevan et al, 2012). Critical Social Theory also challenges individuals to "gain insight through self-reflection to further their understanding of how social forces such as power and oppression influence the interpretation of knowledge and past experience" (Bevan et al., 2012, p. 3). In research that is informed by critical social theory, one will examine individual experience but also consider how experience is shaped by social, political and historical context; knowledge is both historically constructed and socially situated (Haldenby et al., 2007). Critical Social Theory lends itself to this research project as vulnerable groups, such as those experiencing homelessness, often feel marginalized and oppressed. By using a Critical Social Theory lens, it gave me the space to self-reflect on my own underlying assumptions and beliefs surrounding homelessness, death and EOLC.

Combining Hermeneutic Phenomenology and Critical Social Theory

Both critical social theory and interpretive phenomenology acknowledge the complexity of experience. In this research I set out to explore the lived experience of palliative and EOLC for individuals who are experiencing homelessness and living with progressive, life-limiting disease. It focused on the perceptions and meaning that individuals gave to: a) their experience of end-of-life care; b) concerns and preferences for end-of-life care; and, c) accessibility to end-of-life care services. Both critical social theory and interpretive phenomenology illuminate the knowledge of the participant based on their lived experience. Utilizing an interpretive phenomenological methodology and the theoretical lens of critical social theory allowed me to go beyond describing the phenomenon, to interpreting how the phenomenon was experienced within a sociopolitical context. Access to palliative services is often challenging for even the general population. When an individual is experiencing homelessness, accessibility is even more challenging and the unjust social structures that make up our healthcare system become prominent. Both phenomenology and critical social theory allow for self-reflection of the researcher's own understanding and biases that exist surrounding the phenomenon under study. As a healthcare professional and researcher, I am in a position of privilege and have had to ask myself sometimes uncomfortable questions surrounding my own personal judgements and biases. In doing this, I was able to enhance my personal understanding of the experience that those who are precariously housed and living with progressive life limiting disease have in context with the palliative healthcare system.

Research Design

Sampling and Recruitment

Within the hermeneutic phenomenological framework, purposive sampling is often used as this technique aids in the selection of information-rich cases leading to information-rich data (Palinkas et al., 2015). Purposive sampling refers to "strategies in which the researcher exercises his or her own judgment about who will provide the best perspective on the phenomenon of interest" (Abrams, 2010, p. 3). Given the context of my chosen sample population, purposive sampling alone did not suffice. Snowball sampling or "word of mouth" sampling was also used as historically this population is deemed hard to reach for a multitude of reasons such as difficulty in locating due to frequent change of address or street living, fear of authority, lack of trust in research or perceived harms of research, mistreatment or exploitation, and transportation issues (Bonevski et al., 2014; Pawelz, 2017). Snowball sampling also allowed for the generation of familiarity, trust and rapport as individuals were approached by a person with whom they already have developed a relationship (Pawelz, 2017). This was a very important aspect of consideration when working with individuals experiencing homelessness. I believe that building a trusting relationship with each participant is one of the most crucial steps in the research process. In order to achieve a trusting relationship, I stayed consistent by conducting the interviews and will personally disseminate all knowledge gained. I was non-judgemental, respectful, and patient with each participant and interview, and I acknowledged that trust building takes time.

In July 2020, I began contacting services in the HRM by telephone or email that serve individuals experiencing homelessness using a contact script (See Appendix A). I gained authorization to send a recruitment poster (See Appendix B) with contact information to various shelters around HRM explaining all details and purposes of this study. Due to COVID-19, public health restrictions at the time of recruitment, recruitment posters were sent via email and each organization generously printed and posted them on my behalf. Interviews were conducted from August to October 2020 over the phone.

I desired a sample size of 3-6 people in accordance with phenomenological and qualitative methodology (Creswell, 2013; Morse, 2000). Englander (2012) suggests that in order to achieve richness and depth of an experience, at least three participants are required for a phenomenological study. He also states that a small number can be an advantage, as with a phenomenological study, it is the participant's lived experience and how well the researcher can describe that experience that is important (Englander, 2012). I was able to obtain a sample size of three participants. Although, with three participants, a case-study methods approach could have been used, I, along with my supervisor, made the decision to remain true to the original plan of utilizing phenomenological methodology with a critical social theory lens. The participants provided insightful and deep narratives surrounding their lived experience which deserved to be explored not just by describing their individual stories, but also by illuminating and interpreting their stories through a sociopolitical context. This lens was crucial as each participant faced endless social and structural injustices which will be obvious in the findings of this study.

The inclusion criteria were as follows:

- Ability to speak and understand English
- Over the age of 18
- Current or previous experience of homelessness
- A diagnosis of advanced disease including, but not limited to, COPD, cancer, HIV/AIDS, alcoholism, and substance addiction

The exclusion criteria were as follows:

- Inability to commit to the research plan for data collection

Gaining a diverse sample with individuals of different ages, gender identities, cultural and religious backgrounds guided my purposive sampling strategy. Each participant contacted me directly via telephone. Participants were then asked a number of questions during the screening protocol process to assess for eligibility (see Appendix C for Screening Protocol).

Interviews

Within the theoretical and philosophical tenants of hermeneutic phenomenology, in-depth interviews were used as the primary method for data collection (Creswell, 2013). To conduct a hermeneutic interview, a simple and flexible guideline was used to incorporate the research questions (See Appendix D for interview guide). Interviews were conducted in a non-judgmental manner utilizing a dialogical focused and conversational framework to acquire rich and meaningful data (Broom, 2005). Interviews were audio recorded with concurrent note taking, behaviors such as silence and laughter helped with the transcription process as it gave rich information that was added to the verbal answer of the participant. Immediately after each interview I wrote down additional details and elaborated on reflections made during the interview process for initial thoughts on interpretation (Benner, 1984; Patton, 2002).

The interviews were all conducted over the phone due to the coronavirus (COVID-19) pandemic and the public health guidelines that were in place during that time. My initial plan was to conduct interviews face-to-face at a mutually agreeable safe space at a date and time of each participant's convenience. The Halifax Library on Spring Garden Road would have been a potential interview space as it has private rooms in which community members are able to book. The location of the library is close to many shelters and on a direct bus route. I instead had to adapt and be quite flexible, making sure I was ready with my computer and audio-recorder at all times to conduct an interview due to the circumstances of my participants (i.e., access to phone, potential to move to a new location). If I didn't conduct each interview on the spot, I may have lost a potential participant. In fact, one participant called while I was out for a drive, getting my 7-month-old to sleep. I pulled over to a safe location and made myself available to talk. Luckily my daughter slept through the majority of the conversation. Being on a maternity leave from my full-time job at the time of recruitment made being available for interviews at any time more feasible.

Ethical Issues in Conducting Research with a Vulnerable Population

This study required approval from the Dalhousie Research Ethics Board (REB). As this study relies on accessing individuals who are deemed vulnerable, a full Research Ethics Board review was warranted. Individuals experiencing homelessness are a population who have been exploited historically and required special considerations and protection. Recruitment, interviews and mobilization of findings have been done in a non-judgmental manner, with protection of human dignity at the forefront. Once eligibility was established by using the screening protocol, participants provided verbal informed consent over the phone prior to the interviewing stage. They were given ample time to ask questions and discuss the study. Participants were advised that they could withdraw from the interview at any time or refuse to answer any question and that it was completely voluntary. If the choice to withdraw from the study was made, any data already provided would be destroyed and not used in any report of results. After completing the interview, participants had up to two weeks to decide if they wanted to remove their data from the study. After that time, it would have become impossible to remove because it would already be analyzed/anonymized. Participants were also made aware that withdrawal from this study would not have any impact on their access to services, or on the care that they receive from such services. It was also noted during the consent process that this research may not benefit them directly. However, their participation could provide important information that could help other individuals, who are experiencing homelessness and living with life-limiting disease, to access and have better quality end-of-life care. Each participant showed capacity/competency to consent by being able to reiterate the overall purpose of the research, and any foreseeable risk/benefits of taking part in this research study. See Appendix E for consent documentation. Verbal, over the phone consent was obtained. I then signed, dated and stored this document in a locked filing cabinet.

I also had to consider that some individuals who are precariously housed experience violence, trauma and abuse in their everyday lives. Individuals who are experiencing homelessness may have pre-existing mental illness and substance use disorders. With that and with the nature of this research topic, EOL/EOLC, I prepared a list of support services (e.g. social workers, case managers and Mobile Outreach Street Health) to distribute if warranted. See Appendix F for a list of supports. I also would have stopped the interview immediately when asked or if apparent distress had occurred.

The Human Participants Review Committee at York University formulated guidelines on conducting research with people who are experiencing homelessness. See Appendix G for guidelines. In these guidelines, it is suggested that the researcher must consider the implications of discovery or discussion of criminal acts or behavior as with the situational factors associated with homelessness, engaging in illegal activities such as the consumption, or sale, of illegal substances may come up in conversation. Participants were advised that the researcher could not provide absolute assurance of confidentiality if the researcher's records were subpoenaed in a court case. Participants were also made aware as per Article 5.2 of the 2nd edition Tri-Council Policy Statement (TCPS 2) that other limits on confidentiality included disclosure of abuse or neglect of a child or vulnerable adult.

Ensuring Confidentiality and Anonymity

The audio recording device was locked in a filing cabinet that only I, the primary investigator, had access to for protection and security of the data. I also transcribed each interview myself further ensuring confidentiality. Each interview was transcribed verbatim, ensuring the use of pseudonyms as recommended by Creswell (2013). All electronic data and backup drives were kept on a password locked USB which was located in a secured filing cabinet to ensure confidentiality and anonymity. Any hardcopies were also locked in the designated secured filing cabinet.

Reflexivity

In a phenomenological study, reflexivity must take place throughout the entire process to support rigor and credibility (Benner, 1994). From the beginning, my own experiences have affected why I have chosen the issue of homelessness and EOLC to be researched. My own experiences have affected the relationships I formed with each participant, my interpretation of findings and how I wrote up the results (Gilgun, 2011). Growing up in the small town of Glace Bay Nova Scotia, my family knew what it meant to have limited access to economic resources. My father, who is the hardest working man I know, had to work back breaking jobs his entire life to ensure his daughters always had a roof over their heads. Maybe it was the fact that he always stayed proud and humble, or maybe I was just a naïve-happy-little girl… I did not realize that my family was living in deep-housing poverty, as that was all that I knew, until I was old enough to understand what that meant. My positionalities as such, are important to disclose as my personal upbringing and my professional career, give me both an insider/outsider perspective in relation to the sociopolitical contexts of this study. My fore-structure and my “being-in-the-world” was constantly analyzed in order to recognize any bias or assumptions through the act of self-reflection. I had to consider my own perceptions of EOLC, gender, race, values and beliefs and how this could potentially affect the interviews and data analysis (Creswell, 2013). A reflexive journal was kept to examine my personal assumptions and goals. In doing this, I have created a level of transparency by making decisions, and the thinking behind these decisions visible (Ortlipp, 2008). The reflexive journal was kept in a locked filing cabinet accessible only by me.

Data Analysis

The hermeneutic circle was implemented as the main method of data analysis. Hermeneutic interpretive phenomenology is not linear; reading, reflective writing and interpretation all happen concurrently (Crist & Tanner, 2002). After transcription, each interview was read carefully, multiple times, and then again looked at as a whole. Transcriptions, field notes and reflexive journals were used as documents to aid in theme identification. Crist and Tanner (2002) have published a thematic analysis guide for hermeneutic interpretive phenomenology based on the work of Benner (1994) and the hermeneutic circle, they developed five phases which I followed during the data analysis process.

Phase 1 - Early Focus and Lines of Inquiry: The first phase included a critical evaluation of the first interview with my supervisor. If there was anything unclear or missing in the transcripts a discussion took place regarding the potential need for changing or rearranging research questions. “Lines of inquiry resulting from initial interpretations guide subsequent interviews and direct future sampling to provide deeper, richer understanding” (Crist & Tanner, 2002, p. 204). This phase illustrates that hermeneutic interpretative phenomenology is not linear.

Phase 2 - Central Concerns, Exemplars and Paradigm Cases: This phase consisted of the identification of important themes or meanings that unfolded amongst the data. Next, I developed summaries of each informant’s stories including central concerns and excerpts to aid in interpretation. As interpretations were formed, writing and revision took place. Exemplars were developed to specify common themes throughout each informant’s stories based on their experience, attitudes and beliefs surrounding EOLC. One story in particular was quite compelling, so I returned to it again at a later date and looked at it through a new perspective. Benner (1994) recognizes this as a “paradigm case” and defines this as “strong instances of concerns or ways of being in the world, doing a practice, or taking up a project" (Benner, 1994, p. 113). The criteria of what a paradigm case may be does not need to be identified in advance; instead, a paradigm case is identified through the perceptions or understandings made through the discovery phase (Benner, 1994).

Phase 3 - Shared Meaning: Written summaries of each informant’s story were able to show connections and patterns between meanings and any incongruences. At this phase, the informant`s shared concerns or experiences became clearer and interpretation was able to occur thereafter (Crist & Tanner, 2002).

Phase 4 - Final Interpretations: Concomitant interpretative writing began to flow and helped clarify emerging interpretations. Final, in-depth interpretations of common themes and exemplars then occurred.

Phase 5 - Dissemination of the Interpretation: A document of final interpretations was then refined with input from my supervisor. Meetings were held with my supervisor and an iterative process of interpretation between field notes and summaries resulted. Microsoft Word was used for the purpose of facilitating data storage, organization and retrieval as analysis took place. Each informant was protected by the use of pseudonyms. All technology used was passkey locked to maintain security.

Trustworthiness

In much of the literature, establishing rigour in a qualitative study is of much debate (Creswell, 2013; Polit & Beck, 2006). The term “trustworthiness” and “rigour” are often used interchangeably. Lincoln and Guba (1985) introduced ideas on trustworthiness informed by naturalistic inquiry which provided qualitative researchers new ways of endorsing validity, reliability and generalizability. According to Lincoln and Guba (1985), trustworthiness of a qualitative study can be established when credibility, dependability and confirmability and transferability are evident.

Credibility

Credibility refers to the value and believability of research findings. A qualitative research study is considered credible when the experiences of the participants are captured by the researcher in a way that each participant would easily recognize their described experience as their own (Sandelowski, 1986). Credibility is achieved when the researcher describes and interprets their own experience and behaviors in relation to those of the participants (Sandelowski, 1986). The three key techniques in ensuring credibility identified by Lincoln and Guba (1985) are prolonged engagement, persistent observation and triangulation. The researcher must spend an adequate amount of time in the field in order to understand the phenomenon of interest and multiple data sources must be used to produce an overall understanding. These sources include interviews, observation and reflexive journals. Member checking or participant feedback is a technique often used in exploring the credibility of a qualitative research study by giving the participants the opportunity to confirm or deny the accuracy of the researcher’s interpretations. (Lincoln and Guba, 1985). However, member checking can sometimes cause unintentional harm in studies looking at those who are considered marginalized or who have had past-traumas when asking participants to “re-live” the data collected, specifically if the interpretations have a negative tone (Candela, 2019; Hallett, 2013) In keeping with this recommendation, I opted not to member-check in order to protect the participants well-being as the findings from this study take an in-depth look at the social and structural injustices individuals experiencing homelessness face. Furthermore, given the transient lifestyles of those experiencing homelessness, following up after the interpretations are made is not an easy task. For example, two of the participants in this study did not own a phone and were unsure of their future living arrangements making member-checking impractical. I did however employ triangulation through utilizing multiple sources during the data analysis process which included the participant interview and my reflective journal.

Transferability

Transferability is said to be the qualitative version of external validity (Tobin & Begley, 2004). Transferability is considered on a case-to-case basis as the reader must review the research findings and determine if the information can be transferred to another population or context (Creswell, 2007; Lincoln & Guba, 1985). An important aspect of a phenomenological study is providing thick descriptions and quotes which support confidence in the findings (Benner, 1994). As this is an interpretative hermeneutic study, the essence of a shared experience by individuals in a specific setting is what is to be achieved. With this, if the research were to be repeated, the potential for similarities or variances, may be concluded (Polit & Beck, 2008). I have provided detailed and robust descriptions of my experience during data collection so that the reader can apply transferability judgements for themselves.

Confirmability & Dependability

Confirmability and dependability are met when the researcher is able to describe and interpret their experience (Whitehead, 2004). Polit and Beck (2006) suggest that researchers leave an audit trail through six classes of records: “1) raw data such as field notes and interview transcripts; 2) data reduction and analysis products; 3) process notes; 4) materials relating to intentions and dispositions such as personal notes on intentions; 5) instrument development information such as pilot topic guides; and 6) data reconstruction products such as drafts of the final report" (p. 336).

The ability of the researcher to describe and interpret their experience is an integral part of the research process as well as their ability to recognize the potential effects of their personal characteristics may have on data collection (Whitehead, 2004; Guba & Lincoln, 1985). This has been achieved by keeping a detailed reflexive journal, used during theme development, in which I have included all thoughts and feelings in order to ensure that any biases are made known.

Summary

An interpretive (hermeneutic) phenomenological philosophical lens and methodology was used in combination with critical social theory to explore the lived experience individuals who are precariously housed and living with progressive illness experience EOL/EOLC. I have focused on the perceptions and meaning individuals give to: a) their experience of end-of-life care; b) concerns and preferences for end-of-life care; and, c) accessibility to end-of-life care services. In-depth ethical considerations were made to protect the sample population and a list of support services was available prior to the interviewing process began. I utilized the work of Crist and Jenner (2002) as a thematic analysis guide which is based on the work of Benner (1994) and Gadamer`s hermeneutic circle. Although there were many obstacles in recruitment due to the population of interest and because of COVID-19, I made sure to overcome them. As I believe in equity and social justice, this research project will bring awareness of the many barriers that individuals who are experiencing homelessness face in regard to quality EOL/EOLC. Everyone has the right to die with dignity and free of pain. Interpretive (hermeneutic) phenomenology was the perfect fit to truly gain an understanding of the perceptions EOL/EOLC people who are precariously housed with progressive illness hold and the meaning behind these experiences. Through understanding the experience, care-workers can be better informed and the quality of end-of-life care for this population may be enhanced.

Chapter IV: FINDINGS

The purpose of this study was to gain insight into how, and in what way, individuals who are precariously housed and living with progressive illness(es) experience palliative and EOLC. The following chapter paints a picture of who the participating individuals were, the use of a paradigm case, as well as an examination of the data as a whole, and as individual parts, through the methodology of phenomenology and theoretical lens of critical social theory. While none of the participants involved in this study were actively receiving palliative or end-of-life care, it was evident through our conversations that this point was a theme in and of itself. What also emerged from the interviews was a deeper discussion about the homeless community and the struggles that they face every single day. Participants used the interview as a way to share their journeys into homelessness, substance use, familial fallouts, road to recoveries, their experiences during the ongoing COVID-19 pandemic, and experiences with their health and the healthcare system as a whole. Their openness to share their life experiences and histories is an important component of this study as I believe it demonstrates how poverty, access to healthcare and health are intertwined in what can only be labeled as a vicious cycle. In the sections to follow, all identifying information was removed including participants names, communities and services which they used. Pseudonyms were given to each participant in the form of fictional names, in order to protect each participant's privacy but also to humanize their stories. All quotations are verbatim. Some words may be offensive to some readers.

The Participants: Nate, Lilli and Darcy

In the following paragraph, the sociodemographic characteristics of the individuals who took part in this study will be presented, and their living arrangements at the time of interviewing will be described, followed by a brief description of each participant's current health status. I was able to recruit three participants, two of whom identified as male and one who identified as female, all of whom were currently experiencing homelessness. “Nate” was living in an assisted living environment for those with chronic alcohol dependency. “Lilli” and “Darcy” were involved in a romantic relationship at the time of interviewing and were placed in a local hotel for a few weeks by a local non-profit organization due to COVID-19 restrictions at the time of interviewing. Lilli and Darcy were tent living prior to this arrangement for a few months and mentioned that they were unsure of where they would be going the weekend following the interview. The participants’ ages ranged from 36-60. One participant identified as atheist, one identified that heaven is where they would go when they died, and one did not disclose any religious or spiritual beliefs.

Nate had many health conditions at the time of interviewing such as chronic alcoholism, high blood pressure, and mental health issues. Nate also mentioned many other health ailments during the interview such as impaired mobility, poor balance, impaired vision, loss of sensation to his right hand, chronic swelling of bilateral legs, leg infection with open wounds, frequent urination, “gums that are growing over teeth”, insomnia, hernia, chest pain “sometimes”, and breathing issues. Nate also mentioned that he was a chronic smoker and taking two medications; he was unsure what they were called but thought one might be for high blood pressure.

Lilli was diagnosed with stage 3 stomach cancer, depression, bipolar disorder, borderline personality disorder and also struggled with addictions. She had a severe motor vehicle accident which resulted in “arthritic” like pain to the left side of her body. Lilli mentioned that she had methadone and other medication prescribed but had a hard time taking medication even on a “good day”. This participant was the only one who had explored end-of-life treatment at one point during her disease process from the perspective of medically assisted death.

Darcy mentioned that he struggled with post-traumatic stress disorder (PTSD), anxiety, and addictions. He had many seizures over the last several months, but was unsure why, and he had not sought medical attention at the time of interview. He also was taking methadone, Ritalin, Wellbutrin and Lithium at the time of interview, but he didn`t mentioned what each medication was being used to treat.

During interviewing, each participant mentioned familial disputes and fallouts. Two participants mentioned abusive histories and traumatic life events - including abusive family members, partners and abuse by authority figures - which led them into a homeless trajectory. One participant voiced:

> Sure yep, 36 years old, basically I lived in [rural hometown] until I was like 13. When I was 9 years old I got kicked out of my house, my mom and dad's house, my dad was abusive, so I moved in with my nan, right, so I lived with her until I was almost 23. I ah …how I ended up living in an abandoned house in [rural hometown] in the winter time, struggling like, I woke up with icicles hanging off my eye lids, cause I was sleeping with just a curtain, I had a curtain, yano what I mean, hanging from the window. (Darcy)

The other participant experienced financial loss which also led them into a homelessness trajectory:

> No, I went home drunk. I was going to AA [alcohol anonymous] here. I went home one day and stayed in my father's shed and I was eatin` nothing and then the bank took my house and I got behind and…of course…and I brought the money to raise the roof and I did, in the garage, to find a place to live, …lost the house and so then I got behind a little cause I was laid off and stuff, and they took the house and remortgaged it. So they added the two together and added up to about $60,000 and they wouldn't pay it all at once, they

> wouldn’t take the sum of money for the rent. See it’s a rental property - I had upstairs and downstairs. What they did is I told them to pay me. First month they took my money and they and the bank took my money and put it all on a credit card and that wasn’t secured so I didn’t mind that I was gonna go bankrupt. And I was gonna pay the house mortgage but the… ran the show and I got ripped off so many it’s a laugh, so I move on. So I was in AA and I was looking for a place to stay, cause I cancelled my life insurance and it’s hard for me to find a place when my licence is gone. (Nate)

Each participant voiced how they were currently working towards a more stable future, such as attending Alcoholics Anonymous and taking methadone treatment as a way to battle their current addictions. One participant narrated how important it was to utilize the resources that are available to them as a way to exit homelessness:

> You have to at this point …like I dunno, I don’t want to live, I don’t want to live homeless forever and that’s the thing. People use it as a sympathy tactic and just say ‘oh I’m down and out and you see that I’m living in a tent and I don’t have this or I don’t have that’… but then when we see you down the road selling a little bit of stuff for whatever for yourself, for food or whatever, that’s why you are in that situation because you are not taking care of your needs and your necessities. They are not helping themselves get any better. And if you are our age and are still keeping it up then you’re not gonna change… and we are keeping that stuff up. That’s the difference, we still have our issues and we still have our struggles but we are putting one foot in front of the other and we are reaching out to our families and our resources and stuff like that. We are not just taking advantage of them. (Lilli)

In the following section, I paint a picture of what each participant’s life circumstance looked like and how their experiences were shaped by their sociopolitical contexts in order to better understand how, and in what way, individuals who are experiencing homelessness and living with progressive illness(es), experience palliative and EOLC. Each participant had abusive, violent and traumatizing past experiences leading them into homeless trajectories which have shaped their perceptions of death, dying and EOLC.

Paradigm Case

During the preliminary data analysis phase, Lilli`s story in particular was quite compelling, so I returned to it again at a later date and looked at it through a new perspective after talking it over with my supervisor. This conversation provided an in-depth vocalization of the lived experience and perceptions in which an individual who is both experiencing homelessness and living with a progressive illness(es) had surrounding EOL/EOLC. Benner (1994) recognized this as a “paradigm case” and defined it as “strong instances of concerns or ways of being in the world, doing a practice, or taking up a project" (Benner, 1994, p. 113). Lilli`s story made a deep and lasting impact on my own personal understanding and was used to support data analysis. Lilli`s story provided a moment of revelation in which it was discovered that each theme is intertwined and related to the vicious cycle of homelessness itself. This vicious cycle deeply impacted the participants social determinants of health and led them into a dying trajectory.

The Vicious Cycle of Homelessness: An End-of-life Trajectory

The cyclical nature of homelessness is a complex issue. From the contributing structural and systemic factors to one’s personal challenges and experiences (e.g., mental health/addictions), once in a homeless state, it is extremely hard to exit, especially if that individual has progressive life limiting illness(es). When experiencing homelessness, while also experiencing progressive life limiting illness(es), having access to safe shelter, nutritious foods and equitable healthcare is essential in escaping homelessness and a dying trajectory.

During the discovery process, I continuously read and re-read each transcription carefully and then looked at the data as a whole. This is in keeping with the hermeneutic circle as a means of data analysis. Much like the hermeneutic circle, it became very clear that experiencing homelessness and living with progressive illness(es) was in no way linear but instead cyclical or a vicious cycle. At this point in discovery, I truly had to challenge my own beliefs and prejudices and consider the perceptions that individuals experiencing homelessness and living with progressive illness(es) have surrounding EOL/palliative care through the lens of critical social theory. In doing this, I had to not only look at each individual's experience but also look at their experience in a social, political and historical context. This led to the overarching meaning behind the experience of homelessness and EOLC, *The Vicious Cycle of Homelessness: An End-of-life Trajectory.*

The vicious cycle of homelessness deeply impacted each participant`s social determinants of health. For example, food insecurity is a harsh reality and daily struggle for each participant in this study. Participants in this study had poor and potentially life-threatening health outcomes due to lack of nutritious food sources. During my conversation with Lilli, the vicious cycle of homelessness was heartbreakingly apparent. Lilli was diagnosed with Stage 3 stomach cancer early 2019, just prior to the global COVID-19 pandemic. In order for her to have potentially lifesaving surgery she was told that she would have to gain weight. However, at the time of this interview she only had access to a box of Kraft Dinner. Nate shared what it was like to have food insecurity while struggling with alcoholism: “Drank too much and I didn't eat until I couldn't walk or anything and they took me to the hospital." That was one of his most recent recollections of being hospitalized. Once released from hospital he continued to struggle and lived off of "cold Kraft Dinner and peanut butter sandwiches."

Another example of how *the vicious cycle of homelessness* affected participants in this study was when Nate shared that not owning a government ID or health card made accessing most services extremely difficult. In fact, to get a government ID, you need some type of official ID. He also stated that he would like to donate his body to science when he dies but was concerned that no one would know that unless he had it written on the back of his ID. Without official identification, individuals who are already considered vulnerable become even more vulnerable and marginalized by not having access to healthcare, employment or social security such as welfare. Participants in this study also described how not having a permanent address or stable shelter meant disruptions in receiving important mail such as disability cheques or income assistance. Lilli painted an in-depth picture of what tent living was like and how unstable housing impacted her physical and mental health:

> So well we were doing laundry in a bucket and hanging it outside the tent and then peeing in a bucket, you know not in the same bucket thankfully all in the same area, and then when it would rain or bad wind, and you know none of our stuff for the most part really went missing. We didn't have any issues there but just sometimes we knew that there had been people there cause it's on a trail, a walking trail, we were right in the middle of a walking trail, behind that [local service], and the people that would be walking their dogs or their kids they were all always pleasant, and 'good morning' and so on and so forth. And we had no issues of anyone getting into trouble there - it was just the bathroom issues and having no shower. We were going to the lake and we had no shower.

> We were going in the lake, we were clean we weren't dirty or anything, but not having somewhere… it was just too much all at once and then having our health issues on top of it, it's just a lot. (Lilli)

The overarching theme, The Vicious Cycle of Homelessness: An End-of-life Trajectory was important to note prior to diving into the primary themes of this study as the social, political and historical contexts shape each and every part of the participant`s lived experience and perception of EOL/palliative care. Individuals experiencing homelessness are caught in a vicious cycle of deteriorating circumstances, this vicious cycle affects their mental, social and physical wellbeing leading to increased risk of progressive illness and poor health outcomes. This relates back to the increased demand for equitable EOLC services and the need to illuminate the voices of those who have the lived experience of moving through the vicious cycle of homelessness while also enduring progressive illness(es). Each primary theme and their accompanying subthemes relate back to *The Vicious Cycle of Homelessness: An End-of-life Trajectory* and provide an in-depth understanding into *how* and *in what way* individuals who are experiencing homelessness and living with progressive illness(es), experience palliative and EOLC (see Figure 2).

Figure 2: Overview of the 5 primary themes related to the overarching theme: *The Vicious Cycle of Homelessness: An End-of-life Trajectory*, which illuminates the individuals' experience from a social, political and historical context.

Note: Each of the 5 primary themes in this diagram overlaps with the overarching theme, *The Vicious Cycle of Homelessness: An End-of-life Trajectory*, to portray the interrelatedness between them.

It`s Like A Big Red X When I Show Up

Findings from this study resulted in the theme, *It's Like a Big Red X When I Show Up*, which explored the judgements and stereotypes participants faced when accessing health care services. This theme was further broken down into four subthemes: *Stereotype, Discrimination and Distrust; They Let Me Stay a Few Extra Days; One Ailment at a Time; and COVID-19: How to Access What is Already Inaccessible.* Each subtheme portrayed the experience that participants had when accessing health care services which ultimately led to poor healthcare experiences and the inability to advocate for their healthcare needs. The experience of discrimination and stigma surrounding addictions was also brought to light. Often, individuals experiencing homelessness have complex healthcare needs and present with comorbidities including mental health and substance use disorders. This theme demonstrated how individuals in this study felt as though not all of their healthcare needs were being addressed. Finally, this theme reflected on the experience that each participant had during the COVID-19 pandemic public health mandated quarantine, demonstrating how the homeless population is disproportionally affected by COVID-19 creating further barriers in accessing social and medical services.

Stereotype, Discrimination and Distrust

The following narratives show how participants in this study felt deeply stereotyped for being on methadone treatment for their substance use disorders. This is not an uncommon finding throughout the literature as there is a high level of stigma surrounding addictions, often due to lack of education or training (ref). Individuals experiencing homelessness often neglect to seek medical attention for this reason, or feel as though they cannot advocate for their healthcare needs.

Lilli was a former Licenced Practical Nurse who had not only worked in healthcare but also utilized healthcare services due to her struggles with addiction, mental health and stomach cancer. When initially asked about her experience with the healthcare system she deemed it a *"loaded question"*. Later in the interview she provided deep insight into how she felt when accessing the healthcare system:

> When you have our stereotypical thing of being an addict, or on methadone, it's the same thing, you are in that category, the same as myself. I have medical professional training but I'm still known as an addict because I have addiction issues that I have suffered with.

> And to know all of that medical stuff and know what it is I need, and then to be discriminated against, not because of my colour, or my race, or my gender but because I have an issue that takes a hold of my mind and my right head space sometimes I can't help that. I've been through treatment I've been to rehab so many times and it's just a lot of pressure, I know what I need and that's to have stable housing, and food in front of us. (Lilli)

Lilli was very emotional at this point in the interview. She had sought treatment for her substance use and mental health disorders but felt that without stable housing and food, getting better was a far reach. She also felt that having a background in nursing may hinder her healthcare experience further:

> I've had both, I had a hard time, well some people at the hospital have a hard time dealing with me just because I know the medical world. And sometimes that's a negative thing, because sometimes if I don't think that I'm getting what I think I need at a certain degree because I'm a nurse as well and even if I'm not in my right head space I still have my stuff. I still know what is going on with my body or inside my head or whatever. (Lilli)

An element of distrust has arisen as Lilli feels that she is not getting the respect that she needs when attempting to advocate for her healthcare experience:

> If somebodies not going to give me the right respect to let me speak and tell them what it is that I think I need…. then I'm not gonna have the respect to sit there and let them treat me like a Guinee pig, or whatever, and have all these different things that I know isn't gonna work for me. (Lilli)

Darcy shared similar views about his healthcare experience. He believed/thought that because he takes methadone treatment for his substance use disorder that he is automatically stereotyped:

> They don’t treat me very good even though I’m going through what I’m going through. They don’t treat me very well, and do you wanna know why? Because I’m on methadone; That is why. I’m on methadone and they don’t treat me well, they stereotype me so bad…it’s unbelievable. They do, it’s not that I feel it, they are, they do… honest to god even when I’m not awake, when I wake up there, it’s a big red X when I show up. They stereotype me bad. (Darcy)

I later gave Darcy some community-based recommendations to seek medical attention and he expressed that he felt no one cared about his situation:

> Like I reached out to them already, but it doesn’t seem like they, it doesn’t seem like they care much, and they are busy too right. So I’m not sure if they don’t care, maybe that’s how I feel but, yano I’ve struggled all my life and no one cared, until I got with her right [referring to his partner Lilli]. (Darcy)

They Let me Stay a Few Extra Days

The subtheme *They Let me Stay a Few Extra Days* illuminated the importance of acknowledging and recognizing homelessness when an individual from this population accesses healthcare services. This experience, although in stark contrast from the other participants, recognizes how being treated with respect, resulted in a positive healthcare experience for Nate. Not only did he have a positive experience, he also voiced that the health care providers let him stay a few extra days to ensure a safe discharge from hospital. He did not feel judged or stigmatized for his substance use disorder or homeless state. Instead, he was treated with kindness, respect and empathy which resulted in having an overall positive experience:

> Well my friends came here, and he's a cab driver, and we… they were gonna take me in the cab but the cab driver said they should get me an ambulance. So they put me in the ambulance… [friends name] was there and, like I said, they were busy with him they never bothered with me… going with my stuff. Said I was going to the hospital. So they took me from [rural hometown] to [nearest hospital] and they pumped a whole bunch of drugs, not drugs, intravenous in me. Yep. And they know I was homeless so they made me stay a few extra days. They were nice, I got more help out of strangers than I did with my family. (Nate)

One Ailment at a Time

When an individual experiencing homelessness utilizes healthcare services, they often present with comorbidities and multiple symptomatic concerns. This can lead to poor experiences and poor health outcomes for the person, specifically if all social determinants of health (i.e., safe shelter and food sources) are not being addressed. Nate portrayed this experience in the following excerpt, which resulted in the subtheme *One Ailment at a Time*, serving to reflect the need for total person-centered care.

> So once they find out you got high blood pressure, they're not worried about anything else… go off the deep end about that…when they… I can live with my aches, I'm managing, and they give me pills, high blood pressure pills, I don't know if my high blood pressure did that or not, my hand is asleep. (Nate)

COVID-19: How to Access What is Already Inaccessible?

The COVID-19 pandemic has disproportionally affected those who are marginalized, specifically those who are experiencing homelessness, in many ways. Not only are individuals experiencing homelessness at an increased risk of contracting COVID-19 due to unsafe living conditions such as overcrowding in shelters, but they also have a high prevalence of comorbidities, such as respiratory and cardiac conditions, which put them at an increased risk of developing severe COVID-19 symptoms. This subtheme demonstrated how the COVID-19 pandemic creates yet another barrier in accessing healthcare and social support services for those experiencing homelessness. This is a very important, current and relevant issue as without adequate access to healthcare services, especially during the COVID-19 pandemic, the health of those experiencing homelessness can deteriorate very quickly. This subtheme also demonstrated insight into participants' living arrangements at the time of the mandated COVID-19 quarantine and the struggles that they endured to provide some background context.

During the COVID-19 mandated quarantine, Nate was sheltered in a local high school gymnasium where there were approximately 30 other people experiencing homelessness. He shared that there were a bunch of cots set up and meals provided. However, he voiced that he thought somebody tested positive for COVID-19, so they were all made to leave the gymnasium. He was later provided a room in a local hotel: "Somebody had the COVID and they all got tested and then we left… kicked every one of us out cause of school, I dunno. So then they put us in the [local] hotel for two months, that was neat."

Nate voiced that accessing medical care has been increasingly difficult due to the COVID-19 pandemic, it also has disrupted his access to Alcoholics Anonymous (AA) which is a service that he utilized once or twice a week prior. This disruption could be quite detrimental for

Nate`s health. Nate also expressed how COVID-19 is always an “excuse” that people are using in the following narratives:

> Because of COVID and stuff I guess. Everybody says that, I dunno takes a long time of course…. COVID. (Nate)
>
> Yes, in hospitals, like the mental hospital in [rural town]. AA really. I went to AA down below once or twice a week but anyhow COVID got all that wrecked. I’m up here now so. Like I said, I’m trying to make a different life I don’t know what to do anymore. But there’s so much. I’m trying to buy a cigarette roller but I can’t even find one, Quickway don’t got none either, you won’t find one in [city]. Somebody told me the COVID is always a good excuse now. COVID did everything. (Nate)

During the mandated COVID-19 quarantine, Lilli and Darcy were residing in a rooming house which was largely occupied by men. This felt unsafe and uncomfortable for Lilli. Living in a building with many occupants also made Lilli and Darcy feel unsafe because of their underlying health conditions and COVID-19. They soon after left to stay in a hotel for a short period before pitching a tent in an area off a local highway:

> Alright we ah like I said he was [her partner] living in a rooming house and it wasn’t working out there. It wasn’t an ideal situation due to the fact that it was mostly men there and the epidemic was going on. So it was hard living in a building at all with all of that going on. You have to worry about your own health issues… and he’s got seizures going on that come and go that we’re trying to get dealt with and get himself situated and find out why they are happening. So we left from there and went to the hotel and there were other factors that, yano, made us not be able to stay there for a long time because I had my health issues and was struggling in many ways so we left that hotel um…

> We were in a hotel for a while, we were in a tent, we were in a tent for 2 months. For the most part the tent wasn't bad. I'm from, we are both from [rural hometown] so we went camping all of our lives and I mean I used to camp out for fun even in the rain. I didn't give a shit. But when it comes to being sick and tenting or camping not being a choice anymore that's what plays on a person's head and mind, when you know that's your only option. (Lilli)

I then asked about access to food and water. A local MLA helped them in their time of need and communicated through contactless drop-offs.

> Well at first we were just going to using the resources like churches and the different places that we know that we can reach out to like soup kitchens or whatever… and. But that's not something we had to do on a regular basis before it got to that point …so it. We knew that we were really grateful for the help that we got from them and, like I said, the MLA for area on the [off a local highway] where our tent was she was. One time she gave us a $50 gift card for Boston Pizza and that was on probably 6 or 7 times, or maybe more. She would do a little bad with a note and a little meal and she would always bring us big gallon bottles of water so we had fresh water and a little note and we communicated with her back and forth that way. So that …we were really grateful for that. (Lilli)

The COVID-19 pandemic affected Lilli`s physical and emotional wellbeing in many ways. She voiced that she had trouble taking her prescribed medications on a "good day", especially when sick with cancer and without the support of her family. She found it extremely hard to be away from her family due to the public health mandated household "bubbles." Lilli was very emotional during the following excerpt:

> I always had bad days, I’ve been off my meds for quite a while now and I was struggling. I struggle to take my meds on a good day let alone when I’m sick with cancer and away from my whole family and the bubbles and not being able to travel. My family and [partner’s family] are down on the [rural hometown]. Our parents, my mom passed away but my dad and [partners name] dad are very close in age. They aren’t old but they are in their early 60`s, [partners name] mom as well and they are pretty tough, they are from the country but [partners name] dad is scared to death of the virus, you know what I mean? (Lilli)

Lilli`s stomach cancer diagnosis came just prior to the COVID-19 pandemic. This truly made things difficult for her in many aspects. She got to the point where she was looking into medically assisted death options. Not only did she not want to get sicker, but at this point she didn`t want to get better either:

> Yea, yea, it’s a struggle because all this happened in March and then the epidemic came out and it was just a lot. It was just a lot. My plan was just to go for assisted suicide because I didn’t want to get any sicker, kind of thing, or try anything to try and get healthy if that makes any sense. But I have a little boy, he just turned 14 yesterday actually on the 30th. (Lilli)

The thought of missing out on her son’s big life events made her think a lot more about what medically assisted death would mean, she voiced that the COVID-19 pandemic was actually a blessing in disguise for her for this reason:

> And this would have been at the end of part of march I spoke to them briefly [Medical Assistance in Dying care provider] and they were getting ready to fax off the paperwork to me and do all this… or not…whatever the protocol for that type of thing would be. But

> when the virus came out, ya know, the flights were all screwed up and I think it was actually probably for the best that I didn’t get out there to do that because it was sort of a split-second decision if you know what I mean. I wasn’t in my right head space and now I’ve had the time to realize I don’t want to do that, I don’t want to not see my son graduate, or get married, or anything like that. (Lilli)

As previously mentioned, Lilli also has bipolar disorder, borderline personality disorder, depression and was in a very serious motor vehicle accident 15 years previously. I asked if she felt that any of her health conditions were exacerbated by the COVID-19 pandemic:

> Yea because if even before the virus came out… because I had my accident, my spleen got ruptured because I am pretty small. I was small back then too so with the impact of hitting me with the 18-wheeler, I was only in a Sunfire. Hitting me head on, it was way too much. If I had of been any bigger, just because of the way my body was… I was so close to the steering wheel that I probably wouldn`t of survived it. (Lilli)

Without a spleen, this potentially puts Lilli at greater risk for infections, bleeding and anemia. She knows that catching the COVID-19 virus could potentially be fatal for her because of this. She was really quite emotional during this part of our interview.

Darcy also was affected by the COVID-19 pandemic. He too, struggled with accessing healthcare services and not just for the obvious reasons. Darcy struggles with debilitating anxiety and PTSD. Because of this he feels that he needs his partner beside him when being seen by a health care provider; but because of the ongoing COVID-19 pandemic, she can`t be there: “I do have to get treatment, ya; it’s just they won’t let her in the hospital cause of this COVID thing… and I need her there with me, ya know what I mean.” I then gave him some information about local healthcare services. He voiced that seeking medical attention is even more difficult due to

COVID-19*:* “Yea, I should check that out hey, I’ve been trying to get in touch with them but because of this virus its hard.”

The barriers in accessing healthcare services that exist for individuals experiencing homelessness are many. This often results in poor health outcomes and affects their willingness to seek medical attention when necessary. COVID-19 has further exacerbated this experience and shaped the current life circumstances of each participant and the stories which they shared in this study.

Am I Sick?

The theme *Am I Sick?* was apparent through the descriptions that each participant gave regarding their overall health. This theme will be further broken down into two subthemes: “*I`m Healthy as an Ox but…”* and *“Willingness to Seek Medical Attention”* which described the meaning of the experience of living with a progressive life limiting illness while also experiencing homelessness. Participants in this study neglected to seek medical attention, and/or were unable to access medical care, and/or were unsure of their diagnosis and/or prognosis, and/or were uncertain as to what their prescribed medications were for, or neglected to take their prescribed medications at times.

I`m Healthy as An Ox But…

The subtheme *I`m Healthy as an Ox But…*illuminated how individuals in the homelessness community may not have a full picture of their health status. This is due to complex and multifaceted reasons, some of which have been highlighted throughout this study such as barriers in access, neglecting to seek medical attention due to poor past experiences, or lack of knowledge.

To reiterate, Nate, has chronic alcoholism with diagnosed hypertension. The last time he was hospitalized was due to heavy drinking and lack of food. Since that time he voiced that his health has been dwindling and has developed many symptoms - including impaired mobility, poor balance, impaired vision, loss of sensation to right hand, chronic swelling of bilateral legs, leg infection with open wounds, frequent urination, “gums that are growing over teeth”, insomnia, hernia, chronic smoker, chest pain “sometimes”, and breathing issues. Unfortunately, he has been without a family doctor since his practitioner died over two years ago. He voiced:

> I’m healthy, well I was healthy, I don’t know what happened to me, old age or something. My life and my health seemed to go down hill pretty fast. I was all healthy, I never went to the doctor in a long time but when I did, he got my blood pressure fixed up. He died…then I didn’t have a doctor for about 2 years in [rural hometown]. Then I moved up here and got tangled up in what they call [community health service]. (Nate)

He then discussed a recent incident involving his legs:

> Yea, and I was scratching my legs when they were all swelled up and they got infected. They still swell up, it’s hard for me to move them. My mobility is gone, it’s hard for me to get around, but I can get around, I don’t need a walker or anything yet. I can’t bend down, so I don’t even wear socks anymore, they are hard and my toenails are getting so long, I gotta try and cut them, nobody will come cut them I don’t think. I asked [community health service] to do that, [nurses name] was going to but never got around to it. They kept on moving me around so much I don’t know. (Nate)

As previously mentioned, during the initial lockdown during the COVID-19 pandemic Nate was placed at a local high school gymnasium with approximately 30 other individuals experiencing homelessness. I asked if he was ever afraid of contracting the virus and he voiced:

> No, I probably won't get it… anyway I'm healthy as an ox. I never got sick, no headache or nothing, no toothaches, that would have been bad. My gums are growing over and I still didn't got no toothaches. But down there, I could hardly breathe down there, but I was smoking those cheap cigarettes. (Nate)

We then discussed his chronic alcoholism and if he had any known liver or kidney damage. He said:

> Not that I know of, I don't get hangovers, but I don't sleep very good. Don't know. I tried that Nyquil. I know that's bad, but I tried some of that. I don't if that's working or not. I only got 4 hours of sleep last night I was up and I laid down and had a nap and I laid down around 4 o'clock and I just woke up in a way. I must have fell asleep sometime but…That is one of the reasons why I drank. I used to drink when I couldn't sleep, have a couple hours like right now. I don't know when I lay down - I got a hernia. When I lay down, I get up every 15 mins to pee. I don't know if it's that or what. (Nate)

He then spoke about his breathing issues and what he thought that might be related to:

> Well hard to say which one. The one I didn't like was my breathing. I could hardly breathe down there in the [local shelter]. Now, the air pollution down there… or is it the smoking those Indian cigarettes [sic]. Which one is it, do you know? Nobody tested me anyhow. All they did was take my blood pressure. I've been smoking 40-50 years… ya might as well say so, not surprised I have a wheeze. (Nate)

During the interview Nate, having moved in from a rural community, made multiple comments regarding how confusing the city was to live in which made things even more difficult for him. He wasn't sure how to use the bus system and didn`t know where things were located, including the hospital. However, he voiced that not knowing where the hospital was didn`t matter because he doesn`t get sick: “I don’t even know where the hospital is here; hospital ..take me by ambulance, I don’t get sick, yanoo, I don’t really get sick.” I then proceeded to ask about his sore legs*:*

> They are still all swelled up and my mobility is all gone, my balance is all gone… Sometimes I gotta hold onto a wall. I can’t walk down the steps its hard on me so I gotta hang onto a rail to go down. (Nate)

When asked about what it was like accessing the healthcare system he replied:

> I don’t use the healthcare system much I’m healthy. I can live with my aches, I’m managing, and they give me pills, high blood pressure pills. I don’t know if my high blood pressure did that or not - my hand is asleep. They don’t bother me, at least I got a hand to use, yano. Putting my puzzle together I can use my left hand. Can’t use my right because I can’t get the pieces together. Ya know you can’t turn it you can’t feel with it. (Nate)

Nate was able to schedule an appointment with a Physician about 1-month post this interview but mentioned that the time it was scheduled for was not convenient. He was also taking two medications but was unsure what they were called: “yea two little pills, I don’t know. The nurses were here, their high blood pressure machine was broken.” In the previous few quotes Nate was giving detail about different symptoms he has experienced. He knows that he feels a certain why but really isn`t sure why. He mentions that the few times he has sought medical attention they only seemed to focus on one system, one complaint, even though he has been experiencing a considerably large amount of discomforts.

Willingness to Seek Medical Attention

Participants in this study, at times, neglected to seek medical attention until symptoms were quite severe, or even life threatening, for various and complex reasons. These experiences resulted in the subtheme *Willingness to Seek Medical Attention.*

Nate described throughout his interview times in which he was unwilling to seek medical attention because his symptoms weren`t “bothering him” enough. He also provided insight into a time when he felt severely unwell but continued to have reservations about seeking care: “I couldn’t walk or anything. He talked me into going to the hospital, I wasn’t gonna go”. Luckily, in this incident, the paramedic encouraged him to go to the hospital after a friend had called an ambulance on his behalf when found unable to walk due to alcohol consumption. At one point during his most recent hospitalization he was told that he was going to die: “You’re gonna die”, really? I was like this all my life; I tell everybody it is what it is”. “It is what it is” was a quote heard often during my time spent speaking with Nate and will be reintroduced under the theme “existential struggle.”

Lilli was diagnosed with stage 3 stomach cancer. She voiced that she ignored the symptoms she was experiencing for quite some time before eventually seeking medical attention. She seemed to be in denial as she was so young and played the symptoms off as something more minor until she became very ill:

> I was in a motor vehicle accident, I had a head on collision with a number of health issues, and then just in March, um I… I knew a few things like I had been really exhausted, and pain in my back, just like different weird things that I kind of ignored; Yea I knew something was up, I was kind of thinking it was something more minor… like I was thinking it might have been like a stomach ulcer or something like that. I didn’t

> ever think it was going to be stomach cancer obviously, but I had problems most of my life in some way or another so I kind of just kind of … I'm only 37 years old, there's nothing wrong with me… and just kind of go with it, and go with the flow… but then I just kind of got to the point I knew there was something very wrong. I was staying in [rural hometown] where I`m from, with my sister at the time… and I couldn't get out of bed for 3 days in a row without a struggle. I said 'yano I got to go and get looked at'. So when I went, everything was obviously going on for quite a long extended period of time because it's already 3rd stage. But it`s very small, it`s very minimum compared to what it could be, so I'm lucky that way… And it's in my stomach so the other part of my stomach is injured and it's damaged pretty severely in some ways, um… But I've been meaning to see the doctor, the surgeon, the specialist that I've seen… um… He said that might benefit me if that makes any sense, um, because it doesn't have as much area to attack in the other part of my gut on the other side of my stomach. (Lilli)

She is now at a crossroads where her cancer is considered "stable", but in order to get the potentially lifesaving surgery to remove it, she needs to gain weight. "And since March, to my knowledge, anytime they cut… or ultrasounds, or anything… is to their knowledge… nothings changed. Nothings gotten worse so they said if I gain some weight then we are going to do a simple surgery." Fast-forward 6 months later, and she was still in a great deal of pain. She self-medicates with marijuana to stay comfortable. "For the most part, I have a lot of pain that I smoke, I smoke marijuana, I smoke weed for over a year, now that it is legalized. I smoke it mostly now for pain. It keeps me comfortable". On top of the pain from her stomach cancer she also experiences chronic pain from her motor vehicle accident 15 years ago as well as mental health issues.

> Um the only other thing, I have mental health issues of course, but the only other health issue that I know of is like arthritic pain in my left hand side, because my hip on my left is fake. I have very little bone in my left hand side all the way down to my ankle because my bones were shattered, my kneecap as well my elbow on the left side, I got metal in my jaw. (Lilli)

Lilli was diagnosed with bipolar and borderline personality disorders. She thought that her mental health has gotten worse in the last 6 months:

> I have bipolar, I have borderline personality disorder, and I have a …episode for 18 months and I …A long time ago I lived overseas; I was living in Dubai in Saudi Arabia. Yea that was an experience in itself. So I've seen a lot of trauma, a lot of people get hurt, I've seen a lot of people get killed, I've seen a lot of bad things I wish I never did and that was before I even got sick, that was before my mental health. Craziness, none of this… we all had our struggles, but my health has just gotten the better of me in the last probably 6 months or so. (Lilli)

Lilli also provided insight into how accessing healthcare services can be difficult. Luckily, she has found a great resource in her community, about whom she spoke very highly, to help navigate the system. Through her words it is evident that a relationship built on trust is crucial.

> Absolutely because you know that there is help for that to for your health issues. But sometimes they are so hidden away, or so expensive, or so not able to easily access is what it is… and you know… there are so many resources out there for people who are in our situation but people don't even try to reach out. Like [street navigator] for instance… sometimes he gives out $20 gift cards and stuff like that. He's a great guy, and he doesn't hold anything against anybody, he doesn't judge you. You will hear the odd swear word

> out of his mouth… He doesn't look at you like you are different than what he is, he sees that you have an issue and that you are struggling and that's it. He does his job in a very professional way but if you don't know who he is because of his demeanor and because of just how he looks, you think he's just the same. You don't know who he works for sometimes, he doesn't dress in a certain way, nobody really knows who he is unless you've gotten help from him. He doesn't approach people, he's respectful, he's not critical, he's not rude, he's just very, very easy going and approachable. (Lilli)

Darcy has extreme anxiety and PTSD. He has experienced many traumas in his life including parental and authoritative abuse. As previously mentioned, he had been abused by his father at a very young age until his grandmother took him in. At the age of 23 he lived in an abandoned house during the wintertime which was extremely difficult.

> Sure yep, 36 years old, basically I lived in [rural hometown] until I was like 13, when I was 9 years old. I got kicked out of my house, my mom and dad's house, my dad was abusive , so I moved in with my nan, right So I lived with her until I was almost 23. I,ah …how I ended up living in an abandoned house in [rural hometown] in the winter time, struggling like, I woke up with icicles hanging off my eye lids, cause I was sleeping with just a curtain, I had a curtain… yano what I mean… hanging from the window. (Darcy)

Out of an act of desperation to escape the cold and hunger, he did something to land in prison: "I wanted to get out of that abandoned house and that's all it was. I didn't do it to hurt anybody or nothing, I literally did it for an act of desperation." While in prison, he voiced that he experienced extreme violence and abuse from the guards, so much so that he thought about suicide; his cellmate stopped this from happening." Darcy gave great detail into this very emotional experience, but for the protection of his identity, that information will not be shared.

Darcy`s narrative focused mainly on his difficulties with mental health including PTSD and addictions. However, he had also been experiencing seizures. “Post-traumatic stress and I have, um, I’m obviously taking seizures but I dunno what that’s for…. Um, I’m on Concerta and Welbutrin and Lithium.” He gave great detail on how he felt when experiencing a seizure but despite being cognizant of this seizure like activity, he neglected to seek medical attention*:*

> I don’t, sometimes I can, sometimes I can bring myself out of it for some reason, sometimes I can’t, and then sometimes it’s like my muscles, my arms my legs I got no control over them. …yep yep… Like I can hear everybody but I can’t find, sometimes I can’t talk, it’s like my tongue swells up, I can’t talk. (Darcy)

When asked if he had a diagnosed seizure disorder he responded: “I’m not sure, I didn’t get like diagnosed. I get… like the ambulance called on me a lot, like.” He then talked about his latest experience having a seizure and how the paramedic team wanted to take him to the hospital… but he didn`t want to leave his partner:

> I was in the ambulance for about 20-30 minutes and they just checked me over there, and they wanted me to go, they begged me, but I couldn’t leave my little lady right. But they begged me, they even had the head of…they begged me to go, I could even see tears in the one guy’s eyes like they really wanted me to go right. I didn’t want to leave [partners name] I didn’t want to leave her; we had a lot of stuff to do that day. (Darcy)

Darcy then talked about other times that he had woken up in the hospital but wasn`t sure how or why. He always left when he noticed that his partner was not there: “um I don’t know I just wake up in a hospital and then when I see that she’s not there I just leave, I love her.”

He voiced that his seizures have been ongoing for several months. When asked if he had a Family Doctor, or if he is seen regularly by a health care provider, his response was simply, “no”.

Each participant in this study expressed multiple concerns regarding their health. Due to various reasons such as unwillingness to seek medical attention, uncertainty about their diagnosis/prognosis and inability to access healthcare services, each individual had gone without proper care for their progressive illness(es) - both mental and physical. This will be discussed further in Chapter V as this is in congruence with much of the current literature surrounding this topic.

Existential Struggle

There are many definitions and descriptions regarding existential struggle which can be found in much of the palliative and spiritual care literature. The description in which I relate to, and that I believe the participants in this study related to, is the following: “Lack of meaning or purpose, loss of connectedness to others, thoughts about the dying process, struggles around the state of being, difficulty in finding a sense of self, loss of hope, loss of autonomy, and loss of temporality” (Bates, 2016). Each participant in this study had a shared lived experience, which at some point in the last years to months, they did not care if they lived or died. These findings resulted in the following theme: *Existential Struggle.*

Nate experienced existential struggle in almost all aspects. Throughout the entire interview he used language such as “it is what it is”, “I don`t really care”, and “my life is gone”. In this first excerpt he provides deep insight into his emotional wellbeing and what he thought of his current situation. (WARNING: The following content may be disturbing or triggering to some readers).

> I don’t really care if I live or die; it’s all gone, there’s nothing left of me. So I don’t really care about life or death. I don’t care if I get Corona. There’s nothing left for me. My life is all gone. My good life is all gone. (Nate)

He was quite emotional during this part of the interview but wanted to continue the conversation. He discussed how he felt completely alone and that “all the good parts” of him were gone.

> I have nothing now, I don’t have my family, I got no kids or nothing, I got nothing. Well, I got a hernia, my dickie doo don’t get hard anymore [sic], so yano its all gone. My good part of life is gone down the drain. My family is a little fucked up in the head [sic]. If they wanna fire me after 33 years, go ahead. But it’s like I tell them. I’m not killing myself. I went this long staying alive, so I’m not gonna kill myself but I don’t care if I die or not, it’s all gone. Another day is another day. (Nate)

It is important to note that Nate claimed not to be suicidal at the time of this interview and a list of support services was available. See appendix F for list of support services. He voiced that he would not want to struggle at the EOL but “what choice do you have” and when it comes to living with pain that “you got no choice, it is what it is”. During this part of the conversation I asked about his knowledge surrounding palliative/end-of-life/hospice care. There was a clear lack of knowledge about this topic. He was concerned that a hospice centre would take his money and put everyone in one room to look after them: “They take your pension money and they take everything you own; cause they put everyone in a room and look after them. I know you gotta pay them and stuff.”

As mentioned, Nate was told by a health care provider that he was going to die if he continued living the way that he was living. Again, his mentality was on an “it is what it is” spectrum as displayed in the following quotes: “You’re gonna die” really? I was like this all my life”, “I tell everybody it is what it is”, “That’s right, what are you gonna do about it? If the good lord wants you, he will come and take you.” However, Nate believed that you do not have a say in how you die as displayed in the following quotes: “That’s the way I look at it. I just hope it’s fast and painless, but you got no say in that matter”, “Take it as it comes” and “If it gets bad I`ll just OD.” He also used sentences such as “Every day is the same day” and “When you die you die, I don`t believe there is an afterlife” in keeping with his experience of existential struggle.

Lilli discussed a time in which she sought information regarding medically assisted death due to her stomach cancer. In the following quote her experience of existential struggle was apparent.

> Yea, yea, it’s a struggle because I …All this happened in March and then the epidemic came out and it was just a lot. It was just a lot. My plan was just to go for assisted suicide because I didn’t want to get any sicker kind of thing… or try anything to try and get healthy if that makes any sense ….but I have a little boy he just turned 14 yesterday actually on the 30th., so. (Lilli)

She reached a point in her illness where she did not want to get any sicker, but also did not want to try anything in order to get healthy. We then talked about her thoughts surrounding death, dying and end-of-life care.

> About passing away? Sometimes if I am having a shitty day, if I’m having a bad day, yano… It makes me think if I have to struggle like this - so bad and be in so much pain - what is the point of still carrying on, not like I’m suicidal. I’m not any more or any less suicidal when I got sick there then I was before. (Lilli)

Again, it is important to note that a list of support services was available to each participant (see Appendix F).

Darcy`s experience of existential struggle was narrated in a more subtle way. We were on the topic of "good" death versus "bad" death. He voiced that dying in a violent manner, or dying in general, is something that he thought about often. "Sometimes I do, all the time about the question I just answered." Darcy also showed deep anxiety surrounding dying without his partner, or his partner not being with him, in general. He mentioned these anxieties many times throughout the interview in different ways. He voiced that when he dies, he would like to go to heaven; but not if that meant he would be without her. "I`d like to go to heaven, I would love to but I don`t want to be without her." This quote could be interpreted in different ways; however, it was clear that the thought of being without his partner in any capacity was anxiety provoking.

All participants had some component of existential struggle, specifically surrounding death. Nate experienced this in his daily life - he voiced that he did not care if he lived or died because he felt that he had nothing meaningful left in his life. Lilli had a very specific moment in time in which she thought about dying. In that moment, during the time of her stomach cancer diagnosis, she didn`t want to get sicker but also didn`t care if she got better. She also thought about dying in her day to day life whenever she experienced pain. Similarly, Darcy also voiced that he thought about dying, or how he will die, in his day to day life. Although there are many definitions and descriptions behind the meaning of existential struggle, it was clear that each participant experienced the phenomena in some way. This finding truly stresses how important psychosocial care is when someone is experiencing homelessness and living with progressive illness(es).

Short and Sweet

Each participant described what they thought a "good" death, or an ideal EOL situation, would look like to them. Through these accounts, the theme, *Short and Sweet* emerged.

Preferences toward and the experience of a “good” death is multifaceted and is largely shaped by one’s life contexts. Social structures such as age, class and gender are embedded into the interpretation of how individuals interpret their life experiences, including death and dying (Ko et al., 2014). Each participant in this study voiced their perceptions of what a “good” death would be. It was clear that their preference in how they would want to die would be to die comfortably, in their sleep, without pain. Ultimately, they did not want to experience any form of suffering at the EOL. Going to Heaven and being surrounded by loved ones, whether that be family or intimate partners, were also important to the participants in this study. The theme *Short and Sweet* is represented by the following three subthemes: *I Just Want to Fall Asleep, I Want to Die at Home - Wherever That May Be,* and *Surrounded by Those Who Love Me*, illuminating the preferences and concerns that individuals who are experiencing homelessness and living with progressive life limiting illness(es) have surrounding EOLC.

I Just Want to Fall Asleep

The meaning behind the subtheme, *I Just Want to Fall Asleep,* was illustrated in how the individuals in this study described their ideal EOL situation. Participants voiced that their ideal EOL situation would involve just going to sleep and not waking up. Dying in your sleep is often referred as dying peacefully, without suffering and is often reflected by being blissfully unaware of impending death. To grow old and die was also described as an ideal EOL situation, which is interrelated with the idea of dying peacefully, without suffering and carrying out one’s perceived life expectancy. Another participant voiced that they would like to go to heaven when they died, demonstrating the need for religious/spiritual connection at the EOL. Nate described a “good” death as one where you “*fall asleep and not wake up.”* He also voiced that he wasn`t scared of death and noted how he would not want to experience suffering at the EOL. When asked about his ideal EOL experience he said: *"*I'd do like everybody, grow old and die." Darcy described a "good" death as one where you just "fall asleep." He also voiced "I`d like to go to Heaven," when asked about his ideal EOL situation.

I Want to Die at Home, Wherever That May Be

The subtheme, *I Want to Die at Home, Wherever That May Be,* explored the uniqueness of dying at home as a desire amongst a population that mainstream society may view as being 'without' a home. For individuals experiencing homelessness, home may be a shelter, tent or park bench and thus the act of *dying at home* remains a relevant desire and preference for EOLC. People often wish to die at home as this is a comfortable and familiar surrounding. However, the support needed to die comfortably at home, wherever that may be, can be intensive, and requires access to many services such as palliative and home care, creating a barrier for dying at home for individuals experiencing homelessness.

Lilli described a "good" death as one that involved: "Just to be wherever it is I'm living, and comfortable and pain free." When asked about her ideal EOLC situation she voiced that she did not have a living will at this time and would prefer to die at home, not in a palliative care setting.

> Yea I would want to be at home, I wouldn't want to be in assisted living or a hospital or anything like that, I'd rather just be at home. Yea, I don't want to go in like palliative care and have people that I don't know looking after me. (Lilli)

Lilli was very clear about her wishes in not wanting to have people she didn`t know looking after her at the EOL. Instead, she wished to die wherever it was that she was living at the time.

Surrounded by Those Who Love Me

When describing a "good" death or an ideal EOL situation, participants in this study voiced the importance of being surrounded by loved ones. This desire resulted in the subtheme, *Surrounded by Those who Love Me.* Often, individuals experiencing homelessness have cut or lost ties with their family. For some, the desire to be surrounded by family, friends, and partners at the EOL denotes the importance of reuniting and finding closure in any remaining conflicts one might have. However, for others this may mean being surrounded by people who are currently present in their lives, such as romantic partners, shelter workers, and friends.

When describing a "good" death, Lilli voiced that she would want to die at home "and just have the people that I love with me." Darcy voiced how he had lost ties with his family, but has been encouraged by Lilli to reunite with them.

> I don't have anybody but her really. Like I don't, I haven't talked to my family in I don't know how long. When I got with her, a couple months was it 5 or 6 months? …And then she started getting me to contact them, right. But I haven't talked to them in 14 years, until I got with her. So, she actually tried to get me to reignite with them, right. (Darcy)

Despite the potential to reunite with family, Darcy voiced that he would not want them present in an EOL situation. He said: "No I`d just want her" meaning he would just want Lilli with him at the EOL.

Alone and in Pain

The following theme, *Alone and in Pain* was portrayed in how each participant described what they thought a "bad" death would look like to them and was further represented by subthemes: *I Don`t Want to Suffer* and *Dying Alone or Without 'Nothing'*. Participants voiced that death by violence, suffering, and dying alone or "without nothing" constitute "bad" or undignified deaths. The perceptions of a “bad” death are interrelated with perceptions of a “good” death as the ideas of *suffering* or *pain* are naturally described as undesirable.

I Don`t Want to Suffer

The subtheme, *I Don`t Want to Suffer* was reflected in how the participants described suffering to be the epitome of what constitutes a “bad” death. The perception of suffering was described by the participants in this study as being related to a cancer diagnosis, dying by suicide, or in a tragic or violent way such as being murdered or getting hit by a car.. This demonstrated the high level of danger that individuals experiencing homelessness face through their harsh living environments. Individuals in this study have encountered traumatizing acts of violence and have lost acquaintances through the act of suicide which affected their perceptions of undignified deaths. Nate replied when asked what he thought a “bad” death would look like: *“*Suffering, cancer and suffering… And pain all day, and people who kill themselves. I know a few people who did that.”. He also voiced: “That’s the way I look at it. I just hope it’s fast and painless, but you got no say in that matter.” Darcy voiced that a “bad” death would include dying in a tragic way: “A bad death would be getting hurt or murdered or anything like that or getting hit by a car. Yano that would be a bad death to me… or dying without the one that I love beside me.”

Dying Alone or Without ‘Nothing’

Participants also described a “bad” death as one that included dying alone, or without loved ones by their side. These accounts resulted in the subtheme, *Dying Alone or Without ‘Nothing’.* Dying without ‘nothing’ was a concern, specifically for one participant, which indicated how he perceived his current quality of life as being poor. This same participant spent time reflecting on his ‘past’ life prior to homelessness and described his current situation as one in which he is ‘watching his good life gone’ and having nothing good left. Lilli voiced that “a bad death would be passing away by myself and not having my family with me,” which coincided with her earlier wish to be surrounded by loved ones in an ideal EOL situation. Darcy had a similar response in that a “bad” EOL experience would be not having his partner with him. Contradictory to his earlier reply to what a “good” death would look like, Nate voiced that: “that’s a bad death, dying asleep and not waking up, dying without nothing.” “Having nothing” or *“*watching his good life gone” are phrases that he has used throughout our conversation as noted under the theme “Existential Struggle.” Feeling like there was nothing of value left in his life - whether that be his health or financial means - was a central concern regarding his attitude and beliefs surrounding EOL.

It was evident by the narratives that each participant gave when describing what a “bad” EOL situation would look like, that individuals perceived suffering, dying alone, or ‘without nothing’ as central concerns. Although the perceptions of a “bad” death may be similar to other housed populations, the statistics in which these experiences actually occur for those experiencing homelessness shape this perception and heighten these concerns.

Conclusion

Chapter IV presented the background story of each participant including their living arrangements (at the time of interviewing) and health history. This is a diverse group with progressive illness(es) ranging from hypertension, addictive disorders, mental illnesses and cancer. Each participant provided deep narratives regarding their experience, preferences and concerns regarding potential EOLC situations as well as their overall experiences with the healthcare system. This resulted in the overarching theme, *The Vicious Cycle of Homelessness: An End-of-life Trajectory*, which illuminated the individuals’ experience from a social, political and historical context. The five primary themes: *It`s Like A Big Red X When I Show Up; Am I Sick?; Existential Struggle; Short and Sweet; and Alone and in Pain* along with the subthemes presented within each were developed and relate back to the overarching theme, *The Vicious Cycle of Homelessness: An End-of-life Trajectory*, while providing an in-depth understanding into how, and what way, individuals who are experiencing homelessness and living with progressive illness(es), experience palliative and EOLC. A relevant and unique subtheme titled, "*COVID-19: How to Access What is Already Inaccessible"* was also presented under the theme "*It`s Like a Big Red X When I Show Up*", as each participant's experience with accessing the healthcare that they needed at the time of this study was greatly affected due to the ongoing COVID-19 pandemic. A paradigm case was also presented in this chapter as this case was often a point of discussion with my supervisor due to the deep and insightful narrative this participant brought to light. The following chapter will interpret each lived experience further within each theme and discuss lessons learned, new knowledge gained and how this information can be integrated into policy and practice.

Chapter V: Discussion

In this chapter I will discuss the results presented in Chapter IV to further our understanding of the lived experience of homelessness and EOLC. This chapter will also present what is already known, and what new knowledge this study adds to the small body of literature surrounding this topic. The implications for practice, policy and research will be addressed, the strengths and limitations of this study will be presented, followed by self-reflection and concluding remarks.

The purpose of this thesis was to address how, and in what way, individuals who are experiencing homelessness and living with progressive illness, experience palliative and EOLC. More specifically, I focused on the perceptions and meaning that individuals gave to: a) their experience of end-of-life care; b) concerns and preferences for end-of-life care; and, c) accessibility to end-of-life care services. I sought to answer the following questions:

1) What is the experience of palliative and EOLC among individuals living with progressive life limiting illness who are also experiencing homelessness?
2) What meaning do individuals - living with progressive life-limiting illness who are also experiencing homelessness - give to death, dying and EOLC?
3) What concerns do individuals - living with progressive life-limiting illness who are also experiencing homelessness - have with respect to their EOLC or potential EOLC experience?
4) What preferences do individuals - with progressive life-limiting illness who are also experiencing homelessness - have in regard to EOLC needs?

5) What perceived and/or real barriers do individuals face in accessing EOLC services when living with progressive life-limiting illness and also experiencing homelessness?

To address these questions, I will summarize and discuss the key findings as they relate to the purpose of this research.

Findings

Three individuals experiencing homelessness - who also were living with progressive illness(es) - participated in this study and shared their experiences, concerns and preferences for EOLC. The meaning in which each individual gave to death and dying was uncovered and the perceived and/or real barriers that participants faced in accessing health/EOLC services were discussed. These accounts resulted in the overarching theme: *The Vicious Cycle of Homelessness: An End-of-life Trajectory,* which illuminated the individuals' experience from a sociopolitical context. The five themes - *It`s Like A Big Red X When I Show Up, Am I Sick?, Existential Struggle, Short and Sweet, and Alone and in Pain* - were developed within, and relate back to, *The Vicious Cycle of Homelessness: An End-of-life Trajectory*. Each primary theme was further broken down into subthemes to explore specific narratives in greater depth.

The Vicious Cycle of Homelessness: An End-of-life Trajectory

The overarching theme of this study reflects how participants in this study are caught in a vicious cycle of deteriorating circumstances. This vicious cycle affects their mental, social and physical wellbeing. Their state of homelessness not only served to create new health issues, it also exacerbated existing ones. This is largely due to the inability to access appropriate aid and healthcare services and supports. The day to day challenges of homelessness such as finding nutritious food sources, accessing clean water and hygiene products and even just finding a safe place to sleep, deeply affect their emotional and physical wellbeing. The vicious cycle of homelessness and how it affects the participants' perceptions, concerns and preferences surrounding EOL and their overall health are ingrained in the results of this study. The inability to access or afford nutritious food landed one participant in the hospital and kept another participant from undergoing potentially life-saving stomach cancer surgery.

When reflecting on food insecurity from a critical social theory lens, it is evident that food insecurity is more than just a lack of access to nutritious foods, it is a social injustice that stems from many structural issues, negative impacts of climate change, and the production of biofuels (Koizumi, 2015). According to Statistics Canada (2020), in 2017-2018 12.7% of households across Canada suffered from food insecurity. In Nova Scotia, 15.4% of households suffered from food insecurity which is the highest rate in any Canadian province (Statistics Canada, 2020; Vibert, 2020). There have been numerous studies tying food insecurity to an increased risk of chronic health conditions such as diabetes, cancer, hypertension and COPD (Gregory & Coleman-Jensen 2017; Leung et al., 2020; Vibert, 2020). This results in an increased need for equitable palliative/EOLC services.

Evidence shows that the vicious cycle of homelessness and experiencing mental health disorders are also closely linked. Mental health disorders such as depression, anxiety and schizophrenia are more prevalent amongst those experiencing homelessness. Homelessness increases the risk of mental health disorders and having a mental health disorder increases the likelihood of experiencing homelessness, demonstrating its cyclical nature (World Health Organization, 2007). The literature also demonstrates similar findings surrounding the use of alcohol and other drugs amongst this population. Addictive disorders increase the likelihood of experiencing homelessness, and homelessness increases the risk of addictive disorders

(Thompson et al., 2004). It is important to recognize that the use of substances such as alcohol or illicit drugs, may be a way in which individuals self-medicate for pain, or cope with life-long trauma and difficult life circumstances (McNaughton, 2008). Substance use can also compromise immune systems and increase the risk of bloodborne diseases such as HIV and Hepatitis B and C (Marshall et al., 2008; Nyamathi et al., 2013). The vicious cycle of homelessness may lead to an individual having tri-morbidities including progressive illness, mental health and addictive disorders (Hulchanski, 2009). As such, caring and treating individuals experiencing homelessness becomes more challenging, negative healthcare experiences erupt and more and more barriers in accessing health and EOLC services begin to surface. Ultimately, this leads to poor health outcomes and prognoses. This results in the increased demand for equitable EOLC services and the need to illuminate the voices of those who have the lived experience of moving through the vicious cycle of homelessness while also enduring progressive illness(es).

It's Like a Big Red X When I Show Up

Participants in this study felt that they were being discriminated, stereotyped and judged by health care providers when accessing healthcare services or when advocating for their healthcare needs, leading to distrust toward health care providers and ultimately, poor healthcare experiences. They believed that this was due to their homeless state and addictive disorders which required methadone treatment. This finding is supported by the small, but growing body of literature which demonstrates how stigma, discrimination and judgement results in poor healthcare experiences. This perceived negative relationship with health care providers may result in the avoidance of seeking palliative/EOLC services (Hudson et al., 2016; Song et al., 2007). In a study completed by De Veer et al. (2018), individuals experiencing homelessness voiced that they often did not have any confidence in health care providers because they believed that they were not being treated equitably and perceived a feeling of disparage. It was also concluded that the participating individuals had feelings of shame due to ongoing addictions and physical neglect (De Veer et al., 2018). When looking at this issue from the perspective of the health care provider, it appears that the negative attitudes that individuals experiencing homelessness perceive are the unfortunate reality in many cases. A systemic review conducted by Parkinson (2009) on the attitudes of nurses towards people who were experiencing homelessness indicated that throughout the literature, themes regarding the existence of negative attitudes were apparent, people who are experiencing homelessness are often dehumanised, and nurses` prejudice act as a barrier for people experiencing homelessness to access healthcare (Parkinson, 2009).

There is a lack of understanding among health care providers regarding addictions and palliative medicine in general, making it hard for health care providers to provide adequate pain and symptom management (McNeil & Guirguis-Younger, 2011; Webb, 2015). The use of methadone, cocaine, alcohol or antidepressants may alter the reactions individuals have to palliative pain and symptom control medications resulting in suboptimal pain control; current palliative/hospice care protocols often do not take this into account (De Veer et al., 2018). Results in the De Veer et al. (2018) study also concluded that physicians involved in caring for individuals experiencing homelessness at the EOL noticed that pharmacists and psychiatrists lacked knowledge surrounding optimal pain medication dosages for individuals with addictive disorders which resulted in insecurity when prescribing, and in turn, may lead to poor EOLC experiences. There is also a misconception that palliative care is often thought to be associated only with terminal care; however, palliative care can improve quality of life for a person with progressive illness - whether the illness is terminal or not.

COVID-19: How to Access What is Already Inaccessible?

Another important finding presented in this study was how the global COVID-19 pandemic disproportionately affected the participants in this study by creating yet another barrier in accessing health and social services. Participants in this study also felt that their physical and mental health began deteriorating at a more rapid pace during the COVID-19 pandemic, especially during the public health mandated quarantine. Due to their pre-existing comorbidities (i.e. cancer, hypertension) and immunocompromised state, participants in this study were at an increased risk of contracting the COVID-19 virus. They were also at an increased risk due to overcrowded shelters and high occupancy housing, making socially distancing much more challenging. Two participants in this study moved into a tent beside of a local highway as they felt this was safer than the overcrowded housing arrangement in which they were living. In doing this, they were able to socially distance; however, access to clean water and food became a challenge, exacerbating their pre-existing physical and mental health ailments.

At the time in which this thesis was written, the novel COVID-19 virus had been making its way through Canada for approximately 8 months. Globally, the COVID-19 pandemic has heightened the awareness of the housing crisis that exists in all parts of the world. It also brought to light the systemic and structural racism that puts Black and Indigenous communities at higher risk of experiencing homelessness. Members of minority groups are not only facing higher risks from COVID-19 due to homelessness, they also are at serious risk of newly entering a state of homelessness due to economic disruptions as a result of COVID-19 (Doran at al., 2020). Doran et al. (2020) also wrote that “housing is health care” (p. 2), as individuals experiencing homelessness are at an increased risk for contracting COVID-19; an outbreak amongst those experiencing homelessness could threaten already burdened health systems. The Centres for

Disease Control and Infection (2020) has published guidelines on how to best serve those experiencing homelessness after studying outbreaks that have occurred across the United States in homeless shelters. These guidelines recommend socially distancing, infection control practices, mask wearing, and promptly isolating anyone who is symptomatic or tests positive. However, the complex nature and transient lifestyles of those experiencing homelessness make it difficult to practice these recommendations. For example, results from this study indicate that the participants lacked health awareness. Kar et al. (2020) also voiced that individuals who are experiencing homelessness, and who also have mental health disorders, are deprived of their basic rights and often do not have access to health-related information which may result in lack of knowledge and nonadherence of personal protective measures. Furthermore, the closure of many services such as community centres, may exacerbate existing mental health or addictive disorders for those who have become accustomed to receiving extra social supports (Perri et al., 2020). Ultimately, the higher risk factors for contracting the COVID-19 virus, the higher risk of critical illness due to pre-existing comorbidities and inaccessibility to health and social services, increase the demand for EOLC services for the homelessness population. The results from this study add to the existing body of knowledge surrounding COVID-19 and its effects on those experiencing homelessness. However, the results from this study also present a new narrative, one that is from the perspective of those experiencing homelessness and living with progressive illness(es). The results from this study indicate how COVID-19 not only exacerbated pre-existing physical and mental health illnesses, it also created yet another barrier in accessing health and social services.

Although the purpose of this thesis was not to address the impacts of COVID-19 on individuals experiencing homelessness, COVID-19 has shaped the current context in which the individuals in this study live. This new context, or way of being in the world, in turn, contributes to the meaning, perceptions and concerns that participants have for death, dying and EOLC. One participant voiced that he didn’t care if he contracted the COVID-19 virus, as life and death are meaningless to him. This is strong evidence of the need for equitable heath, social and palliative services that treat the person holistically, without discrimination and prejudice.

Am I Sick?

Findings in this study indicate that participants neglected to seek medical attention, lacked knowledge of the full picture surrounding their diagnoses and/or prognosis, were uncertain what their prescribed medications were intended to address, or neglected to take their prescribed medications at times due to mental health disorders and access problems. Participants often neglected to seek medical attention until their symptoms were debilitating in nature. At one point in his illness trajectory, Nate ignored seeking medical attention until he was unable to walk, Lilli ignored her symptoms of stomach cancer until she couldn`t get out of bed, and Darcy continues to neglect seeking health care for his ongoing seizure activity. The reasons participants neglected to seek medical attention or accessed medical care late, are complex and individualized. There was an overall sense that the participants in this study lacked health awareness, which is an important finding as it could relate to the fact that despite being quite ill, participants did not recognize the need for EOLC. In addition, the previous mentioned perceptions of stigma and discrimination and negative past experiences with health care providers create animosity toward seeking help. Past-traumas and current mental health disorders (i.e., anxiety and PTSD) are also among the list of reasons with which individuals struggled to seek medical attention, gain health awareness and take prescribed medications. These findings are supported by much of the literature surrounding individuals experiencing homelessness.

From a palliative care perspective, De Veer et al. (2018) found that late access to palliative care services was a common theme amongst individuals experiencing homelessness. It was found that this result was due to health care providers having difficulty in recognizing palliative care needs of individuals experiencing homelessness, ambivalence felt by individuals experiencing homelessness towards searching for and accepting care, and the lack of existing palliative care services specialized for individuals experiencing homelessness. MacWilliams et al. (2014) found similar results in that individuals experiencing homelessness usually only presented to the hospital once very unwell. If the prognosis was poor the individual would remain in hospital until they died or would sometimes discharge themselves, resulting in a cycle of emergency room admissions. The inability to adhere to treatment regimens such as taking prescribed medications was also a finding in the MacWilliams et al. (2014) study which corresponds with the findings in this study. However, for the participants in this study, it was determined that non-compliance is often due to the state of the individual's mental health. For example, Darcy often left the hospital against medical advice due to his debilitating anxiety and PTSD from previous traumas. The literature also states how individuals experiencing homelessness may overlook their healthcare needs, or neglect to seek care, as they must focus on basic human needs as a priority and live in survival mode (Baggett et al., 2010; Omerov et al., 2019; Stajduhar et al., 2018; Vuillermoz et al., 2017). Stajduhar et al. (2018) found that when individuals experiencing homelessness received a legitimate palliative diagnosis, not only did they experience good care, some felt that it was the best care they have ever received. However, it was not until the end of their lives that these individuals finally received the compassionate, equitable care that everyone deserves.

Existential Struggle

Another finding of the study focused on the experience of existential struggle amongst individuals who are precariously housed and living with progressive illness(es). Participants in this study, at some point in their illness trajectory, did not care if they lived or died. This experience was individualized, and each participant experienced this feeling in varying intensities. Nate spoke of feeling like he had nothing good left in his life, so he didn`t really care about life or death, or even if he contracted the COVID-19 virus. Lilli, when faced with the diagnosis of stomach cancer, sought medically assisted death because she felt that she didn`t want to get any sicker, but also didn`t care to get better. Participants also voiced how some days, being in pain made it hard to go on and how death was a thought in their day to day lives. Existential struggle has many interpretations and broad definitions making it a poorly understood phenomenon. For the participants in this study, their existential struggle was related to their thoughts about dying and the dying process and the perceived lack of meaning or purpose in their lives. Participants in this study suffered with mental health and addictive disorders, past traumas, and progressive illness(es) that cause somatic pain. In much of the literature, existential suffering is interchanged with spiritual issues; however, for the participants in this study their existential suffering was independent of spirituality or religion. This coincides with some literature that states that existential and spiritual issues are completely separate concepts (Boston et al., 2011). An integrated literature review conducted by Boston et al. (2011) looked at existential suffering in palliative care settings and concluded that existential struggle is often seen in the context of psychological symptoms. This literature review also discussed how the distinction between depression and existential suffering is extremely challenging as there are no clear strategies in defining, or assessing, existential suffering (Boston et al., 2011). Despite inconsistent understandings surrounding the definition of existential struggle, it goes without question that attending to a person’s physical and psychosocial wellbeing are important and vital parts of providing person-centered palliative care. Little to no research has been identified that looks at existential struggle amongst individuals experiencing homelessness in general or in an EOL situation. This result demonstrates the need for whole person-centered care including mental, spiritual, and psychosocial care for individuals experiencing homelessness living with progressive illness(es), especially in a palliative/EOLC context.

Short and Sweet/Alone and in Pain

The final two themes of this study bring to light the perceptions that individuals experiencing homelessness living with progressive illness(es) have surrounding death, dying and EOLC. Participants concerns and preferences surrounding their idealized EOL situation were illustrated when each participant described what a “good” and “bad” death looked like to them. The social and political structures that shape each participant`s lived experience including gender, race, the vicious cycle of homelessness, and currently living through a global pandemic, are embedded into their constructs of death and dying. Results from this study indicate that a “good” death, or an ideal EOL situation for individuals in this study, would be one that happened in their sleep, without pain or suffering. Participants also voiced the desire to be surrounded by those who loved them. However, this did not necessarily mean family. For example, Darcy voiced that he would not want his family with him at the EOL, just his current romantic partner. Lilli voiced that she would want her EOL experience to be wherever it was that she was living at the time, and not in a palliative care or health care setting. This result emphasises how mainstream perceptions of “home” may not fit that of those experiencing homelessness. The provision of EOLC at “home” for individuals in this population may include a shelter, assisted living, tent or park bench. This result also brings to light the importance of “family” as EOL care giver. For some individuals experiencing homelessness, “family” may be non-traditional (i.e., street family, shelter workers, street navigators). Stajduhar et al. (2018) recommends challenging the assumptions and policies that prevent non-traditional family from caring for their loved one at the EOL.

The study participants expressed the desire to die comfortably, without suffering, at home and surrounded by those who love them. This result is also supported by the small body of literature available that looks at important aspects of EOLC for those experiencing homelessness. According to the literature, the discourse that has been identified surrounding what constitutes a “good” death, or ideal EOL situation, for this population include: the desire for a “peaceful” death that is without pain or suffering, making a spiritual or religious connection, making amends with family and friends, and seeking reconciliation or taking care of inner conflicts (Ko et al., 2015; Song et al., 2007; Tarzian et al., 2005).

The discourse surrounding what constitutes a “bad” death for the participants in this study involved suffering, dying alone, or through an act of violence such as being murdered or getting hit by a car. This finding too, is supported by the small body of literature surrounding the concerns that individuals experiencing homelessness have in regard to death, dying and EOLC. Concerns of dying through violence, drug overdoses, and dying alone, or anonymously were amongst this discourse (Hudson et al., 2016; Ko et al., 2015; Song et al., 2007). The Health Care for Homeless Clinicians Network (2018) indicated that some individuals experiencing homelessness may perceive that a “short and sweet” death is preferable to “endless suffering” due to the inequalities in care and poor allocation of resources for this community.

Implications for Practice, Policy and Education

My mission, aims, and approach focuses on advancing health and social justice for those living in disadvantaged environments while informing care and practice change. First and foremost, utilization of my position of knowledge, privilege, and clinical insight as a Registered Nurse will allow me to mobilize my findings and give back to the homelessness community. I plan to disseminate this information through "lunch and learn" style education sessions for individuals experiencing homelessness as well as create infographic posters and pamphlets with palliative/EOLC information to distribute to local shelters and at other community-based homelessness services with hopes to reach a wider audience. Being able to recognize serious symptoms and progressive illness in oneself and seeking care sooner is a crucial. Having a general understanding of what palliative care is and how it can and should be accessed prior to one's final days is vital. Knowing what palliative resources are available locally is imperative. Engaging members of the homelessness community and taking findings back to them truly acknowledges their role and reinforces the impact of their voice.

Translating knowledge gained from this study into practice is essential in moving toward a more equitable and humanistic approach in caring for those experiencing homelessness at the EOL. This approach needs to begin far beyond the point in which palliative/EOLC services are needed. This can be achieved by addressing the social determinants of health as a precursor to equitable palliative care (Stajduhar et al., 2018). The findings from this study have the potential to inform the education and practice of healthcare providers, community-based organizations, outreach programs, shelter workers, hospice centers and palliative inpatient units. Through the theme, *"It`s Like A Big Red X When I Show Up"*, it was discovered that the participants in this study felt deeply stigmatized, judged and discriminated against for both their state of homelessness as well as for their addictions. One participant voiced that he wasn`t treated very good due to the fact that he was on methadone. As a Registered Nurse who spent time working in the Emergency Department, the label "drug seeking" or "frequent flyer" is used more often than I`d like to admit. This needs to change. This change can begin to happen by ensuring nursing and allied health care providers educational programs focus on patient-centered, trauma-informed and harm-reduction approaches to care. Nurses and allied health care providers can also be mindful to use non-stigmatizing, person-first language in order to reduce stigma and negative bias when caring for individuals experiencing homelessness or those with addictive disorders. During my conversations with each participant, it was clear that escaping homelessness and battling their addictions was of extreme importance to them. For example, Lilli voiced the importance of accessing available resources as high priority each and every day in order to get back on her feet. She showed just how resilient she could be despite her hardships. She also showed courage when she proclaimed that she sought Medically Assistance in Dying services. In fact, each participant showed courage just by participating in this study and sharing their emotional journeys. In highlighting one's self-determination, we as healthcare providers can utilize a strengths-based approach in order to empower individuals and move toward a more preventative and collaborative framework, specifically for those who are considered marginalized by society or in this case, those experiencing homelessness and living with progressive illness/mental health and addictive disorders (Pattoni, 2012). Education surrounding existential struggle, mental and spiritual health is also imperative. This focus should be embedded into all health care education and integrated into all health discipline programs at the undergraduate, graduate, post-graduate and continuing education levels. By initiating this frame of thinking early, aspiring healthcare providers may carry this approach into their professional careers. Furthermore, when partnering with these entities, centering the voice of those experiencing homelessness will be at the forefront. This approach is emancipatory in that it will illuminate the hidden experiences of a marginalized population with an overwhelming need for holistic, collaborative, and accessible EOLC.

The findings from this study may contribute to the wider academic community and policy-making teams in public health. One way in which this will be accomplished is by publishing a peer-reviewed manuscript. My mission is to implement findings into upstream areas of health systems planning and provincial decision making. In doing so, I may contribute to national and provincial advocacy initiatives, knowledge, and care structures that promote equitable access to EOLC for people who are experiencing homelessness. Prior to the completion of this thesis, I have already begun to have meetings with "like-minded" individuals who serve those experiencing homelessness in the Halifax Regional Municipality (i.e. members of the Mobile Outreach Street Health, Hospice Halifax and United Way teams) to discuss how we can provide equitable EOLC for our neighbors experiencing homelessness. Findings from this study may also force organizations, such as Hospice Halifax, to take a look at existing policies and guidelines (i.e. behavioral policies, abstinence policies and zero tolerance policies) and ask, does this current framework promote equitable access for all? In doing this, organizations may move toward harm-reduction approaches to care - which may promote access and decrease the likelihood of an individual avoiding care or leaving health/EOL care setting prematurely (Stajduhar et al., 2018). Including individuals with the lived experience of homelessness in policy, evaluation and program planning can help ensure plans are effective and serve to strengthen outreach and engagement efforts (Centre for Disease Control and Prevention, 2020).

Recommendations for Future Research

As mentioned, only a small body of literature exists surrounding the concerns, preferences and perceptions that individuals experiencing homelessness and living with progressive illness(es) have surrounding palliative and EOLC. Most of the literature is from the perspective of health care, or homelessness service, providers. In order to strengthen our understanding of this phenomenon, more in-depth qualitative research is needed from the perspective of those with the lived experience, especially from a diverse population. It would also be of high importance to gain the perspective of those who are actively receiving palliative or EOLC. However, this would not be an easy task as evidence from both this study and available literature shows that individuals experiencing homelessness often do not access health or EOLC services until symptoms are severe or death is imminent. This can be due to social injustices, marginalization, past negative experiences, and lack of health awareness. Further research surrounding the existential struggles that individuals experiencing homelessness face, especially in a palliative care context, is also recommended. Focusing on how, and in what way, this phenomenon is experienced will increase the knowledge that health care providers have on how to assess, differentiate, and care for individuals experiencing homelessness at the EOL more holistically.

In order to aid in recruitment for this study, it was imperative that I was available to conduct interviews at the moment the potential participant contacted me as illustrated in Chapter III. Due to the transient nature of individuals experiencing homelessness, scheduling a date and time to conduct interviews in advance may result in the loss of a potential participant, as they may no longer be in the same area or may no longer have access to telephone/internet. Such access is recommended to ensure availability during recruitment efforts to secure enrollment of all interested and eligible participants.

Although my initial plan was to conduct interviews face-to-face in order to develop trust and rapport, this was not an option due to the COVID-19 pandemic, Research Ethics Board recommendations, and Dalhousie Universities COVID-19 policy. Fortunately, I was able to contact an individual who worked in the homelessness community to aid in recruitment efforts. This individual truly embodied a trusting relationship, which is a quality that is very much needed in recruitment of individuals in the homelessness community. It is recommended that a relationship built on trust and respect be developed with potential participants, or that a well-known key stakeholder from the community who embodies these traits, is part of recruitment efforts. As a methodological approach for future research, interpretive phenomenology with a critical social theory lens may be considered as both the philosophical and theoretical principals of these approaches allow room for not only the interpretation of the lived experience of a phenomenon, but also how this phenomenon is experienced through a sociopolitical context. This is vital in order to shed light on the social and structural injustices individuals experiencing homelessness face, especially when it comes to access to services such as EOLC.

Finally, in order to implement findings into upstream areas of health systems planning and provincial decision making, research is needed that includes large scale qualitative or quantitative studies to more fully identify and describe the need for specialized homelessness EOLC services on a local level.

Strengths and Limitations

A strength of this study is that it is among the first to explore the perceptions, concerns and preferences of EOL/palliative care from the perspective of those who are experiencing homelessness and living with progressive illness(es). A small sample size was anticipated as this population is often deemed hard to reach (i.e., transient lifestyle). As a qualitative study, the results reflect an in depth understanding of the experience of a small group, rather than a broader more generalizable reflection of the experience of a larger group (Creswell, 2007). Nevertheless, small sample sizes may have limited potential to assume generalizability. Therefore, the small sample size in this study can be both a strength and a limitation. However, the sample population had a level of diversity and made up of individuals of different identified genders, ages, living arrangements and progressive illness(es). A strength of this study is that despite the varying diagnoses and prognoses of progressive illness(es), participants shared and described many similar experiences in terms of access and their concerns/preferences for EOLC.

In keeping with the hermeneutic phenomenology philosophical principals, I have provided detailed and robust descriptions of my experience during data collection so that the reader can apply transferability judgements for themselves. I have also provided many verbatim quotes to support findings, serving to strengthen this study (Benner, 1994; Polit & Beck, 2008). Hermeneutic phenomenology is a philosophy in which the researcher is required to extract philosophical principles and apply them to the study. This is open to criticism and may be seen as a limitation as the process of translating philosophy into practice involves the researcher`s interpretation. There are also limitations in regard to interviewing as a method in data collection, as participants may alter their behavior while under investigation (Polit & Beck, 2008).

Two of the participants in this study were involved in a romantic relationship and living together at the time of interviewing; their shared experiences due to their close relationship may be seen as a limitation to this study. Each participant was interviewed separately, as I only talked to one participant at a time; however, they would have been together, sharing a telephone which could have affected the information that they shared with me. However, it was clear that they relied on each other for emotional support due to past traumas and their mental health. The nature of this topic including death, dying and EOLC is heavy, and as these individuals have been marginalized, traumatized, victimized and exploited historically, it was important to be flexible in my interviewing approach and allow room for them to support one and other, however they needed.

Self-Reflection and Concluding Remarks

In reflection, my positionality, which includes the experience of housing poverty as a child and now my professional experience with caring for an individual experiencing homelessness at the EOL, were the reasons in which I started this journey. I wanted to enhance my understanding of how, and in what way, individuals who are experiencing homelessness and living with progressive illness, experience palliative and EOLC. When my patient died, after drinking a bottle of "Drano", suffering, without family or friends at his bedside, without identification and just the designation of "John Doe" to humanize the situation, I couldn't help but feel as though we, as a society, failed him. The harsh reality of the social injustice this population faces became apparent. I came to understand through reviewing the small body of literature and now through my own study, that the way in which "John Doe" died, is a fear shared amongst those experiencing homelessness. Participants in this study described dying alone as a bad, or undignified, way to die. Participants instead valued an EOL experience that was without suffering, surrounded by those who love them, and in a familiar place, wherever that may be. The findings from this study suggested that if given the choice, participants would not want to utilize formal palliative care centres such as hospice or hospital based palliative care floors. As a Registered Nurse, with a passion for palliative care, this result truly surprised me. I have always considered hospice and palliative care institutions as beautiful services in which anyone at the end of life could go and have a peaceful and meaningful dying experience; as such, I thought the findings from this study would indicate that individuals experiencing homelessness would too, wish to access these services. I thought that if the participants in this study showed interest in formal hospice and palliative care services, I could use this information to force local organizations to truly assess whether their service was accessible for those experiencing homelessness. However, through the participants in this study, I learned that is goes much deeper than just fighting for equitable access, it is also about challenging our own biases and views of what we consider as "traditional" or "dignified" dying experiences.

Through the interviewing process, I took every effort to ensure an authentic relationship was built. This, at times, meant sharing personal stories, allowing myself to show emotion and be flexible by using a conversational approach during each interview. I do believe that this relationship, which may be seen as controversial for some researchers from an ethical perspective, created space in which the participant could share their lived experience, which was often an emotional journey, without feeling judged or discriminated against. This led to meaningful conversations and as a result an in-depth look into the experience, perception and meaning, individuals experiencing homelessness give to death, dying and EOL. Karabanow and colleagues (2018) view this approach as one that follows anti-oppressive principles which leads to more reflective, transparent and accountable framing in our data collection methods with vulnerable populations.

An interpretive phenomenological methodology with the philosophical lens of critical social theory was helpful in pushing me to go beyond describing the phenomenon, to interpreting how the phenomenon was experienced within a sociopolitical context. This frame of thinking led to the overarching theme, *The Vicious Cycle of Homelessness: An End-of-life Trajectory,* which deeply influenced how participants perceived death, dying and the EOL experience. The vicious cycle of homelessness also illuminates how assessing and caring for all social determinants of health for this population is vital in ensuring equitable, humanistic health and EOLC. In conclusion, Lilli said it best: *"I know what I need and that's food in front of me and a roof over my head."*

References

Abrams, L. (2010). Sampling 'Hard to Reach' Populations in Qualitative Research: The Case of Incarcerated Youth. *Qualitative Social Work, 9*(4), 536-550.

Affordable Housing Association of Nova Scotia. (2015). Halifax, NS. 2015 Halifax Homeless Point in Time Count: A Survey of People Living on the Streets and Shelters. Retrieved from http://housingandhomelessness.ca/wp-content/uploads/2015/12/We-Are-Here-The-HRM-Point-In-Time-Count-Web-Updated-Version.pdf

Affordable Housing Association of Nova Scotia (2018). Halifax, NS. 2018 Halifax Homeless Point in Time Count: Everyone Counts. Retrieved from https://static1.squarespace.com/static/5a65f576aeb625ade6b35818/t/5bc78e6bf4e1fc6e882af412/1539804783894/2018+Halifax+Point+in+Time+Count+Report.pdf

Aleman, A. (2017). What are the palliative care services available to the homeless population in Canada. Retrieved from https://www.homelesshub.ca/blog/what-are-palliative-care-services-available-homeless-population-canada

Ali, N. (2016). Public Mental Healthcare & Services. *Canadian Observatory on Homelessness.* Retrieved from http://homelesshub.ca/blog/public-mental-healthcare-service-delivery-0

American Public Health Association. (2017). What is public health. Retrieved from https://www.apha.org/what-is-public-health

Baggett, T., O'Connell, J., Singer, D., & Rigotti, N. (2010). The unmet health care needs of homeless adults: A national study. *American Journal of Public Health, 100*(7), 1326-1333.

Bates, A. (2016). Addressing Existential Suffering. Retrieved from https://bcmj.org/articles/addressing-existential-suffering#:~:text=Themes%20common%20to%20the%20descriptions,autonomy%2C%20and%20loss%20of%20temporality.

Belanger, Y., Awosoga, O., & Weasel-Head, G. (2013). Homelessness, Urban Aboriginal People, and the Need for a National Enumeration. Retrieved from http://www.academia.edu/2065162/_Homelessness_Urban_Aboriginal_People_and_the_Need_for_a_National_Enumeration._

Benner, P., 1994. Interpretive phenomenology: Embodiment, caring, and ethics in health and illness. *Sage Publications*, Thousand Oaks, CA.

Bevan, J., Senn-Reeves, J., Inventor, B., Greiner, S., Mayer, K., Rivard, M., & Hamilton, R. (2012). Critical social theory approach to disclosure of genomic incidental findings. *Nursing Ethics, 19*(6), 819-828.

Boston, P., Bruce, A., & Schreiber, R. (2011). Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management, 41*(3), 604-618.

Browne, A. (2000). The potential contributions of critical social theory to nursing science. *Canadian Journal of Nursing Research, 32*(2), 35-55.

Bunds, K., Newman, J., & Giardina, M. (2014). The Spectacle of Disposability: Bumfights, Commodity Abjection, and the Politics of Homelessness. *Critical Studies in Media Communication, 32*(4), 1-15.

Burge F, Lawson B, Johnston G. (2005). Where a cancer patient dies: the effect of rural residency. J Rural Health. 2005;21(3):233–238.

Burt, M., Aron, L.Y., & Lee, E. (2001). Helping America's homeless: Emergency shelter or affordable housing? Washington, DC: The Urban Institute Press.

Canadian Hospice Palliative Care Association. (2013). What Canadians Say: The Way Forward Survey Report.

Canadian Institute for Health Information. (2018). Access to Palliative Care in Canada. Retrieved from https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf

Canadian Medical Association. (2013). Healthcare in Canada: What Makes Us Sick? Retrieved from https://www.cma.ca/multimedia/CMA/Content_Images/Inside_cma/Advocacy/HCT/What-makes-us-sick_en.pdf

Canadian Observatory on Homelessness. (2017). Halifax, NS. Homeless Hub 10 years, Making Research Matter. Retrieved from http://homelesshub.ca/community-profiles/nova-scotia/halifax Canadian Population Health Initiative of the Canadian Institute for Health Information. (2009). 2.3

Canadian Partnership Against Cancer. (2019). 5,000+ paramedics in six provinces to provide palliative care in the home. Retrieved from https://www.partnershipagainstcancer.ca/news-events/news/article/5000-paramedics-six-provinces-palliative-care-home/

Canavan, Réamonn, Barry, Margaret M, Matanov, Aleksandra, Barros, Henrique, Gabor, Edina, Greacen, Tim, Holcnerová, Petra, Kluge, Ulrike, Nicaise, Pablo, Moskalewicz, Jacek, Díaz-Olalla, José Manuel, Straßmayr, Christa, Schene, Aart H, Soares, Joaquim J F, Gaddini, Andrea & Priebe, Stefan. (2012). Service provision and barriers to care for homeless people with mental health problems across 14 European capital cities. *BMC Health Services Research*, *12*, 222. http://doi.org/10.1186/1472-6963-12-222

Candela, A. (2019). Exploring the Function of Member Checking. *The Qualitative Report, 24*(3), 619-628.

Chamberlain, C., & Johnson, G. (2013). Pathways into adult homelessness. *Journal of Sociology, 49*(1), 60-77.

Corfu, N. (2018) When it comes to end-of-life care, options for Halifax`s homeless are few. *CBC news.* Retrieved January, 2018 from http://www.cbc.ca/news/canada/nova-scotia/homeless-dying-halifax-hospital-shelter-hospice-end-of-life-palliative-care-1.4493230

Crane, M., & Warnes, A. M. (2010). Homelessness among older people and service responses. *Reviews in Clinical Gerontology*, **20**(4), 354–363

Creswell, J.W. (2013). Qualitative inquiry and research design. Choosing among five approaches. (3rd ed). Thousand Oaks, CA: Sage.

Crist, J., & Tanner, C. (2002) Interpretation/Analysis Methods in Hermeneutic Interpretive Phenomenology. *Nursing Research* 52.3 (2003): 202-05. Web.

De Veer, A.J.E, Stringer, B, Van Meijel, B, Verkaik, Renate, & Francke, A.L. (2018). Access to palliative care for homeless people: Complex lives, complex care. *BMC Palliative Care, 17*(1), Urn:issn:1472-684x.

Davis-Berman, J. (2016). *Social work & society. Social Work & Society* (Vol. 14). University of Bielefeld, Center for Social Service Studies. Retrieved from http://www.socwork.net/sws/article/view/459/844

Doran, R., Mccormack, M., Shelley, R., & Gelberg. (2018). Substance use and homelessness among emergency department patients. *Drug and Alcohol Dependence, 188*, 328-333.

Doran, Cha, Cho, DiPietro, Gelberg, & Kushel. (2020). Housing as Health Care During and After COVID-19 Crisis. Retrieved October 16th, 2020 from https://deepblue.lib.umich.edu/handle/2027.42/154767

Englander, M. (2012). The Interview: Data Collection in Descriptive Phenomenological Human Scientific Research. *Journal of Phenomenological Psychology, 43*(1), 13-35.

Frankish, C., Hwang, S., & Quantz, D. (2005). Homelessness and Health in Canada: Research Lessons and Priorities. *Canadian Journal of Public Health, 96*, S23-9.

Gaetz, S., & O'Grady, B. (2002). Making Money: Exploring the Economy of Young Homeless Workers. *Work, Employment & Society, 16*(3), 433-456.

Gaetz, S., Barr, C., Friesen, A., Harris, B., Hill, C., Kovacs-Burns, K., Pauly, B., Pearce, B., Turner, A., & Marsolais, A. (2012) Canadian Definition of Homelessness. Toronto: Canadian Observatory on Homelessness Press.

Gaetz, Donaldson, Richter & Gulliver. (2013). The State of Homelessness in Canada. Retrieved from https://www.homelesshub.ca/about-homelessness/homelessness-101/how-many-people-are-homeless-canada

Gaetz, S., Dej, E., Richter, T., & Redman, M. (2016). The State of Homelessness in Canada 2016. Retrieved from http://homelesshub.ca/sites/default/files/SOHC16_final_20Oct2016.pdf

Government of Canada. (2020) National Homelessness Information Initiative. Retrieved from https://www.canada.ca/en/employment-social development/programs/homelessness/hifis.html

Gregory, C., & Coleman-Jensen, A. (2017). Food Insecurity, Chronic Disease, and Health Among Working-Age Adults. *IDEAS Working Paper Series from RePEc,* IDEAS Working Paper Series from RePEc, 2017

Habermas (1972). Knowledge and human interests. Portsmouth, N.H. Heinemann Education Books.

Hakanson, C., Sandberg, J., Ekstedt, M., Kenne Sarenmalm, E., Christiansen, M., & Ohlen, J. (2016). Providing Palliative Care in a Swedish Support Home for People Who Are Homeless. *Qual Health Res.* 2016;26(9):1252-62

Haldenby, A., Berman, H., & Forchuk, C. (2007). Homelessness and Health in Adolescents. *Qualitative Health Research, 17*(9), 1232-1244.

Hallett, R. (2013). Dangers of member checking. In W. Midgley, P. A. Danaher, & M. Baguley (Eds.), The role of participants in education research: Ethics, epistemologies, and methods. (pp. 29-39). New York, NY: Routledge.

Health Canada (2001). Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada. Retrieved from https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-certain-equit-acces/2001-certain-equit-acces-eng.pdf

Health Care for the Homeless Clinicians` Network (2018). Adapting Your Practice: Recommendations for End-of-Life Care for People Experiencing Homelessness.Retrieved October, 2020 from https://nhchc.org/wp-content/uploads/2019/08/2018-end-of-life-care-guidelines.pdf

Hudson, B. F., Flemming, K., Shulman, C., & Candy, B. (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care*, *15*(1), 96. https://doi.org/10.1186/s12904-016-0168-6

Hulchanski, J., University of Toronto. Cities Centre, Canadian Homelessness Research Network, Homeless Hub, & Canadian Electronic Library. (2009). Finding home policy options for addressing homelessness in Canada (Canadian electronic library. Canadian public policy collection). Toronto, Ont.]: Cities Centre Press.

Hwang, S. W. (2001). Homelessness and health. *Canadian Medical Association Journal, 164(2), 229–233.*

Hwang, S., & Henderson, M. (2010). Health Care Utilization in Homeless People: Translating Research into Policy and Practice. Retrieved from https://meps.ahrq.gov/data_files/publications/workingpapers/wp_10002.pdf

Hwang, S., Ueng, J., Chiu, S., Kiss, A., Tolomiczenko, G., Cowan, L., Levison, W., & Redelmeier, D. (2010). Universal health insurance and health care access for homeless persons. *American Journal of Public Health, 100*(8), 1454-1461

Hwang, S., Dowbor, T., Devotta, K., & Pedersen, C. (2017). Palliative Care Services for People Experiencing Homelessness in Toronto: A preliminary needs assessment.

Kar, S. K., Arafat, S., Marthoenis, M., & Kabir, R. (2020). Homeless mentally ill people and COVID-19 pandemic: The two-way sword for LMICs. *Asian journal of psychiatry*, *51*, 102067. https://doi.org/10.1016/j.ajp.2020.102067

Karabanow, J. (2003). Creating a Culture of Hope: Lessons from Street Children Agencies in Canada and Guatemala. *International Social Work.*

Karabanow, J., Kidd, S., Frederick, T., Mcluckie, A., & Quick, J. (2018). Methodological reflections on research with street youth. *Journal of Social Work : JSW, 18*(5), 578-597

Khandor, E. & Mason, K. (2007) The Street Health Report. Retrieved from https://www.homelesshub.ca/sites/default/files/attachments/SHReport2007.pdf

Khandor, E., Mason, K., Chambers, C., Rossiter, K., Cowan, L., & Hwang, S. W. (2011). Access to primary health care among homeless adults in Toronto, Canada: results from the Street Health survey. *Open Medicine*, *5*(2), e94–e103.

Ko, E., Kwak, J., & Nelson-Becker, H. (2015). What Constitutes a Good and Bad Death?: Perspectives of Homeless Older Adults. *Death Studies*, *39*(7), 422–432. https://doi.org/10.1080/07481187.2014.958629

Kushel, M. B., Perry, S., Bangsberg, D., Clark, R., & Moss, A. R. (2002). Emergency department use among the homeless and marginally housed: results from a community-based study. *American journal of public health*, *92*(5), 778–784. https://doi.org/10.2105/ajph.92.5.778

Leung, C., Kullgren, J., Malani, P., Singer, D., Kirch, M., Solway, E., & Wolfson, J. (2020). Food insecurity is associated with multiple chronic conditions and physical health status among older US adults. *Preventive Medicine Reports, 20*, 101211

MacWilliams, J., Bramwell, M., Brown, S., & O'Connor, M. (2014). Reaching out to Ray: Delivering palliative care services to a homeless person in Melbourne, Australia. *International Journal of Palliative Nursing, 20*(2), 83-88.

Maddison, A. R., Asada, Y., Burge, F., Johnston, G. W., & Urquhart, R. (2012). Inequalities in end-of-life care for colorectal cancer patients in Nova Scotia, Canada. *Journal of palliative care*, *28*(2), 90-6.

Marshall, B., Kerr, T., Livingstone, C., Li, K., Montaner, J., & Wood, E. (2008). High prevalence of HIV infection among homeless and street-involved Aboriginal youth in a Canadian setting. *Harm Reduction Journal, 5*(1), 35.

McNaughton, C. (2008). Transitions through homelessness, substance use, and the effect of material marginalization and psychological trauma. *Drugs: Education, Prevention, and Policy, 2008, Vol.15(2), P.177-188, 15*(2), 177-188.

McNeil, R., & Guirguis-Younger, M. (2012). Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services professionals. *Palliative Medicine*, *26*(4), 350–359. https://doi.org/10.1177/0269216311402713

McNeil, R., Guirguis-Younger, M., & Dilley, L. B. (2012). Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. *BMC Palliative Care*, *11*(1), 14. https://doi.org/10.1186/1472-684X-11-14

Morse, J. M. (2000). Determining Sample Size. *Qualitative Health Research*, *10*(1), 3–5. https://doi.org/10.1177/104973200129118183

National Coalition for the Homeless. (2009). Homelessness Among Elderly Persons. Retrieved from https://homelesshub.ca/sites/default/files/attachments/gnw03acr.pdf

Normand, Li, Thomson, & Jarlais. (2013). Harm reduction. *Journal of Food and Drug Analysis, 21*(4), S10-S12

Oelke, N., Thurston, W., & Turner, D. (2016). Aboriginal Homelessness: A Framework for Best Practice in the Context of Structural Violence. *International Indigenous Policy Journal, 7*(2), International Indigenous Policy Journal, 2016, Vol.7(2)

O`Leary, B. (2016). Unhoused in Toronto: The delivery and experience of hospital healthcare services for homeless people. Retrieved from http://homelesshub.ca/sites/default/files/Unhoused%20in%20Toronto%20-%20Bill%20O%27Leary.pdf

Omerov, P., Craftman, &., Mattsson, E., & Klarare, A. (2020). Homeless persons' experiences of health- and social care: A systematic integrative review. *Health & Social Care in the Community, 28*(1), 1-11

Ontario Palliative Care Network. (2018). Palliative Care: Care for Adults with Progressive, Life-Limiting Illness. Retrieved October, 2020 from http://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf

Palinkas, L., Horwitz, A., Green, S., Wisdom, M., Duan, C., & Hoagwood, J. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533-544.

Parkinson, R. (2009). Nurses Attitudes Towards People Who Are Homeless: A Literature Review. Retrieved from http://diversityhealthcare.imedpub.com/nurses-attitudes-towards-people-who-are-homeless-a-literature-review.php?aid=2049

Pattoni, L. (2012). Strengths-based approaches for working with individuals. Retrieved from https://www.iriss.org.uk/resources/insights/strengths-based-approaches-working-individuals

Pawelz, J. (2017). Researching Gangs: How to Reach Hard-to-Reach Populations and Negotiate Tricky Issues in the Field; Das Erforschen von Gangs: Wie schwer zugängliche Populationen erreicht und heikle Angelegenheiten im Feld gemeistert werden können. *19*(1)

Perri, M., Dosani, N., & Hwang, S. (2020). COVID-19 and people experiencing homelessness: Challenges and mitigation strategies. *CMAJ : Canadian Medical Association Journal = Journal De L'Association Medicale Canadienne, 192*(26), E716-E719.

Podymow, T., Turnbull, J., & Coyle, D. (2006). Shelter-based palliative care for the homeless terminally ill. *Palliative Medicine, 20*(2), 81-86.

Quon, A. (2018). Number of Nova Scotians wait listed for family doctor tops 50,000. Retrieved September 20th, 2018 from https://globalnews.ca/news/4259595/nova-scotia-doctors-wait-list/

Saewyc, E. M., Skay, C.L., Pettingell, S.L., Reis, E.A., Bearinger, L., Resnick, M., Murphy, A., & Combs, Leigh. (2006). Hazards of Stigma: The Sexual and Physical Abuse of Gay, Lesbian, and Bisexual Adolescents in the United States and Canada. *Child Welfare, 85*(2), 195-213.

Sekharan, V. (2014). Infographic Wednesday-Social Determinants of Health. Canadian Observatory on Homelessness/Homeless Hub. Retrieved from http://www.homelesshub.ca/blog/infographic-wednesday-social-determinants-health

Shulman, C., Hudson, B., Low, J., Hewett, N., Daley, J., Kennedy, P., Davis, S., Brophy, N., Howard, D., Vivat, B., & Stone, P. (2018). End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine, 32*(1), 36-45.

Smith, R. (2000). A good death. An important aim for health services and for us all. *BMJ (Clinical Research Ed.), 320*(7228), 129-30.

Song, J., Bartels, D. M., Ratner, E. R., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Dying on the Streets: Homeless Persons' Concerns and Desires about End of Life Care. *Journal of General Internal Medicine*, *22*(4), 435–441. https://doi.org/10.1007/s11606-006-0046-7

Song, J., Ratner, E. R., Bartels, D. M., Alderton, L., Hudson, B., & Ahluwalia, J. S. (2007). Experiences With and Attitudes Toward Death and Dying Among Homeless Persons. *Journal of General Internal Medicine*, *22*(4), 427–434. https://doi.org/10.1007/s11606-006-0045-8

Stajduhar, K. I., Mollison, A., Gleave, D., & Hwang, S. W. (2017). When cancer hits the streets. *Current oncology (Toronto, Ont.)*, *24*(3), 149-150.

Stajduhar, K., & Mollison, A. (2018) Too Little, Too Late: How we fail vulnerable Canadians as they die and what to do about it. Retrieved November 6th, 2020 from https://www.uvic.ca/research/groups/peol/assets/docs/too-little-too-late.pdf

Statistics Canada. (2018). Deaths and age-standardized mortality rate, by province and territory (Deaths). Retrieved from http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/hlth86a-eng.htm

Statistics Canada. (2020). Household food insecurity, 2017/2018. Retrieved November 6th, 2020 from https://www150.statcan.gc.ca/n1/pub/82-625-x/2020001/article/00001-eng.htm

Street Health Report. (2007). Homelessness, Mental Health and Substance Abuse. Retrieved from http://www.streethealth.ca/downloads/homelessness-mental-health-and-substance-use-research-bulletin-4-october-2008.pdf

Tarzian, A., Neal, M., & O'Neil, J. (2005). Attitudes, experiences, and beliefs affecting end-of-life decision-making among homeless individuals. *Journal of Palliative Medicine, 8*(1), 36-48.

Thomas, B. (2012). Homelessness Kills: An analysis of the mortality of homeless people in early twenty-first century England, London Crisis.

Thompson, S., Pollio, D., Eyrich, K., Bradbury, E., & North, C. (2004). Successfully exiting homelessness: Experiences of formerly homeless mentally ill individuals. *Evaluation and Program Planning, 27*(4), 423-431.

Trypuc, B., & Robinson, J. (2009). Homeless in Canada a funder's primer in understanding the tragedy on Canada's streets (Canadian Electronic Library. Canadian public policy collection). King City, Ont.: Charity Intelligence Canada.

Ubelacker, S. (2014, Aug 3). Palliative care for the homeless: Mobile program brings comfort and treatment. Retrieved September, 2018 from https://www.ctvnews.ca/health/palliative-care-for-the-homeless-mobile-program-brings-comfort-and-treatment-1.1945269

Vibert, J. (2020). Nova Scotia has highest rate of food insecurity. Retrieved November 6th, 2020 from https://www.thechronicleherald.ca/opinion/local-perspectives/jim-vibert-nova-scotia-has-highest-rate-of-food-insecurity-413280/#:~:text=as%20poverty%20gets.-,In%202017%2D18%2C%20across%20Canada%2C%2012.7%20per%20cent%20of,of%20households%20experience%20food%20insecurity.

Vuillermoz, C., Vandentorren, S., Brondeel, R., & Chauvin, P. (2017). Unmet healthcare needs in homeless women with children in the Greater Paris area in France. *PloS One, 12*(9), E0184138.

Webb, W., Mitchell, T., Nyatanga, B., & Snelling, P. (2017). 42 'Who cares and what matters?': Exploring end of life priorities of homeless adults in the uk. *BMJ Supportive & Palliative Care, 7*(3), A363.

Whiffen, G., King, N. (2019). Atlantic Canada needs more doctors. Where are they? Retrieved from https://www.thechronicleherald.ca/in-depth/doctor-shortage/atlantic-canada-needs-more-doctors-where-are-they-278198/

Wodak, A., & Cooney, A. (2006). Do Needle Syringe Programs Reduce HIV Infection Among Injecting Drug Users: A Comprehensive Review of the International Evidence. *Substance Use & Misuse, 41*(6-7), 777-813.

Wolch, J., Dear, M., & Akita, A. (1988). Explaining Homelessness, *Journal of the American Planning Association,* 54:4, 443-453, DOI: 10.1080/01944368808976671

Woolley, E. (2015) What are the pathways to homelessness in old age? Retrieved from https://www.homelesshub.ca/blog/what-are-pathways-homelessness-old-age

Woolley, E. (2015). Is Harm Reduction an Appropriate Response to Addictions? Canadian Observatory on Homelessness. Retrieved from https://www.homelesshub.ca/blog/harm-reduction-appropriate-response-addictions

World Health Organization. (2014). Progress on the implementation of the Rio Political Declaration. What are social determinants of health? Retrieved from http://www.who.int/social_determinants/en/

Yeo, S., Ratnam, C., Paradis, E., Oudshoorn, A., Nessa, B., Mosher, J., Macphail, S., Greene, S., Gaetz, S., Forchuk, C., Casimir, C., Buccieri, K., Bonnycastle, M., Berman, H., Arsenault., J, Amponash, A., & Aguila, K. (2015). A framework for Ending Women`s and Girls` Homelessness. Retrieved from http://www.abeoudshoorn.com/wp-content/uploads/2015/08/A-Framework-for-Ending-Womens-and-Girls-Homelessness.pdf

Appendix A: Homelessness Services Contact Script

Initial contact via telephone and/or email:

Hello,

My name is Cait Vihvelin. I am a registered nurse and Master of Science in Nursing student at Dalhousie University. As part of my Master's thesis research, under the supervision of Dr. Lori Weeks, I am conducting a research study looking at how, and in what ways, individuals who are experiencing homelessness and living with progressive illness(es), experience end-of-life care. More specifically, my research will focus on the perceptions and meaning individuals who are experiencing homelessness give to: a) their experience of end-of-life care; b) concerns and preferences for end-of-life care; and c) accessibility to end-of-life care services. This information will be collected during a 1-hour telephone or video conference interview.

As part of my recruitment strategy I am contacting hospice and community-based organizations who care for, and work with, individuals experiencing homelessness who are also living with chronic illness. The inclusion/exclusion criteria are as follows: 1) Ability to speak and understand English; 2) Aged 18 years or older; 3) Current or previous experience of homelessness; 4) Living with progressive illness such as COPD, cancer, HIV/AIDS, liver and kidney disorders. The exclusion criteria for this study are 1) Inability for the participant to commit to research plan for data collection (i.e. potential shifts in location outside of Nova Scotia); 2) Current or former patients under the care of Cait Vihvelin. I would greatly appreciate if you could share information about my study with potential participants and allow me to leave my contact information and posters with the specific details outlining the purpose of my study at your organization. You can either have the potential participant contact me directly or get permission for me to contact them. Participants will receive $25 for sharing their stories.

Participants may also receive up to $25 for travel reimbursement (if needed for access to a phone). The research team can provide a pay-as-you go phone with minutes on it at your organization for interviewing if required.

I believe that my research will inform care and contribute to the limited body of knowledge on this topic while also advancing the health of individuals experiencing homelessness who are also living with chronic illness.

If you have any questions, do not hesitate to ask. You can reach me at eolcare@dal.ca or (902) 494-7114

Thank you for your time

Appendix B: Recruitment Poster

DALHOUSIE
UNIVERSITY

Homelessness and End-of-life Care

If you are experiencing homelessness and are living with a “life-limiting” disease, you may be eligible to participate in a research study

Study Purpose

The purpose of this research is to gain a better understanding of how and in what ways people who are homeless and living with chronic life-shortening illness(es) experience palliative and end-of-life care.

Participants will receive:

- $25 for your time
- & up to $25 for travel reimbursement if required

Are you eligible?

- You are 18 years or older
- Can speak and understand English
- Are currently experiencing homelessness or have in the past
- Have a diagnosis of a “life-shortening” illness such as COPD, cancer, HIV/aids, liver and/or kidney disorders etc.

For more information, call or email:

- Cait V, BScN, RN
- eolcare@dal.ca
- 902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Cait V.
eolcare@dal.ca
902-494-7114

Appendix C: Screening Protocol

Instructions:

Please do not verbally reply to questions 1-5 & 7.

Eligibility questions:

1. Can you speak and understand English?
2. Are you 18 years or older?
3. Are you currently experiencing or have previously experienced homelessness?
4. Are you living with a progressive illness? Ex. COPD, cancer, HIV/Aids, liver and/or kidney disorders.
5. Are you able to commit approximately 1.5 hours of your time?
6. Do you have access to phone/laptop/email?
7. Have you ever participated in a Lymphoma clinical trial with me (Cait Vihvelin) as your nurse?

Did you answer 'no' to any of these questions? If so, you are not eligible to participate

Appendix D: Semi-structured Interview Guide

2. When you saw my poster, what was it that made you interested in speaking with me?
3. I’d like to start off by learning about you and your history. Tell me a bit about yourself. (Probes: Age, housing history, employment history, self-identified gender).
4. Tell me about your health and any life-limiting illnesses you may have? What has it been like recently?
5. Tell me more about your healthcare experience since you have been experiencing homelessness. Try describing a specific example of a time when you felt really unwell and what happened.
6. What does (or would) end-of-life care look like for you? (Probes: Tell me about any concerns you might have with end-of-life care, what would an ideal end-of-life care situation look like for you?)
7. What would a “good death” look like for you? What would a “bad death” look like for you?
8. Based on what you know about end-of-life care/palliative care, what would you like to see be done differently?

Probes and notes to generate more detail:

- Use participants own words to formulate questions that elicit further description.
- Open probe: ‘You mentioned … Describe a specific example of that …’
- Open probe: ‘You mentioned … Tell me about that …’

Appendix E: Consent Form

DALHOUSIE
UNIVERSITY

CONSENT FORM

Project title: Homelessness and End-of-life Care: A First Voice Perspective.

Lead researcher:	Cait Vihvelin, BScN, RN eolcare@dal.ca (902) 494-7114
Other researchers:	Dr. Brenda Sabo Brenda.Sabo@dal.ca (902) 494-3121
	Dr. Lori Weeks Lori.Weeks@dal.ca (902) 494-7114
Funding provided by:	This study is being funded by the School of Nursing Research and Development Fund, Dalhousie University.

Introduction

We invite you to take part in a research study being conducted by, Cait Vihvelin, who is a student at Dalhousie University. Choosing whether or not to take part in this research is entirely your choice. There will be no impact on the services you receive if you decide not to participate in the research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit, risk, inconvenience or discomfort that you might experience.

You should discuss any questions you have now or later about this study with the Lead Researcher, Cait Vihvelin. Please ask as many questions as you like.

You are being asked to consider participating in this study because you are currently experiencing or have experienced homelessness in the past and are also living with a life limiting illness.

Purpose and Outline of the Research Study

People experiencing homelessness are at an increased risk for serious illness and death. In fact, they are dying at a rate that is 2-3 times higher than the general population due to serious illnesses such as hepatitis, mental health disorders, substance abuse, cancer and heart disease. There is little understanding of the experiences and preferences at end-of-life (EOL) for people who are experiencing homelessness or are vulnerably housed. Many barriers exist around access to palliative and end-of-life care services for those who are experiencing homelessness. The reasons are many and include isolation, stigma, requirements to access health care (e.g., health card), inexperience of health professionals in caring for those who are experiencing homelessness, and decreased trust in healthcare workers by people who are experiencing homelessness. This study aims to gain a better understanding of how and in what ways people who are experiencing homelessness and living with chronic life-shortening illness(es), experience palliative and end-of-life care. This study will inform the care and services of community-based organizations and contribute to the limited body of knowledge on this topic while also advancing the health of individuals experiencing homelessness.

Who Can Take Part in the Research Study

You *may* participate in this study if you are 18 years or older, currently experiencing homelessness or have experienced homelessness in the past, living with a life-limiting illness(es) (ex. HIV/AIDS, COPD, Cancer, liver and/or kidney disease) and have the ability to communicate verbally and in English. If you are *not* able to commit to one 1-hour long over-the-phone interview (plus 30 minutes for questions regarding the study and consent process) or are a current or former patient of the Principal Investigator, you may *not* take part in this research study. There will be 4 to 6 people invited to participate in a one-on-one over the phone interview from within the Halifax Regional Municipality.

What You Will Be Asked to Do

If you agree to participate, you will be asked to take part in one over the phone interview. The interview will be audio-recorded for research purposes only and will consist of questions for discussion surrounding your experiences with homelessness, progressive-life limiting illness, end-of-life and end-of-life care.

Some questions are sensitive and ask about your current health status, current living arrangements, and concerns/preferences for end-of-life/end-of-life care. Interview questions will also focus on your experiences with healthcare and/or palliative/end-of-life care.

If you feel uncomfortable at any time with the questions being asked, you do not have to answer the interview questions and you can withdraw from the study. The interview will be about 1 hour in length (plus 30 minutes for questions regarding the study and consent process). You will be asked to attend 1 over the phone interview to speak about your experiences with homelessness, progressive life-limiting illness and end-of-life care. The interview will be audio taped and transcribed to remove any identifying information about yourself.

You are free to withdraw at any point in time from the research study and for up to two weeks after the interview has taken place. Your audio-recording information will be destroyed and not used further in the study.

Possible Benefits, Risks and Discomforts

Benefits: This research may not benefit you directly. However, your participation could provide important information that could help other individuals who are experiencing homelessness and living with life-limiting disease access and have better quality end-of-life care.

Risks/Discomforts: There are no medical risks to you from participating in this study but taking part in this study may make you feel uncomfortable. You may find the interview questions upsetting or distressing. You can refuse to answer questions, take a break or stop the interview at any time if you experience any discomfort. Additionally, you may disclose information that may identify people or facilities. Any names/facilities mentioned will be de-identified during the transcription process. Transcription is taking the words and dialogue on the audio tape and writing or typing it word for word.

Compensation / Reimbursement

You will be offered a $25 honorarium as a token of appreciation for participation in this study. If you choose to withdraw from the study at any time, you will still receive the honorarium, regardless of your time of withdrawal. You may also be reimbursed for travel costs of up to $25 if needed for telephone access or have travel/ telephone access arrangements made for you by the research team. Please let the lead researcher know in advance if you will be requiring transportation for telephone access.

How your information will be protected:

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. If the results of this study are presented to the public, nobody will be able to tell that you were in the study. There will not be any negative impact on you or for the services in which you receive by participating in this study.

However, complete privacy cannot be guaranteed. For example, the Lead Researcher may be required by law to allow access to research records. If abuse or neglect of a vulnerable adult or child is disclosed at any time during the interview, the lead researcher will be legally obligated to inform the appropriate authorities

If you decide to participate in this study, only the Lead Researcher and her co-supervisors at Dalhousie University will have access to audio-recordings and transcription documents. After the interview is complete, the recording will be destroyed by permanently deleting, and written copies of your interview will be de-identified using a study number on a secure password protected computer. There will be no information that identifies you after the study is complete.

The information that you provide to us will be kept confidential. Only the Lead Researcher and her Co-Supervisors at Dalhousie University will have access to this information. All of your identifying information (such as your name and contact information) will be deleted. We will use a participant number (not your name) in our written and computer records so that the research information we have about you contains no names. During the study, all electronic records will be kept secure on the researcher's password-protected computer and backed up on a password protected USB. All paper records will be kept secure in a locked filing cabinet located at the Lead Researchers home.

We will describe and share our findings in the Lead Researchers student thesis, presentations and journal articles. Names and any other identifying information will be removed so that you will not be identified in any way in our reports.

Data retention: After study closure all research records will be stored securely on a password locked computer and physical copies stored in a locked cabinet in the locked office of the Lead Researchers thesis supervisor Dr. Lori Weeks until 2027. Dr. Lori Weeks will be responsible for disposing of all study materials. Electronic data will be securely destroyed or erased in accordance with Dalhousie's standards of data handling. Paper-based data will be shredded.

If You Decide to Stop Participating

You are free to leave the study at any time. If you decide to stop participating during the interview, you can decide whether you want any of the information that you have provided up to that point to be removed or if you will allow us to use that information. After completing the interview, you can decide for up to two weeks if you want us to remove your data. After that time, it will become impossible for us to remove it because it will already be analyzed/anonymized. Please note that withdrawal from this study will not have any impact on your access to services or on the care that you receive from these services.

How to Obtain Results

If you wish to obtain the results of this study, please contact the Lead Researcher, Cait Vihvelin, at cait.vihvelin@dal.ca in approximately 3 months.

Questions

For further information about the study you may call the Lead Researcher who is the person in charge of this study and/or any other research team member listed below.

The Lead Researcher is:
Cait Vihvelin, RN, BScN
Email: eolcare@dal.ca
Telephone: (902) 494-7114

The study Co-Supervisors are:
Dr. Brenda Sabo
Email: brenda.sabo@dal.ca
Telephone: (902) 494-3121

Dr. Lori Weeks
Email: lori.weeks@dal.ca
Telephone: (902) 494-7114

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-3423, or email: ethics@dal.ca

Documentation Page

Project Title: Homelessness and End-of-life Care: A First Voice Perspective

Lead Researcher: Cait Vihvelin, BScN, RN

eolcare@dal.ca

(902) 494-7114

I have read the explanation about this study to the participant fully. I have given the participant the opportunity to discuss it and answer any questions that the participant had. The participant shows full understanding that they have been asked to take part in one telephone interview, and that the interview will be audio-recorded. The participant understands that direct quotes of things they say may be used without identifying them. The participant understands that their participation is voluntary and that they are free to withdraw from the study at any time, until 2 weeks after their over the phone interview is complete. The participant agreed to take part in this study.

Person obtaining consent:

______________________________	____________________________	____________
Name	Signature	Date

Appendix F: Support Services

1. Mobile Outreach Street Health (MOSH), Primary Healthcare Services, 2131 Gottingen St. Halifax, Nova Scotia, B3K 5Z7

   (902) 429-5290

2. General Phone Lines:

   Emergency- Dial: 911

   Government 24hr health question line- Dial 811

   211 Halifax (information about local services)- Dial 211

   Legal Information Society of Nova Scotia- Dial: 902 455-3135 or 1800-665-9779

   Mental Health Mobile Crisis Line- Dial: 1-888-429-8167 or 902-429-8167

3. Chebucto Family Centre, Social Services Organization, 3 Sylvia Avenue, Spryfield, Nova Scotia B3R 1J7

   (902) 479-3031

4. Mi’kmaq Native Friendship Centre, Cultural Centre that offers coping support, 2158 Gottingen St, Halifax, Nova Scotia. B3K 3B4

   (902) 420-1576

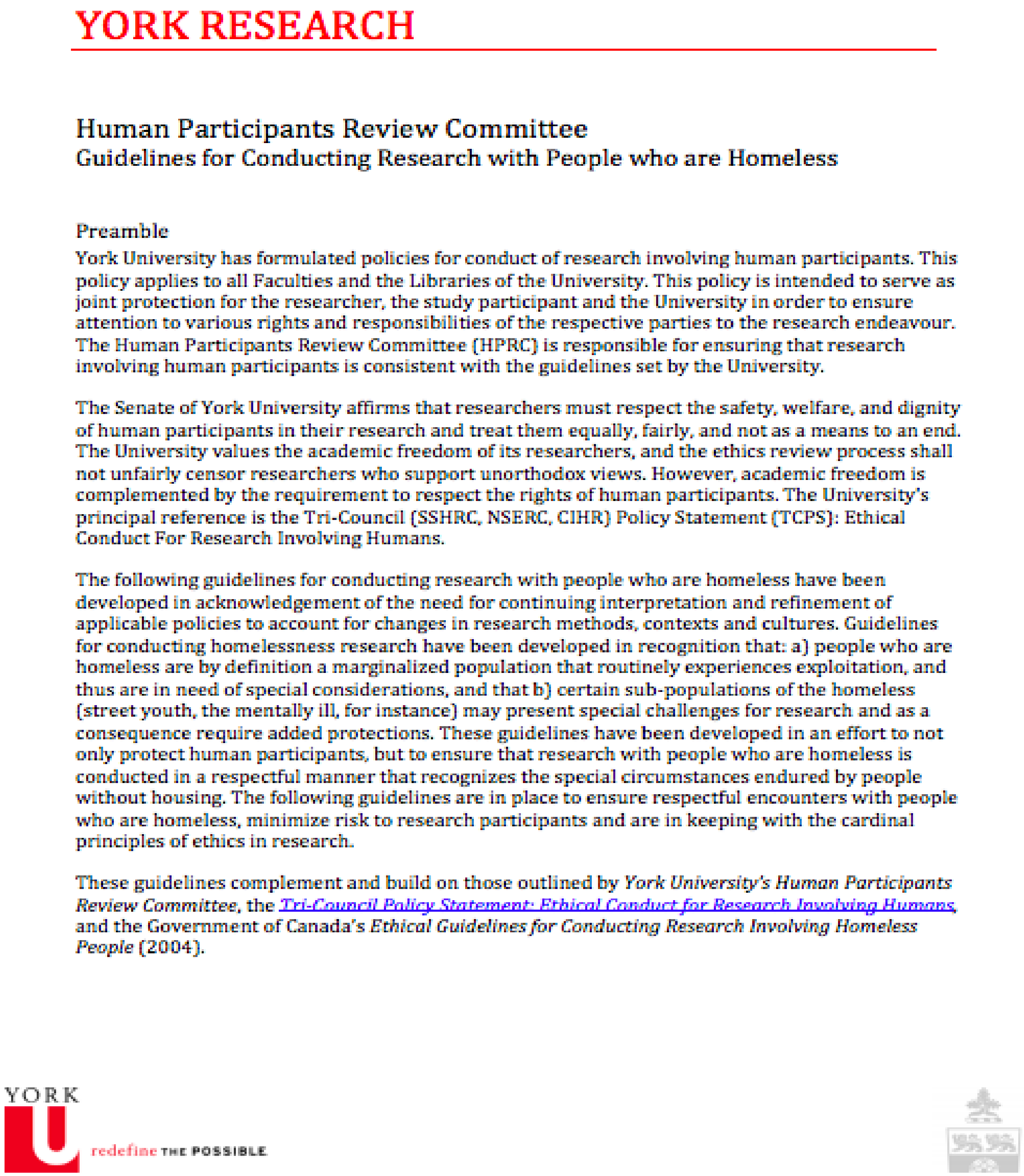
5. Emergency Mental Health Assessment, Nova Scotia Health Authority, 1799 Robie St., Halifax, Nova Scotia, B3H 3A7

   (902) 473-2043

6. North End Community Health Centre, 2131 Gottingen St., 5th floor, Halifax, Nova Scotia, B3K 5Z7

   (902) 420-030

Appendix G: York Research Guidelines for Conducting Research with People who are Homeless



YORK RESEARCH

Human Participants Review Committee
Guidelines for Conducting Research with People who are Homeless

Preamble

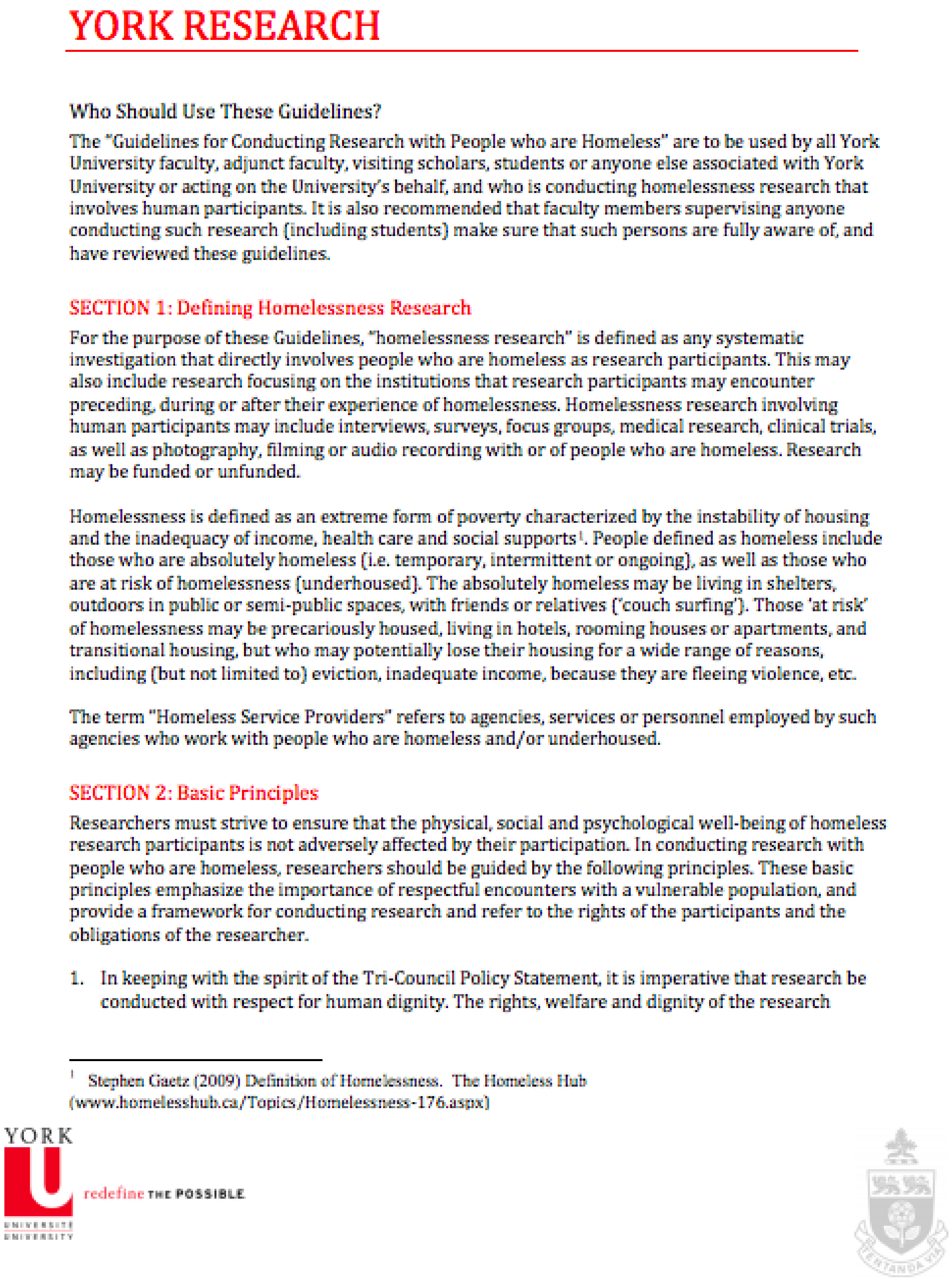
York University has formulated policies for conduct of research involving human participants. This policy applies to all Faculties and the Libraries of the University. This policy is intended to serve as joint protection for the researcher, the study participant and the University in order to ensure attention to various rights and responsibilities of the respective parties to the research endeavour. The Human Participants Review Committee (HPRC) is responsible for ensuring that research involving human participants is consistent with the guidelines set by the University.

The Senate of York University affirms that researchers must respect the safety, welfare, and dignity of human participants in their research and treat them equally, fairly, and not as a means to an end. The University values the academic freedom of its researchers, and the ethics review process shall not unfairly censor researchers who support unorthodox views. However, academic freedom is complemented by the requirement to respect the rights of human participants. The University's principal reference is the Tri-Council (SSHRC, NSERC, CIHR) Policy Statement (TCPS): Ethical Conduct For Research Involving Humans.

The following guidelines for conducting research with people who are homeless have been developed in acknowledgement of the need for continuing interpretation and refinement of applicable policies to account for changes in research methods, contexts and cultures. Guidelines for conducting homelessness research have been developed in recognition that: a) people who are homeless are by definition a marginalized population that routinely experiences exploitation, and thus are in need of special considerations, and that b) certain sub-populations of the homeless (street youth, the mentally ill, for instance) may present special challenges for research and as a consequence require added protections. These guidelines have been developed in an effort to not only protect human participants, but to ensure that research with people who are homeless is conducted in a respectful manner that recognizes the special circumstances endured by people without housing. The following guidelines are in place to ensure respectful encounters with people who are homeless, minimize risk to research participants and are in keeping with the cardinal principles of ethics in research.

These guidelines complement and build on those outlined by *York University's Human Participants Review Committee*, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, and the Government of Canada's *Ethical Guidelines for Conducting Research Involving Homeless People* (2004).

YORK
redefine THE POSSIBLE



YORK RESEARCH

Who Should Use These Guidelines?

The "Guidelines for Conducting Research with People who are Homeless" are to be used by all York University faculty, adjunct faculty, visiting scholars, students or anyone else associated with York University or acting on the University's behalf, and who is conducting homelessness research that involves human participants. It is also recommended that faculty members supervising anyone conducting such research (including students) make sure that such persons are fully aware of, and have reviewed these guidelines.

SECTION 1: Defining Homelessness Research

For the purpose of these Guidelines, "homelessness research" is defined as any systematic investigation that directly involves people who are homeless as research participants. This may also include research focusing on the institutions that research participants may encounter preceding, during or after their experience of homelessness. Homelessness research involving human participants may include interviews, surveys, focus groups, medical research, clinical trials, as well as photography, filming or audio recording with or of people who are homeless. Research may be funded or unfunded.

Homelessness is defined as an extreme form of poverty characterized by the instability of housing and the inadequacy of income, health care and social supports[1]. People defined as homeless include those who are absolutely homeless (i.e. temporary, intermittent or ongoing), as well as those who are at risk of homelessness (underhoused). The absolutely homeless may be living in shelters, outdoors in public or semi-public spaces, with friends or relatives ('couch surfing'). Those 'at risk' of homelessness may be precariously housed, living in hotels, rooming houses or apartments, and transitional housing, but who may potentially lose their housing for a wide range of reasons, including (but not limited to) eviction, inadequate income, because they are fleeing violence, etc.

The term "Homeless Service Providers" refers to agencies, services or personnel employed by such agencies who work with people who are homeless and/or underhoused.

SECTION 2: Basic Principles

Researchers must strive to ensure that the physical, social and psychological well-being of homeless research participants is not adversely affected by their participation. In conducting research with people who are homeless, researchers should be guided by the following principles. These basic principles emphasize the importance of respectful encounters with a vulnerable population, and provide a framework for conducting research and refer to the rights of the participants and the obligations of the researcher.

1. In keeping with the spirit of the Tri-Council Policy Statement, it is imperative that research be conducted with respect for human dignity. The rights, welfare and dignity of the research

---

[1] Stephen Gaetz (2009) Definition of Homelessness. The Homeless Hub (www.homelesshub.ca/Topics/Homelessness-176.aspx)

participant are paramount and therefore necessarily take precedence over the requirements of research.

2. Research with people who are homeless must be conducted in a non-judgmental way. Marginalized populations such as people who are homeless characteristically experience discrimination and social exclusion. This is often compounded by racism, sexism, homophobia and other forms of discrimination. Researchers must not contribute to the marginalization of homeless persons through acting in a way that is judgemental regarding a person's appearance, strategies for making money or personal habits, for instance. Though none of us are free of biases, we must strive to avoid judgemental actions, which include any comments or behaviours that are intended to express disapproval based on moral or personal biases. The exceptions to this are when there is a clear or immanent threat of danger to the researcher, the research subject or a third party.

3. People who are homeless typically lack access to private space, and live much of their lives in the public realm. Researchers do not have special rights or privileges to intrude into the lives of people who are homeless simply because they are in public spaces such as parks, streets or sidewalks. The right of people who are homeless to privacy and security must be respected at all times and this right must be reflected in recruitment methods and research methodology.

4. Researchers should recognize that many people who are homeless have experienced difficult lives characterized by violence, abuse and trauma. While one must be careful not to generalize, it is estimated that up to a third of adults who are homeless experience some form of mental illness, and that rates of depression and suicide are much higher amongst people who are homeless than the general population. Researchers working with people who are homeless must consider the fact that many people they encounter may be suffering from some form of mental illness, trauma, distress or depression.

5. Researchers should be aware of issues of diversity, and how these impact on homelessness. The distinctions and differences that we see in the rest of society – and the discrimination and prejudice that result – are also seen within the homeless population. In this sense, many individuals who are homeless may be marginalized in multiple ways; not only because they are homeless, but also because they are visible minorities, women, sexual minorities, have a disability, are Aboriginal, etc. Some minority groups are overrepresented amongst people who are homeless (sexual minority youth, Aboriginal people, people with disabilities, for example).

6. Research involving people who are homeless must be conducted in recognition of the special ethical issues that may be associated with specific sub-populations.

SECTION 3: Guidelines for Working with People Who are Homeless

Research that contributes to our understanding of the causes and consequences of homelessness is important. The purpose of research guidelines is to ensure that the researcher takes all reasonable precautions to minimize the risk of harm to those participating in studies. The following guidelines outline key considerations and practices that apply to those who conduct research with people who are homeless.

YORK RESEARCH

- **Research must follow HPRC Policies and Guidelines.** All research with people who are homeless conducted by faculty, adjunct faculty, visiting scholars, students or anyone else associated with York University or acting on the University's behalf, must be approved by HPRC in accordance with York University policies, procedures and guidelines for conducting research involving human participants. Students who plan to conduct research with people who are homeless must be under the supervision of a supervisor/supervisory committee at York University. Guidelines for faculty can be found at: http://www.research.yorku.ca, and for graduate students at: http://www.yorku.ca/grads/policies/ethics.html.

- **Research practices should be conducted in ways that minimize distress for homeless research participants.** It will not always be possible for the researcher to make a determination regarding the mental health and wellbeing of someone they are interviewing, regardless of whether he or she is homeless. Nevertheless, when conducting research, one must consider that some research topics, questions and activities may be extremely distressing for people who are homeless (for example, inquiries into experiences of sexual abuse, loss or trauma). While such areas of research are not prohibited, researchers should be sensitive to the potentially stressful impact of their activities, monitor the research participants' responses, and ensure that necessary supports are in place should research questions, the research experience and / or the conduct of the researcher lead to episodes of distress.

  Supports may include ensuring that the research participant has access to, and is made aware of, counselling and supports after the research encounter. Ideally this information should be provided both prior to, and at the conclusion of, the research encounter. Where the research encounter occurs outside of an agency or facility where there is counselling support, it is strongly recommended that the researcher not only make arrangements for, and inform the subject of the availability of such supports, but be able to provide the person access to such supports – including paying for transportation if necessary.

- Researchers engaging in arts-based approaches must consider the long term implications of capturing and presenting images of people who have experienced homelessness. While maintaining the confidentiality of research participants is important, this is not always possible when participants are photographed or filmed. The privacy of people who are homeless must be respected, particularly because their access to private space is limited. People photographed in public spaces may not wish their identity be broadly revealed, for a number of reasons. At the same time, it is important to consider that public images of homelessness may outlast the actual time an individual is homeless, and that many individuals may not approve of a public and permanent record of their homeless experience. It is therefore important that individuals who are homeless give consent for capturing their image, and that this consent is based upon a clear understanding of what the images will be used for, where they will be displayed and for how long.

- Researchers must consider the implications of discovery/discussion of criminal acts or potentially criminal behaviour. Because of their extreme poverty and situational factors associated with street life, many people who are homeless engage in illegal and/or quasi-legal activities in order to survive. This may include the consumption and sale of illegal substances, theft and other petty crime, involvement in the sex trade, and violations under Ontario's Safe

Streets Act. In the course of conducting research, participants may reveal details about their involvement in such activities. This raises several issues for the researcher to consider.

Researchers must make clear to the participant that they cannot provide absolute assurances of confidentiality (for instance, a researcher and their records may be subpoenaed in a court case). At the same time, researchers should be aware that they are not required to divulge information they obtain from a research participant to a police officer, except in cases where the officer in question suspects that a crime is under way at the time of the request.

- Researchers must not assume the role of counsellor or therapist. It is important for researchers to remember that in most cases they are not trained counsellors or therapists, and should not assume this role vis a vis the research subjects. It is also worth noting that in working with marginalized populations, researchers may experience distress themselves when confronted with the difficult life circumstances of the research subjects.