"That Look That Makes You Not Really Want to Be There":
Health Care Experiences of People Who Use Illicit Opioids
In Small Urban and Rural Communities – A Critical Social Theory Analysis

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Abstract

The phenomenon of interest is the health care experiences of people who use illicit opioids in small Ontario urban and rural communities. Using the qualitative constructivist paradigm the perspectives of participants who used opioids and of nurse participants were interpreted using Friere's critical social theory framework to explore sociopolitical, economic and ideological influences. Findings describe a divide between people who use illicit opioids and the nurses who care for them: "It's Like A Switch Gets Flipped" (describing an abrupt change in attitude by nurses once illicit substance use is identified), "Reciprocal Mistrust," "Caring for Women is Different" and "In a Small Town the Stigma Lasts Forever." Discussion places these findings in the context of health care systems as agents of social control, the influence of neoliberalism, and the impact of the global War on Drugs. Findings lead to recommendations for contextualized nursing practice, education and research and for policy change.

Dedication

This work is dedicated to the thousands of people who use illicit substances I have met over the past three decades. Thank you for all you have patiently taught me. This work is also dedicated to front-line harm reduction workers and peer workers, especially those working below the radar in small and rural communities to help people stay safe and healthy. And finally, it is dedicated to the good people of courage I know who love justice and so resist capitalism, neoliberalism and the War on Drugs/War on Drug Users – big respect.

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Table of Contents

Abstract……...ii

Dedication……...……iii

Acknowledgements.……..……..iv

List of Tables…….……xii

List of Figures…….…….…….xiii

Chapter One: Introduction…….……1

1.1 Background……..……2

1.2 Significance of the Study…….3

1.3 Purpose of the Study……3

1.4 A Tale of Two Women: Setting the Context for My Interest in this Work……4

1.5 Theoretical Scaffolding……..……10

Chapter Two: Review of the Literature……..13

2.1 Rural Substance Use……..……13

2.2 Rural Health Care……..……16

2.3 Rural Nursing……..…18

2.4 Health Care Experiences of People Who Use Substances……..……19

2.5 Stigmatizing Health Care Experiences of People Who Use Substances……20

2.6 Nurses' Views of People Who Use Substances……..…21

2.7 Nurses' Views of Harm Reduction……23

2.8 Nursing Care of People Who Use Substances……..24

2.9 Social Determinants of Health……...……26

2.10 Critical Social Theory and Illicit Drug Use……..……26

2.11 Literature Review in Summary…….……27

Chapter Three: Methods……30

3.1 Sampling Strategy and Recruitment……33

Participants who used opioids………34

Nurse participants………36

3.2 Ethical Considerations……37

3.3 Data Gathering……39

Participants who used opioids………41

Nurse participants………43

3.4 Data Management and Analysis……45

3.5 Rigour and Credibility……47

Chapter Four: Findings - Participants Who Used Opioids……50

4.1 Demographic Information and Participant Description……50

4.2 Reflections of Participants Who Used Opioids……52

Looking after your health while using illicit opioids………53

Challenges to staying healthy when using illicit opioids………56

How participants who used opioids saw themselves………57

Experiences of health care………58

It's like a switch gets flipped………58

Multiple intersecting experiences of stigma………59

Judgement, discrimination, and mistrust………60

Some health care providers lack knowledge………63

Specialized programming can facilitate excellent care………64

Unforgettable experiences of health care………65

Impacts of non-traditional ways of earning income………69

What participants who used opioids want to say to nurses……70

Improving the care of people who use opioids………73

Provide more education to nurses on substance use………..73

Learn from people who use opioids………..……73

Create a position in hospital emergency departments to connect with patients who use drugs………...…….74

Provide more drug treatment resources……….……..…74

Create more harm reduction housing……..…..…..74

4.3 Reflections on Findings From Participants Who Used Opioids……..…..…..75

Chapter Five: Findings - Nurse Participants……76

5.1 Demographic Information and Participant Description…….……76

5.2 Reflections of Nurse Participants……….…..77

Caring for people who use illicit opioids………...…77

Challenging behaviours……….....……78

Mistrust……….……78

Frustration………79

Witnessing declining health……….……80

Reflections on suboptimal care………..…….81

Nurses' reflections on the attitude shift noted by people who used opioids (the switch being flipped)……….……..82

Caring for women who use illicit opioids………..84

An unforgettable experiences of providing nursing care……….....….87

Other reflections on caring for people who use illicit opioids……….89

Experience matters………...……89

Education on substance use is lacking………90

The impact of viewing addiction as a disease………..……91

Substance use is not a "normal" path……...……..91

Even "normal" people may use opioids………..……91

5.3 Reflections on Findings From Nurse Participants……...……92

Chapter Six: Interpretive Analysis……..……..93

6.1 It's Like a Switch Gets Flipped………....…….96

What triggers the switch to be flipped? ……...…….97

"The look" – how you know when the switch has been flipped……...…..…99

Consequences of the switch being flipped……….…..100

Why flip the (caring) switch off? ……..…..101

The desire to minimize risks………..……101

Lack of knowledge about substance use and harm reduction…….101

Replicating sociocultural beliefs about substance use………..…102

Compassion fatigue………103

6.2 Nurses Lack Accurate Knowledge about Substance Use……..104

Nurses may minimize the symptoms of opioid withdrawal………..…105

Nurses may believe that substance use is a choice……….……105

Nurses may not understand the etiology of opioid use……….…….106

6.3 Reciprocal Mistrust – An Endless Feedback Loop……..…..…….109

6.4 Experience Matters – But Self Taught May Not Always Be Helpful……...……111

Beginning to understand the context of individual substance use……..…111

Developing a professional façade………112

Addiction as a disease………..……112

6.5 The Myth of Normal – People Who Use Opioids Are Not Like Me……113

6.6 Witnessing the Decline, Feeling Helpless to Intervene – Does This Cause Moral Distress? 116

6.7 "How Dare You?" – Caring for Women is Different……118

6.8 In a Small Town the Stigma Lasts Forever……..…..……119

6.9 Glimmers of Hope……120

6.10 Summary: Two Sides of a Divide……...……122

Chapter Seven: Discussion……125

7.1 The View Through Friere's Critical Social Theory Lens……125

7.2 Health Care Systems as Agents of Social Control……127

7.3 Health Care Systems as Agents of Social Control: Contextualizing Study Findings.....129

7.4 The Rise of Neoliberalism……132

7.5 Neoliberalism and the Global War on Drugs……133

7.6 Neoliberalism and the Global War on Drugs: Contextualizing Study Findings...135

7.7 The Impact of Neoliberalism on Health……137

7.8 The Impact of Neoliberalism on Nursing……138

7.9 Neoliberalism – Blaming Individuals for Their Problems: Contextualizing Study Findings……139

People who use opioids are making unhealthy choices……141

Nurses do not understand why people use opioids………141

People who use opioids are to blame for their problems………142

Nurses feel helpless to meaningfully intervene………143

7.10 Two Sides of a Divide Required by Neoliberalism……145

7.11 Discussion in Summary……146

Chapter Eight: Implications and Recommendations……150

8.1 Resisting the Impacts of Neoliberalism Using Contextualized Responses……150

8.2 Implications and Recommendations for Contextualized Nursing Practice……150

Embrace the concept of trauma-informed nursing………151

Embrace a cultural safety model………152

Embrace a relational inquiry practice model………153

Embrace the principles of harm reduction………154

Managers of nurses must provide role support to nurses………155

Ensure there are workplace strategies in place to support nurses in working with people who use substances………..…..155

Ensure there are workplace strategies in place to mitigate the risk of compassion fatigue and burnout………155

Ensure that nurses have access to ongoing professional development opportunities related to substance use including education by people who use substances……….156

8.3 Implications and Recommendations for Contextualized Nursing Education…...…157

Provide substance use education grounded in trauma-informed principles and harm reduction to nursing students and practising nurses………157

Provide user-led substance use education to nursing students and practising nurses……….157

8.4 Implications and Recommendations for Contextualized Nursing Research……158

8.5 Implications for Policy……...……159

Implement trauma-informed care principles across the Ontario health care system. ……160

Implement harm reduction policies across the Ontario health care system….....160

Expand harm reduction services funding to small and rural communities.....161

Decriminalize illicit psychoactive substances………..……161

8.6 Limitations of the Study……162

8.7 Conclusion – Beginning to Bridge the Divide……..……164

References……...……166

Appendix A: Recruitment Flyer for Participants who Used Opioids……...192

Appendix B: Eligibility Screening Questionnaire for Participants who used Opioids……..…..…193

Appendix C: Nurse Participant Recruitment Flyer…….....…..…195

Appendix D: Consent Script for People Who Use Illicit Opioids…….……196

Appendix E: Demographic Form – Participants who used opioids…….……200

Appendix F: First Interview Guide – Participants who used opioids…….....….203

Appendix G: Second Interview Guide – Participants who used opioids…….204

Appendix H: Consent Form for Nurse Participants…….……205

Appendix I: Demographic Form – Nurse Participants…….……...…….……210

Appendix J: Interview Guide – Nurse Participants……..……211

Glossary….....212

List of Tables

Table 1. **Participants who used opioids demographic data**……...…51

Table 2. **Nurse participants demographic data**…….……76

List of Figures

Figure 1. **The Caring Switch**……..…..…97

Figure 2. **The Caring Switch – Risk Factors, Strategies, Consequences…**…..……..…104

Figure 3. **The Adverse Childhood Experiences (ACES) Pyramid…**……..…108

Figure 4. **Neoliberal Influences on Nursing Care of People Who Use Illicit Opiates in Small/Rural Communities: The Wide Angle Lens**……..……146

Figure 5. **Neoliberal Influences on Nursing Care of People Who Use Illicit Opiates in Small/Rural Communities: The Zoom Lens**……..…..…147

Chapter One: Introduction

In the last twenty five years working as a primary health care nurse in Ontario, Canada, I have worked with people who use substances in a variety of settings, both urban and rural. I began practising in a primary health care setting as a Registered Nurse (RN) in 1989, working as a so-called "street nurse" providing nursing care to homeless people in downtown Toronto. I began to learn about harm reduction principles around that time and did so in a practice setting in which substance use was pervasive and highly visible. When I began practising in the same neighbourhood several years later as a Primary Health Care Nurse Practitioner (PHC-NP), the range of harm reduction supplies and strategies had increased from providing clean needles and syringes to providing other injection equipment (such as individualized drug "cookers" for preparing drugs for injection and single use tourniquets) and safer inhalation kits (for smoking crack cocaine) as well as offering accessible community-based Hepatitis C treatment options and harm reduction peer education for people using substances to support their peers in avoiding preventable injuries and deaths.

Throughout the time I have spent practising in primary health care, I have conducted my nursing work from the philosophical stance of harm reduction. I describe harm reduction as a philosophical approach and not merely a set of specific strategies because it is a way of thinking about substance use that is different than so-called mainstream health system approaches and exceptional, rather than typical, among health care providers, including nurses. Harm reduction recognizes that substance use is part of the fabric of normal human behaviour and that problematic substance use is part of a continuum of use – most of which is not particularly problematic. Providing education and materials to reduce drug-related harms to people compulsively engaged in stigmatized, illegal activities promotes health and prevents illness. My

belief is that harm reduction saves lives and represents an appropriate ethical response for nurses and other health care providers.

1.1 Background

When I began practising as a Primary Health Care NP in a small rural Ontario community in 2007, and later in a small Southern Ontario city, I was struck by the apparent invisibility of people who use substances, even though I knew from anecdotal information and provincial epidemiologic data they existed in significant number. While I could not often see people who use substances visibly in the community, community members talked about unintentional overdose deaths and drug-related suicides in the way that people do when such profoundly-affecting events happen in small communities. One community of 3,000 people in which I practised experienced four drug-related suicide deaths in a span of a few months. Whispered rumours abounded – such as the one that a young person had died by self-inflicted gunshot rather than face the shame of disclosing daily use to family members – as did community-wide grief and sadness. Health care provider colleagues who worked in the emergency room (ER) or as regional coroners provided more anecdotal information about the frequency of apparent drug-seeking behaviour in the ER and about pronouncing people deceased with drug paraphernalia in evidence at the scene.

But how could a nurse practitioner like me get to know the people who were using drugs if I did not know where to "find" them? Were they obtaining harm reduction supplies and information? Did they have access to primary health care? Were they being tested for conditions for which they were at risk, such as Hepatitis C infection? I came to understand that using illicit drugs in a small rural community is difficult in many ways, not the least of which is the fear of

being “outed” as a drug user, with serious implications for one’s job, one’s family, one’s children, and one’s health care. I began to realize that discrimination against people who use drugs by health care professionals might have different and potentially more serious consequences for the health of people living in smaller communities.

1.2 Significance of the Study

Over the last two decades, the illicit use of opioids, including prescription opioids, has risen significantly across Canada. Canada claims the dubious distinction of having the third highest per capita narcotic consumption rate in the world, second only to the United States and Germany respectively (Dhalla et al., 2009). In 2010, the College of Physicians and Surgeons of Ontario (CPSO) released a report on the opioid “public health crisis” in Ontario (CPSO, 2010, p. 5). In people aged 25 to 34 in Ontario, one of every eight deaths is opioid related (Gomes, Mamdani, Dhalla, Cornish, & Paterson, 2014). Improved understanding of the experience of health care for people who use illicit opioids in small and rural communities will fill gaps in current nursing knowledge and has the potential to improve access to care for marginalized people.

1.3 Purpose of the Study

The phenomenon of interest in my study is the health care experiences of people who use illicit opioids in small urban and rural communities. Specifically, I wanted to learn more about whether the experience of being a person who uses illicit opioids in a smaller community affects one’s access to health care services and treatment within the health care system. Access is particularly important in smaller communities because some are medically underserviced and access to care may be inadequate or barely sufficient, even for people having few barriers to

receiving care. The Ontario Ministry of Health and Long Term Care (2012) reported that some rural and remote parts of Ontario experience access challenges across the continuum of care and some rural and northern hospitals report higher hospitalization rates even for conditions typically managed in primary care settings. Further, I wanted to explore the perceptions of nurses working in smaller communities regarding what it is like to care for people who use opioids.

I should state from the outset that throughout this document I will use the term "nurse" for ease of reading to include Registered Nurse and Registered Nurse (Extended Class). Registered Nurses in the Extended Class in Ontario are also known as Nurse Practitioners – Adult, Nurse Practitioners – Paediatrics, and Nurse Practitioners – Primary Health Care (which are the three specialty certificates registered by the College of Nurses of Ontario).

To explore this phenomenon, I used the qualitative constructivist paradigm, which holds that there are multiple interpretations of reality which are contextually-defined and which are constructed through the interaction between researcher and participants (Polit & Beck, 2012), to capture insights about the experiences of health care for people who use illicit opioids in small and rural communities.

1.4 A Tale of Two Women: Setting the Context for My Interest in this Work

I met Janice (a pseudonym) at an outreach nursing clinic in a downtown Toronto shelter. She came in because she had developed an abscess on her upper arm at a much-used injection site. She had been to the local emergency room and was given a prescription for an oral antibiotic which she had yet to fill because she had no drug benefit card. As a homeless woman, the instability of her life was such that she had not collected a social assistance cheque for several months and was living on the minimal "street allowance" stipend provided to some

people who stay in some shelters. She had not had a drug benefit card during that time. Because so many of our clinic's patients faced numerous barriers to obtaining needed medications, we had implemented an emergency fund to cover such costs when there were no other options. I was able to order antibiotics at a local pharmacy and ask that the cost be billed to the clinic. When I saw her two days later, she had started taking the oral antibiotics but her abscess had evolved into an enlarging area of cellulitis and she now required intravenous (IV) antibiotics. I arranged for a community outreach worker to accompany her to an inner city emergency room and she received an initial dose of IV antibiotics and had a venous access device inserted. The emergency room's homelessness support worker arranged for her to have the rest of her course of antibiotics via home care services which were set up at an infirmary where homeless people with serious health issues can reside for the duration of their treatment. While she was there I visited her and used the relative stability of her situation to review her other health issues including her compulsive substance use, severe post-traumatic stress, anxiety and untreated Hepatitis C. She went from the infirmary to a withdrawal management centre for women (colloquially known as "detox") and from there entered residential treatment.

I met Elizabeth (a pseudonym) when she came in to see me at a rural primary care clinic. I had not met her before but my role at the time was to see clinic patients needing same day appointments if their primary providers were out of the office or unable to fit additional patients into their schedules. Elizabeth had walked in, telling the receptionist that she was not feeling well and requesting an appointment with her physician, who was not in the office. She was offered an appointment with me and when I brought her in to my office I could see that she looked unwell and uncomfortable. She was pale, anxious, complaining of feeling cold, and constantly sniffing and wiping her nose. She reported nausea and abdominal cramps and said "I

have a really bad flu." She had her arms folded over her abdomen and was curled forward in her chair. Her presentation made me consider that she might be in opioid withdrawal although there was no indication from her chart that she was using prescribed or illicit opioids. I explored the chronology of her symptoms and asked what medications she was taking. She remarked that she was "supposed to be on oxycodone for my back and lorazepam for my nerves." I did not want to risk offending this woman whom I had never met and who was clearly in some distress. Nonetheless, I decided to suggest the possibility of opioid withdrawal by saying, "I agree you look pretty unwell. Your symptoms actually remind me of what people go through when they are withdrawing from opioids." She looked up at me and then at the floor, and back at me, as if considering her options, and finally said, "I've been using 'hydromorph' for my back because I can't get meds from my doctor." She had been using the potent prescription opioid hydromorphone daily for the past six months and had last used the previous day. She had no money to purchase more. She told me that the last time she ran out of her drug she had presented to the local emergency room where "they have a sign in the waiting room saying no narcotics will be prescribed. It doesn't matter what your issue is – no narcotics." She also told me that her own GP was on call several times weekly and she did not want to go to the hospital only to get the same message she did in the office. "Plus the last time I was there, I heard one of the nurses tell a new nurse that everyone with my last name was a drug addict."

She disclosed that she had been snorting and injecting hydromorphone and that she often re-used needles because of the inability to obtain new needles. When I asked her whether she was aware of the needle exchange program (NEP) in the community, which runs out of a pharmacy, she told me that she did not want to be standing in line for clean needles next to her grandmother who might well be there picking up blood pressure medications. Although

interested in exploring methadone maintenance therapy, she had no vehicle so going on methadone was not an option, as this required driving a 250 kilometre round trip to the nearest clinic. Using the community transportation service would require her to disclose her opioid addiction to the driver and anyone else traveling at the same time to out-of-town specialist appointments. She told me, “If my grandma finds out about this, it will kill her.” I asked her if she knew the person in the community who had recently died from an overdose, and she told me that he was a good friend of hers who had just returned to the community after being in jail for six months. “I guess he lost his tolerance and used too much. I feel so sorry for his girlfriend who found him with a needle in his arm. It was a shame, because he used to get lots of needles from the pharmacy and give them to folks who were too scared to go there themselves.” When I asked whether she had experienced symptoms of depression or anxiety, she started sobbing and told me, “Since I was ten years old.”

Both of these women needed health care services related to their substance use and mental health issues. On the face of it, Janice had the more difficult and potentially life-threatening situation, given her homelessness. But in terms of substance use, the availability of harm reduction supplies and education, and health care for both her obvious and underlying health issues, Elizabeth had much less access to the care and services she needed. Added to that, she was burdened with hiding this serious health issue from her friends, her family, and her health care providers. Struggling with daily, compulsive substance use in a large urban city meant that Janice had access to outreach health services in dozens of locations; harm reduction services in dozens of locations; specialized services such as short term infirmary care to allow her to receive care for serious conditions; and residential withdrawal management services which provided a safe location to wait for residential drug treatment. Whether she used these or not, or

whether she needed them repeatedly over time, and despite the fact that such services are often fully subscribed and not immediately available, she did have a better chance of gaining access to them than did Elizabeth. The nearest residential detox centre for women that Elizabeth could have entered, if she could have found transportation, was approximately 190 kilometres away, one way. If she got there, she would have had no way to get back home without disclosing her substance use to someone she knew with a vehicle.

Pharmacy-located NEPs provide harm reduction supplies in communities without harm reduction infrastructure, but have limited hours of operation and as well have the disadvantage of requiring people to obtain harm reduction supplies in the context of a busy general pharmacy, potentially at the same time as people they know who are there for other reasons. Two rural peer workers (people who use substances who conduct harm reduction outreach and education with their peers) I spoke with in 2010 provided anecdotal evidence that at some pharmacy-located NEPs, relief pharmacists have told clients to "come back when the regular pharmacist is here" and others have required clients returning used needles to place every single used needle in a sharps container, even if there is a line-up of customers behind them watching (Hardill, 2011). "Secondary distribution" of clean needles and other harm reduction supplies by people who inject drugs (peers) is common and important in small and rural communities but is usually informal and peer volunteers are usually untrained in harm reduction/overdose (OD) prevention (Bryant & Hopwood, 2009; Canadian AIDS Society/Canadian Harm Reduction Network, 2008; Jackson, Parker, Dykeman, Gahagan & Karabanow, 2010).

In large urban centres, overdose prevention programs have been set up wherein people who use injection opioids are trained to administer the opioid-reversal agent naloxone (Narcan) in an overdose situation. Similar to emergency doses of epinephrine which are administered by

people or by family/friends after exposure to a life-threatening allergen, naloxone administration allows time for emergency services to be called and arrive to transport someone who has overdosed to a hospital. Accompanied by OD prevention education, such as warnings about loss of drug tolerance following prolonged abstinence, these programs have generally not been available in small communities. In June 2016, the Government of Ontario announced that the province is making naloxone available without a prescription and at no cost to Ontarians at risk of opioid overdose. It remains to be seen as of this writing whether the same stigma associated with obtaining clean needles from a rural pharmacy will apply to obtaining naloxone.

Janice came into the nursing clinic telling me she had an abscess from injecting that needed treatment. The nursing clinics had a reputation among homeless people for providing accessible, compassionate and non-judgmental care. Because she was able to be frank about her health, I was able to promptly arrange the care she needed and ultimately assist her to address some of the underlying issues. Elizabeth had a serious injection opioid problem but presented with “flu” symptoms and pain. I am not sure, given her experiences of health care, that she could have voluntarily disclosed her opioid use. She was fully prepared to withhold this information from her usual provider. She avoided the local emergency room because she had no faith that she would get treated without judgment there. She had no way of getting to methadone treatment or residential addiction services. She had limited means of obtaining clean supplies. She had not had any treatment, ever, despite decades of symptoms, for the issues underlying her compulsive substance use. All of this was true because she lived in a small rural community, like many thousands of people living in hundreds of other small rural communities in Ontario.

I have found that it can be more challenging by far to care for people outside of large cities because the pervasiveness of drug-related stigma often leads them to hide their opioid use.

If they do disclose their use, there are numerous barriers – financial, geographic, and systemic (such as lack of child care and lack of health services) – which impede their access to needed care and services. Importantly, many people in small communities deliberately withhold the fact they are struggling with substance use from their health care providers because of negative and discriminatory attitudes when they do. I chose to learn more about what it is like for a person who uses illicit opioids in small communities to get health care – to surface these myriad hidden and discounted voices – in order to learn from them and explore ways for nurses to provide responsive, compassionate, patient-centred, ethical care.

1.5 Theoretical Scaffolding

Nursing concerns itself fundamentally with the holistic care of human beings. As such, research into phenomena relevant to nursing practice requires integrated exploration situated in the lived experience of human beings (Buxton, 2011). Further, Thorne (2008) argues that nursing knowledge "always evolves in dialectic" as nurses analyze patterns and themes in order to move from the general to the specific individual person (p. 25). Thorne's interpretive description calls upon nurse researchers to draw from traditional interpretive hermeneutics to carefully analyze phenomena but then, importantly, to place that interpretation back into the practice context "with all of its inherent social, political and ideological complexities" in order to alter the viewpoint through which the phenomena are generally viewed (p. 50).

This study was conducted using the epistemological lens of Friere's (1970) critical social theory framework, which argues that the wisdom of oppressed groups contains the most appropriate strategies to improve the conditions of their lives. A critical social theory framework is founded on the assumption that what is perceived to be real is shaped by sociopolitical, economic, cultural and ideological contexts. Further, the epistemology of critical hermeneutics

recognizes that interpretation of meaning (knowledge) is influenced by dominant beliefs and ideologies which may silence the voices of marginalized people (Lopez & Willis, 2004). Given that participants who use drugs are likely to experience multiple, intersecting marginalizing experiences such as poverty, homelessness and involvement in sex work, critical hermeneutic inquiry was used in an effort to make visible traditionally discounted knowledge.

Invoking early critical social theorists, Stevens (1989) challenged nursing to consider environment broadly in terms of socioeconomic and political influences and to ultimately bring about structural changes to reduce oppression. She identified that critical social nursing research questions arise from the concerns of oppressed groups and argued that the goals of "critical social nursing" include describing the effects of oppression on health by illuminating "relations of dominance" (p. 67). Lopez and Willis (2004) suggested that nurse researchers analyze narratives for evidence of themes of oppression. Crowe (2005) described the use of critical discourse analysis in nursing research and argues that doing so assists nurses to examine dominant discourses that influence nursing practice. Crowe reminded us that nursing practice must be understood as political, cultural and social and that "language constructs how we think about and experience ourselves and our relationships with others" (p. 56). Pauly (2008a) proposed that a "critical reinterpretation" of the concept of social justice can assist us in illuminating structural inequities which contribute to drug-related harm (p. 4). Carnegie and Kiger (2009) argued that critical social theory could be utilized as a means of identifying ethical ways to practise in communities experiencing health inequities. Parlour and McCormack (2012) suggested that nursing research undertaken with a critical social theory framework may provide a means to link emancipatory theory and action, raising the possibility of a "critical, emancipatory praxis" (p. 309).

Of relevance to research with people who are marginalized by their use of illicit opioids is Friere's essential argument that oppression and its resultant dehumanization must be recognized and transformed. Friere's framework guided the study and sensitized me "to look for evidence of oppressive themes in the narratives" (Lopez & Willis, 2004, p. 733). Friere's (1970) critical social theory supports analysis which is contextual and which takes into account dominant ideological and social structures which may influence the experience of study participants (Lopez & Willis, 2004). For example, might adherence to the so-called "war on drugs" ideology regarding illicit drug use, which has been favoured by many Canadian legislators, be reflected in the manner in which some nurses treat people who use drugs? Does the illegality of many substances contribute to the harm related to substance use? Might mainstream ideological beliefs about drug use among nurses in some way encourage or condone discriminatory treatment by nurses? Might neoliberal beliefs focusing responsibility exclusively on individuals be replicated in health care settings, and if so, might this focus actually obscure underlying health concerns of people who use substances which then remain untreated? What types of power dynamics are embedded in health care systems in general, and in small community and rural health care systems in particular? What roles do nurses play in their entrenchment? These are the types of questions I considered as I developed the goals and methods of this study; engaged with people who use opioids and nurses; transcribed the interviews; identified themes emerging from the research; and considered potential practice implications.

Chapter Two: Review of the Literature

The nursing and social science literature was searched using CINAHL, Proquest and Scopus. Each search was repeated using the following keywords singly or in combination: substance use, drug use, illicit drug use; opioid use, methadone; mothers on methadone; stigma, discrimination, rural, health care, Ontario; nurses' views; access to health care, harm reduction, harm minimization, nursing, Canada, critical social theory, and nursing. Additionally I searched the internet for links to information about rural Ontario health care access and health issues for rural Ontarians.

2.1 Rural Substance Use

Not only is there little research of any kind with people who use drugs outside of large urban centres, there is a paucity of information on barriers and access to care in small towns or rural communities. The United States Department of Health and Human Services' "Rural Healthy People Survey" concluded that the consequences of drug use in rural areas may be greater than in urban areas because of limited access to treatment, social stigma, geographic isolation, and poverty (Hutchison & Blakely, 2010). A study of rural Australian pharmacists and general practitioners described several challenges including the difficulty recruiting qualified addictions expertise to rural communities; large increases in addictions services demand without increased funding for services; a serious shortage of community pharmacies willing to dispense methadone in rural areas; as well as lack of access to harm reduction supplies and programs, and "resistance to the notion that such (programs) may be beneficial" (Peterson et al, 2007, p. 498).

Transportation over vast distances and the lack of public transportation pose significant barriers to accessing services. Some people with problematic substance use have lost driver's

licenses, lack reliable vehicles or cannot afford gasoline or insurance. Lack of available or affordable child care exacerbates logistical issues (Clay, 2007; Peterson et al, 2007; Canadian AIDS Society/Canadian Harm Reduction Network, 2007). Social and cultural norms in rural communities can make it difficult for people with problematic substance use to seek help. Rural culture may emphasize individualism and self-sufficiency, conservative beliefs, intense religiosity which may lead to rigid norms, strong family ties and distrust of outsiders (Clay, 2007).

In rural British Columbia a 2006 study of 13 First Nations addiction service providers concluded that Indigenous injection drug users were the fastest growing group of new HIV cases in Canada and suggested the importance of incorporating traditional Indigenous practices into harm reduction services. In remote rural populations there are significant geographic barriers such as having to drive six hours to a methadone clinic as well as other barriers in small communities such as fearing the lack of confidentiality and stigma (Wardman & Quantz, 2006). The Canadian AIDS Society and the Canadian Harm Reduction Network held a national Harm Reduction Symposium in Winnipeg in 2007 which highlighted key issues including the fact that rural populations are negatively affected by geographic distances and have very limited access to needle exchange and methadone programs; a growing phenomenon of seniors being victimized through theft of medications or the taking over of their homes as drug houses; a refusal of some physicians to accept substance users as patients and reports of "blacklisting" of substance-using patients by doctors; and concerns about the proliferation of privatized methadone clinics.

Research on Indigenous women aged 14-30 in Vancouver, British Columbia and the smaller community of Prince George found that they were over-represented in new cases of HIV infection and were at increased risk for sex and drug related harm, especially for those involved

in sex work (Mehrabadi et al., 2008). Research conducted in Kamloops, British Columbia concluded that gender and social exclusion amplify barriers affecting health. Interviews with 96 women whose lives were characterized by poverty, substance use, mental health issues, precarious housing and engagement in sex work determined that women are more vulnerable than men to abuse and coercion. Further, because there is more stigma attached to women's drug use, women have less access to harm reduction and treatment services. Barriers included stigmatization, stereotyping, racism, substance use, lower income, lack of education and policies that impair access to care (Carriere, 2008).

Gustafson, Goodyear and Keogh (2008) studied substance use in small urban centres in Newfoundland. They argue that stereotyping and stigma represent barriers which contribute to unsafe practises and lack of access to services. Drug use prevalence rates typically tended to be estimated by demand for treatment services which in turn often underestimated the extent of problems because of under-use of services related to the "perception that everyone knows their neighbour's business" (Gustafson et al., 2008, p. 190). Also in Eastern Canada, Jackson, Parker, Dykeman, Gahagan, and Karabanow (2010), found that some rural people who use substances kept their drug use well-hidden to avoid stigmatization. Many reported spending time alone or away from other users – making it difficult for non-users to connect with those people. Injecting was seen as more stigmatized than other ways of using. Two thirds of the sample was recruited from small towns and rural areas. The authors discovered that, besides more traditional income sources, 21% were involved in informal economies such as panhandling and sex work. They concluded that the individuals in the study spent inordinate amounts of time and effort on a daily basis to manage their addictions. Some participants provided education and supplies to their

peers, assuming a “peer helper” or “natural helper” role – thereby acting as extensions of outreach services.

I found no similar studies in rural Ontario or most of the rest of Canada.

2.2 Rural Health Care

There are many definitions of small and rural communities in Canada. For the purposes of this study, I have chosen to adopt The Ontario Ministry of Agriculture, Food and Rural Affairs’ (OMAFRA) practical definition which considers rural Ontario to be all areas excluding the cities of Greater Sudbury, Hamilton, London, Ottawa, Thunder Bay, Windsor, the regions of Niagara and Waterloo, and the Greater Toronto Area as well as any municipalities within these urban regions having a population of less than 100,000 (OMAFRA, 2007). Other reports referenced may have used various other definitions but for the purpose of this research, I was interested in understanding the differences related to health care for Ontarians who use opioids outside of large urban centres.

An assessment of the health status of rural Canadians conducted by the Canadian Institute for Health Information (2006) analyzed several pan-Canadian databases including the Canadian Cancer Registry and the Canadian Community Health Survey to assess for geographic differences in key health indicators. Among the health risks discovered were poorer socio-economic conditions; lower educational attainment; less-healthy behaviours such as higher smoking rates and lower consumption of fruits and vegetables; and higher overall mortality rates. Rural Canadians are also more likely to die from injuries and poisonings than their urban counterparts and more likely to have higher body mass indices (BMIs). The Ontario Ministry of Health and Long Term Care (2012) reported that the health status of rural residents has been

found to be lower than residents in urban areas, including lower life expectancy, increasing all-cause mortality rates with increasing remoteness, and statistically higher proportions of rural residents reported having a fair/poor health status compared with urban Canadians.

Sibley and Weiner (2011) conducted an analysis of access to care in rural versus urban Canadian communities and found that residents of some rural communities were least likely to have had an influenza vaccination; to have used specialist physicians' services, or to have a regular medical doctor. However, they were also less likely to report having unmet health needs despite having lower primary care utilization, lower usage of specialists and worse health status, leading the authors to consider whether rural residents have a lower threshold at which they report their needs being unmet.

Although Glazier, Gozdyra and Yeritsyan (2011) reported that 99.6% of Ontarians living in communities with less than 30,000 people had access to primary care within thirty minutes in 2009, the Canadian Mental Health Association (2009) reports that residents living in rural and remote regions have poorer access to mental health and addictions services both in terms of number and comprehensiveness. Additionally, CMHA notes that some primary care providers may screen out individuals with complex mental health or addictions needs leaving some vulnerable people without access to primary care which does not seem to be reflected in government reports on health care access.

It is interesting to note that a review of websites with a focus on rural Ontario health and health care such as Gateway Centre of Excellence in Rural Health (www.gatewayruralhealth.ca) and the Rural Ontario Institute which focuses on rural community wellbeing (www.ruralontarioinstitute.ca) contains no mention of substance use issues, services or research.

This despite the former organization housing eleven research chairs including Rural Nursing, Rural Medicine, Rural Pain Medicine, Rural Mental Health, Rural Pharmacy and Rural Health Promotion; and despite the latter institute being funded by the province of Ontario to research rural quality of life and community well-being.

2.3 Rural Nursing

Nurses who work in rural areas face some challenges not experienced in urban settings. Greiner, Glick, Kulbok and Mitchell (2008) undertook a systematic search of rural nursing research in various jurisdictions, including Canada. Their review found that nurses in rural practice settings experienced stressors related to minimal staffing and the perception that in communities lacking health care resources their work sometimes took on the feel of "Band-Aid approaches" (MacLeod & Zimmer, 2005). Stewart et al. (2005) reported that rural nurses attributed work satisfaction to being from within the community. Hunsberger, Maumann, Blythe and Crea (2009) interviewed nurses and managers in 19 rural Ontario hospitals and noted that rural nurses and their patients are bound by multiple contextual relationships (both inside and outside health care settings) which some find very satisfying and others find challenging to navigate. Some remarked that nursing in the community where they resided made them feel valued and appreciated but similar to Andrews et al. (2005) some reported frustration at being consulted about health issues outside of work time. Penz et al. (2007) and McCoy (2009) found that some rural nurses experienced barriers to participating in continuing education including time constraints, workplace constraints, limited offerings, and financial barriers.

2.4 Health Care Experiences of People Who Use Substances

A review of the nursing and harm reduction literature concerning health issues and health care access for people who use opioids was conducted to explore what is known about people who use substances in small and rural communities and specifically what is known about their experiences obtaining health care.

McLaughlin, McKenna and Leslie (2000) interviewed 20 people who use drugs in Northern Ireland who reported receiving poor care from general practitioners. Neale, Tompkins and Sheard (2008) conducted research with 75 people who use injection drugs in England, including a sub-sample living in a small city, and found that some tolerated hostile attitudes from their primary care providers because they believed no other providers would accept them into their practices. They also reported poor treatment in hospitals where they were sometimes accused of wasting valuable health care resources. Lloyd (2010) conducted a literature review on stigmatization of drug users in the United Kingdom and noted that this is a relatively unexplored area. Harvey, Shmied, Nicholls and Dahlen (2015) interviewed mothers on methadone about their experiences in the perinatal period and found that they reported feeling judged by health professionals which reinforced their self-judgment. Some women described being discriminated against in the neonatal intensive care unit and believed that nurses who judged them more harshly may have scored their babies' neonatal abstinence symptoms higher than nurses who did not. Women reported being less likely to engage with services if they experienced judgment or discrimination by health care providers (Harvey et al., 2015).

In the Canadian context, Gustafson, Goodyear and Keogh (2008) studied substance use in small urban centres in Newfoundland, Canada, and found that stereotyping and stigma, including by health care providers, contributed to lack of access to needed care. Jackson et al. (2010) found

that some rural people in Eastern Canada who use substances kept their drug use well-hidden to avoid stigmatization or denial of services, including health care services. Lang, Neil, Wright, Dell, Berenbaum and El-Aneed (2013) found that people who inject drugs in Saskatoon, Canada were seen by service providers (including nurses) to experience several barriers to care including stigma, discrimination and inadequate education of health care providers. McCutcheon and Morrison (2014) found people living in Prince Edward Island who inject drugs reported difficulty obtaining acute and primary care related to stigmatization and discrimination by health care providers. Pauly, McCall, Browne, Parker and Mollison (2015) interviewed patients who use substances and were admitted to hospital in Vancouver, Canada. They found that patients described feeling judged by staff for their use; feeling as though they were under surveillance by staff or seen as drug-seeking; and being made to feel as though they were "helpless victims" of a disease (their substance use). Wise-Harris et al. (2016) interviewed 166 people with mental health and addictions who frequently utilize hospital emergency rooms in a large urban Canadian city and found that participants typically described their visits as necessary despite reporting being stigmatized by hospital staff and discharged without the treatment they had expected. The authors suggest that alternative models of care and focused staff education may be strategies to improve outcomes.

2.5 Stigmatizing Health Care Experiences of People Who Use Substances

Because the concept of stigma arose so frequently from within the literature on health care experiences of people who use substances, I decided to group literature findings on stigma together. Over nearly three decades working with people who use illicit drugs in primary care, the issue of stigma has arisen so often as a barrier to care that my experience also informed my

decision to privilege this particular concept. Building on the foundational work of sociologist Erving Goffman in the 1960s, stigma can be understood as a social process derived from unequal power relations wherein those with power attribute stereotypes and labels to those without power, resulting in discrimination and loss of status by those who are labelled (Goffman, 1963; Harris & McElrath, 2012). Much work on stigma has been done in the area of mental health where it has been found to affect access to care, relationships with health care providers and continuation of treatment (Link & Phalen, 2006; Varas-Diaz, Serrano-Garcia & Toro-Alfonso, 2005). More recent studies have explored the experiences of stigma related to having particular health conditions such as HIV (Parsons, Bond & Nixon, 2015) and Hepatitis C infection (Butt, 2008; Day, Ross & Dolan, 2003) which is attributed to its relationship with illicit substance use.

All of the Canadian studies noted above which looked at experiences of health care of people who use substances described the experience of stigma which posed barriers to care (Gustafson, Goodyear & Keogh 2008; Jackson et al., 2010; Lang et al., 2013; McCutcheon & Morrison, 2014; Wise-Harris et al., 2016). Additionally several international studies also confirm the prevalence of stigma among people who use illicit substances (Ahern, Stuber & Galea, 2007; Harris, 2009; Martin et al., 2006) and dually-stigmatizing circumstances for women who use illicit substances and engage in sex work (Sallman, 2010; Whitaker, Ryan & Cox, 2011).

2.6 Nurses' Views of People Who Use Substances

Peckover and Chidlaw (2007) interviewed British community district nurses about working with people who use substances and found that some experienced fear for their own safety and dealt with this by visiting in pairs and by making their visits shorter and more task-oriented. Ford (2011) conducted a mixed methods study of Australian nurses' therapeutic attitudes to people who use substances and found that, as well as insufficient education on

substance use, nurses also identified "interpersonal challenges" which compromised their ability to provide care including concerns about violence and fears for their own safety; 'manipulative' behaviours which were seen by nurses to compromise the therapeutic relationship between nurse and patient; and failure by patients to take responsibility for their own health and social situations. Further nurses described stress related to practising unsafely because patients did not truthfully disclose their substance use and disruptive behaviours impeding the care of other patients. Some neonatal nurses interviewed by Ford expressed anger, frustration and disapproval when caring for neonates experiencing neonatal abstinence syndrome at what they saw as the irresponsible behaviour of their mothers. Harling and Turner (2011) found that Australian student nurses' attitudes towards illicit drugs reflected societal views and were heavily influenced by stereotypical images and messages around illicit drug use in the media as well as cultural norms.

Lang et al. (2013) found that most health care providers in their Saskatoon-based study, including nurses, had witnessed discrimination against people who inject substances related to their ethnicity, the presence of communicable disease and the fact they injected drugs. Most also agreed they lacked sufficient education about injection drug use. They also noted that many providers described caring for people who inject substances as difficult because such patients may be demanding, take extra time, be impatient and rude, and/or be disruptive to other patients (p. 7). Pauly et al. (2015) interviewed nurses caring for people who use drugs admitted to hospital in a large urban centre in Vancouver, Canada. Some nurses saw substance use as an individual problem for particular patients while others saw it as arising out of life circumstances. Some nurses did appear to resist the characterization of people who use drugs as criminals and

identified that criminalization could lead to some of the harms related to illicit drug use. Some nurses expressed the view that addiction takes over patients' lives like a disease process.

2.7 Nurses' Views of Harm Reduction Strategies

Ford (2010) found that a sample of Australian nurses, which she described as well-positioned to help reduce drug-related harms, lacked accurate knowledge of key treatments and, importantly, were "mistakenly optimistic" about the efficacy of abstinence-based programs (p. 14). Ford (2011) further argued that it might help nurses to care for people who use substances if they were to adopt a harm minimization framework rather than consistently looking for a way to solve people's substance use issues. Ford notes that some nurses find the acceptance of ongoing substance use required by harm reduction approaches difficult.

Pauly (2008a) identifies harm reduction strategies as a set of interventions as well as a philosophical approach which nurses can use to reduce harm, preserve respect for patients, avoid moral judgments and move away from stigmatization. Further it can lead to improved access to health care, which may in turn lead to access to income supports, housing and other social determinants of health. Pauly (2008b) also argues that harm reduction may provide a practical strategy through which nurses who experience values tensions when they are unable to "fix" patients who use substances can provide pragmatic interventions. Smye, Browne, Varcoe and Josewski (2011) advocate using an intersectional lens to allow a more complex understanding of harm reduction using the specific example of methadone maintenance therapy provision to Indigenous people and further place the concept of drug-related harm in the context of continuous broader experiences of oppression.

The Canadian Nurses Association (2011) calls on all nurses caring for people who use illegal drugs to have knowledge about harm reduction. The Registered Nurses' Association of Ontario (2015) Best Practice Guideline for working with people using substances suggests that nurses integrate harm reduction into their work after addressing their own biases. The Canadian Nurses' Association, the Association of Registered Nurses of British Columbia and the Registered Nurses' Association of Ontario held intervenor status in the 2011 Supreme Court of Canada case regarding Vancouver, Canada's supervised injection room which resulted in a unanimous ruling in favour of this particular harm reduction strategy.

Based on this review of literature, the paucity of nursing literature on harm reduction was identified as a significant gap. Further, there would seem to be a disconnect between the stance of some provincial and national nursing organizations which support harm reduction and the lack of knowledge and implementation of harm reduction by nurses in Canada.

2.8 Nursing Care of People Who Use Substances

The Canadian Nurses' Association Code of Ethics for Registered Nurses (CNA, 2008) calls on nurses to recognize and respect the inherent worth of all and to uphold human rights and equity for all people. Some nurse scholars argue that this may not always happen. Pauly (2008b) explored whether nurses experience values tensions between a desire to fix people who use illicit substances and the reality of being unable to do so. She found that some nurses may provide different quality of care to people who use illicit substances including delaying care, providing less information and using inappropriate behaviours such as roughness.

Pauly, Goldstone, McCall, Gold and Payne (2007) observed that nurse-patient therapeutic relationships can be hindered in an environment where people who use substances are

characterized as drug seeking, lacking in personal responsibility, or undeserving of care. Ford (2010) argued that nurses' care of people who use substances is constrained by inadequate knowledge about drugs and alcohol and limited support for their role *vis a vis* policy and practice standards. Monks, Topping and Newell (2012) interviewed nurses who provided care to people who use substances with medical complications on an inpatient unit and found that they reported feeling confident to deal with the physical complications of drug use such as septicemia but less confident to manage drug-specific issues such as withdrawal symptoms. Further, interactions with patients were "emotionally charged and steeped in mutual feelings of distrust" which caused the nurses to minimize contact and detach from those patients (Monks et al., p. 941). The nurses' fears of disruption and violence led to a detached way of working in order to minimize those risks. A small number of nurses who enjoyed working with people who use substances disclosed personal experiences of family or friends who used drugs which seemed to allow them to connect with those patients.

Gustafson, Goodyear and Keough (2008) suggest that nurses are well positioned to provide leadership related to working with people who use substances through collaborative, community based research, education and advocacy. Pauly et al. (2007) call on nurses to engage in research which illuminates the social consequences caused by harmful policies related to drug use and inform the development of nursing practice and policy related to the care of people who use illicit substances. Doane and Varcoe (2007) argue that "difficulty is at the heart of ethically responsive nursing care" and that acknowledging this allows for more ethical and effective nursing relationships with patients whom nurses may perceive as challenging (p. 201). Pauly et al. (2015) propose a model of "cultural safety" to address inequitable health care and access for people experiencing discrimination related to illicit drug use, poverty and homelessness.

2.9 Social Determinants of Health

Because the people who use illicit opioids (and other substances) in my clinical practice have virtually all been people who live on low income, and who face additional intersecting health vulnerabilities including poor quality housing, homelessness, Indigenous status, and serious untreated mental health issues, I approached this project using a social determinants of health (SDOH) lens. Low income is a risk factor for higher prevalence of many health issues, including diabetes type II; hypertension; osteoarthritis; chronic obstructive pulmonary disease; asthma; and an increased likelihood of having more than one chronic condition (Bierman et al., 2009; Lightman, Mitchell & Wilson, 2009). Additionally, those living below the poverty line experience depression at a rate 58% higher than the Canadian average (Fryers, Melzer & Jenkins, 2003; Smith, Matheson, Moineddin & Glazier, 2007) and cardiovascular disease at a rate 17% higher than the Canadian average (Lightman, Mitchell & Wilson, 2008). Low income people experience higher rates of lung, oral and cervical cancers (Conway et al., 2008; Shack et al., 2008). Income inequality contributes to the premature deaths of 40,000 Canadians annually (Statistics Canada, 2014).

2.10 Critical Social Theory and Illicit Drug Use

Application of a critical social theory lens to illicit substance use can be found, although not typically in the nursing or even health care literature. Cooper (2004) conducted an historical analysis of medical theories of opioid addiction in the late nineteenth and mid-twentieth century in America and found that health professionals typically attributed opioid addiction to individual pathology among poor, working class and non-white people; and to external factors among affluent, white people. Contextually Cooper notes that these time periods were characterized by social and political upheaval which threatened the status of wealthy white men. While physicians

located the cause of opioid addiction among impoverished people of colour in their "innate degeneracy and vice" they attributed its cause among white, affluent people to either painful illness or the "stresses of living in modern society" thereby reinforcing inequitable social relations (p. 442). Aggarwal et al. (2012) argue that North American drug policy and medical definitions of substance "abuse" have been politically motivated in order for governments to control ownership of psychoactive substances. Use of those substances without state sanction may lead to legal sanctions which may lead to a diagnosis of "substance abuse" by health professionals whose collective thinking has "acquiesced to what could be called 'drug war diagnostics'" (p. 7) Applying the medical word "narcotic" to the legal descriptions of a wide range of diverse psychoactive plant materials, even those that do not have narcotic properties, such as cocaine or cannabis,

> "gives the illusion of a scientific basis to legal policy and...acts as a legitimation and a defense of government intervention. Here, then, we see the power of the language…to construct a reality, to expropriate authority by the use of persuasive words, and to redefine a social event – the consumption of cannabis, for example – by placing it within a frame so that it becomes seen to be scientifically dangerous…" (Aggarwal et al., 2012, p. 13).

2.11 Literature Review in Summary

Review of the literature revealed a limited amount of information on rural substance use in Canada and a particularly significant gap in this area in Ontario. While there are data available on the health status of rural people in Canada as well as the issues they face regarding access to care, there is a glaring lack of information about substance use. Nurses who work in smaller rural

communities experience some challenges not experienced in urban settings including the need to navigate relationships with patients who may also be friends or family members outside of health care settings and in some cases challenges to participating in continuing education such as lack of geographic proximity to educational offerings and workplace and financial constraints.

The literature regarding the health care experiences of people who use substances in smaller communities, including in Canada, revealed several barriers to getting appropriate care including stigma, discrimination and lack of knowledge by health care providers. Some rural people who use substances do not disclose their use in order to try to avoid stigma and discrimination. Many studies of the health care experiences of people who use substances throughout the world, including all of the Canadian studies I reviewed, reported the presence of stigma and its role in creating barriers to obtaining health care.

Nurses' views of people who use substances reported in the literature included fear for their personal health and safety; fear that some patients would not disclose their substance use therefore compromising safe care; anger and frustration related to so-called manipulative, rude or disruptive behaviour shown by some people who use substances; and disapproval of people seen as not taking responsibility for their health. Some nurses had witnessed discrimination against people who use substances by health care providers. Lack of education on substance use was also identified by nurses. There is a distinct lack of nursing literature on harm reduction and nurses' lack of knowledge on harm reduction was also identified as a significant gap. Additionally, there appears to be a disconnect between a pro-harm reduction position of some provincial and national nursing organizations and the lack of knowledge and implementation of harm reduction by nurses in Canada.

Some nurse researchers have identified that nurses providing care to people who use substances may experience conflicted values because they are unable to "fix" substance use. Some nurses may provide care differently including delaying care, providing less information and providing care more roughly. Nurse-patient interactions are sometimes characterized by distrust and some nurses provide care in a detached way to try to minimize the risks of disruptive behaviours. Some nurse researchers identify nurses as well-positioned to lead harm reduction-informed research and advocacy and some have proposed models of care to try to address inequitable access to health care experienced by people who use illicit substances.

There is very little literature applying a critical social theory lens to substance use within the mainstream health or nursing literature. What exists is most likely to be found in social anthropology or medical geography contexts.

Chapter Three: Methods

The research questions I sought to answer were: 1) What is the experience of health care for people who use illicit opioids and are living in small cities and rural communities? 2) What are the views of nurses practising in small cities and rural communities about providing care to people who use illicit opioids? To explore these questions, I considered carefully what methods would be most appropriate. Given my desire to apply a critical social theory lens to learn from subaltern voices, I used the qualitative constructivist paradigm, which Polit and Beck (2012) describe as an approach that holds that multiple realities are constructed by participants within their social contexts, to learn from small town and rural people who use illicit opioids what their health care experiences were like. Following this, I collected data from nurses practising in small communities to learn what it is like to provide care to people using illicit opioids.

The nursing literature was reviewed to assist with developing appropriate methodological approaches including recruitment, sampling, data collection and analysis. The methodology was situated in interpretive description which, in contrast to traditional phenomenological inquiry, is grounded within "practice knowledge and nursing science" (Thorne, Reimer Kirkham & MacDonald-Emes, 1997, p. 173). The purpose of interpretive description is to answer questions of relevance to practice disciplines – to yield "constructed truths" which provide "an extended or alternative understanding" of phenomena which will ultimately be useful to practice applications (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004, p. 6). As a nurse who has engaged in direct clinical practise almost continuously since 1987, I have (at least) one foot firmly grounded in the practice realm and as such this methodology resonated strongly with me.

Thorne et al. (1997) developed the method of interpretive description to provide an inductive, analytic approach to generating qualitative nursing knowledge which answers complex, contextual questions. Thorne et al. (2004) argue that interpretive description recognizes that "reality is complex, contextual, constructed, and ultimately subjective" (p. 3). Thorne (2008) calls upon nurse researchers to carefully analyze phenomena using interpretive hermeneutics but then exhorts nurse researchers to insert that interpretation into complex nursing practice contexts so that they may be seen through that particular contextual lens (p. 50). Thorne (2011) elaborates further that nursing research is at its heart a practical endeavour which "exists because there is a pressing social need" for which nurses seek to provide solutions (p. 451).

The epistemological underpinnings of interpretive description are rooted in the beliefs that there are multiple constructed realities which are contextual and complex; and that researcher and participant engage in dialogic interaction which is reciprocal and mutually influential (Thorne et al., 2004). Using an inductive analytic approach grounded in the tradition of naturalistic inquiry, I engaged in open-ended, semi-structured, conversational interviews to collaborate with participants who used opioids to explore their experiences of health care. This approach seemed very natural to me and recalled for me the similar manner in which I have learned most of what I know about compulsive substance use, which I have learned from the thousands of people I have met as a nurse over the years I have practised – which has been simply to ask when I do not know something.

Following completion of the interviews with participants who used opioids, I similarly conducted open-ended, semi-structured conversational interviews with nurse participants in order to understand the perspectives of nurses caring for people who use opioids in small communities

and to view the issues articulated by people who use opioids through a nursing lens. I interviewed nurse participants after interviewing people who use opioids in order to obtain nurses' views on some of the issues raised by participants who used opioids.

Before entering the field to begin interviews, I spent significant time trying to anticipate how I would respond to the common pitfalls befalling a novice qualitative researcher. I approached this research as an experienced primary care nurse with a long history of having been immersed in harm reduction philosophies and advocacy which I know is not typical of most nurses or even of most primary care nurses. I have borne witness to hundreds upon hundreds of stories from my patients who use drugs about poor treatment they have received in the health care system, including by nurses; I have pleaded and pleaded with very ill people to attend emergency rooms for life-saving treatment for sepsis and endocarditis and been unsuccessful because of their experiences of poor treatment; I have advocated for people who use drugs to help them get the care they needed; I have strategized ways to circumvent unresponsive health system policies and practices.

At first glance, one could say that my bias as I approached the field work was that the health care system does, indeed, stigmatize and discriminate against people who use substances. How could I seriously undertake a research project whose outcome I thought I knew before I started? As I reflected more deeply on this point, though, I began to see my "biases" as my particular vantage point – as my particular lens – which in fact incorporates my beliefs that health is at its essence political; that intersectional oppressions (such as poverty, homelessness, Indigenous status and drug use) jeopardize the health of many people to whom I have provided and continue to provide nursing care; that ubiquitous neoliberal misinformation propagates the

idea that compulsive substance use is the result of individual failings and not societal breakdown; that compulsive substance use represents in fact a way to cope with the sequelae of all manner of trauma; that the use of psychoactive substances is situated properly within the normal spectrum of the experiences of curious and thoughtful humans since the dawn of human history; that the "addiction as disease" model is inaccurate and harmful; that harm reduction represents the only pragmatic and ethical response to compulsive substance use; that North American drug policy is imbued with racism and classism; and that the economic austerity agenda contributes to a frightening range of consequences not the least of which are worsening societal breakdown, more compulsive substance use, and health care workplaces that are less safe for patients and for nurses.

I have had to consider carefully how to acknowledge my worldview on the one hand while also ensuring the integrity of the process and findings on the other. In a later section I have elaborated the strategies I used to increase qualitative rigour as laid out by Lincoln and Guba (1985). I found helpful Thorne's (2008) suggestion that these measures keep us mindful of the need to keep our data collection and analysis processes on track towards our ultimate research goals and also provide a way to demonstrate evidence of sufficient reflexive processes to enable others to ascribe validity to our conclusions.

3.1 Sampling Strategy and Recruitment

I conducted the field work for this research in the Southern Ontario region which I will call Forest County, within which lies the City of Forest (also a pseudonym), which has a population of just under 80,000 people. Forest County is comprised of several townships covering an area of approximately 4,000 square kilometres and having a permanent population of approximately 50,000 people. The southern part of the county is home to agricultural land and

several small urban communities. The northern part contains smaller municipalities and is well known for seasonal outdoor recreation. Participants who used opioids were interviewed in a community-based agency whose mandate includes education and health promotion for people at risk for HIV. Among its diverse services the agency provides harm reduction supplies to people who use injection and inhalation drugs in order to reduce the transmission risks of HIV and other blood-borne infections. I was trained by agency staff in distribution and statistical recording of harm reduction supplies and helped "staff" the harm reduction depot on the days I attended to conduct interviews.

Participants who used opioids. I obtained permission from a local harm reduction agency to recruit and conduct interviews on-site in a location that operates a harm reduction supplies depot where people who use substances can obtain a wide variety of supplies for the purpose of reducing drug-related harm. I had originally considered recruiting and interviewing people in the agency's more rural satellite locations but infrequency of operating hours at those sites coupled with relatively small client numbers rendered this option impractical. The primary site is open five days per week and provides service to both small city and rural community people who use opioids.

I used purposive sampling utilizing agency staff to identify and recruit initial eligible participants and then used snowball sampling to recruit the others. I posted flyers seeking participants in the harm reduction agency allowing people to approach me on their own (see Appendix A); note that the community name has been changed to a pseudonym in this report). I also posted flyers in other locations known to provide services to people who use illicit opioids such as an addictions services agency. I selected dates and times to be available at the agency

and posted these with the flyer to facilitate potential participants dropping in rather than calling ahead to make appointment times.

Originally I had planned to interview 3-5 individuals including at least half women or trans-women to enable exploration of gender-specific issues. Interest in participating was robust and I quickly discovered that I could have interviewed many more people than planned. I interviewed fourteen people in total, excluding four from the data set after transcription for reasons including an opioid not being someone's primary drug of choice (all of the anecdotes pertaining to crack cocaine, for example) or taking prescribed opioids exclusively and not using opioids illicitly (despite appearing eligible from the screening tool). This left 10 participants whose transcripts were included in the data analysis.

Participants were eligible if they were 19 years of age or older; were currently using illicit opioids by any route at least once monthly; and had been using illicit opioids for at least six months in the past two years (Appendix B). Prospective participants were excluded from participation if they had been under my nursing care in the past two years. The decision to include adults aged 19 and over was made to allow for comparability with research done in other jurisdictions on adult populations and to reduce the likelihood of potentially confounding effects related to developmental issues in adolescents. The decision to exclude former and current patients was made to avoid compromising the nurse-patient therapeutic relationship by exploiting the power imbalances which exist in such relationships.

Although I had anticipated that current or former patients might seek to participate, and had planned in advance to exclude them, one occurrence I did not anticipate was to have a current patient come in to the harm reduction supplies depot and be surprised and I think

unnerved to see me there. I tried to reduce his discomfort by offering to remove myself so he could obtain what he needed from someone else, but his surprise and discomfort at seeing me there was palpable. Later I debriefed with the harm reduction agency manager and I suggested perhaps I ought not to position myself in that part of the office because I did not want my presence to deter anyone from getting needed supplies. She suggested some helpful ways to navigate similar interactions in future and did not see any need to remove me from the room. She also debriefed with the client later and I have since done so with him as well. It was however distressing to me and emphasized to me as a novice researcher the potential impacts of a health care provider doing research in a small community where you may indeed cross paths with people whom you know who may wish to keep parts of their lives private from their primary care providers.

Nurse participants. I recruited a cross-section of nurse participants within the same geographic area. I had planned to recruit 3-5 Registered Nurses (RNs) or Registered Nurses in the Extended Class (RNECs, commonly known as Nurse Practitioners) from acute care, primary care and public health settings in Forest County and Forest City. Response was robust and I decided to interview 6 nurses. I disseminated a recruitment flyer (Appendix C) through the local Registered Nurses' Association of Ontario (RNAO) Chapter; through a local Nurse Practitioner email network which routinely communicates local educational opportunities, employment postings and research participation opportunities; through the local Public Health Unit; through the local hospital; through local primary care networks; and through the School of Nursing at Forest University. Interested participants were invited to contact me by telephone or email to arrange a time and place to complete a face-to-face or telephone interview. Face-to-face interviews took place in a quiet, private location convenient to the participant. Participants with

whom I currently work or have worked in the past were to have been excluded to avoid potentially biased responses based on personal relationships although no prospective participants were nurses with whom I had worked.

3.2 Ethical Considerations

Ethics review was undertaken by the Review Ethics Board (REB) at York University – specifically the Human Participants Review Committee (HPRC). Because it was possible that the sampling strategy would result in the recruitment of homeless individuals, the research was conducted in a manner consistent with York University ethics guidelines for people who are homeless (York University, 2010).

Potential participants were recruited through purposive and snowball sampling at a local harm reduction agency (for people who use opioids) and through dissemination of a recruitment flyer to a diverse range of nursing employers and professional networks (for nurses). Ensuring dignity, confidentiality and freely-given, fully-informed consent was central to my methodology and this was addressed in the following ways. Those agreeing to participate were provided verbal and written information on the study purposes and possible outcomes. The consent form was reviewed until participants were comfortable with it and all their questions answered to their satisfaction. In keeping with HPRC guidelines, and because during the conduct of this research it was likely that participants who used opioids would disclose their involvement with illegal activities, there was a remote but possible risk that third parties might wish to gain access to the data. In order to extend the fullest protection possible for participants who used opioids, no identifying information was recorded and consent was obtained verbally.

Once I began field work with nurses, it became apparent that shift work and scheduling posed some challenges to arranging face-to-face interviews for some participants. I made a

decision to seek ethics revisions to the study protocol to enable telephone interviews when a face-to-face interview was going to be difficult to arrange. This led to revisions in the consent form for nurses wherein there was one version for face-to-face interviews and one version for a telephone interview. A copy of the verbal consent script (for participants who used opioids) and written consent forms and verbal consent script (for nurse participants) can be found in Appendices Four and Eight.

Participants were informed that all data would be securely stored in a locked filing cabinet in the principal investigator's office and will be anonymous. Only the principal investigator and members of the thesis supervisory committee would have access to the data. Demographic data and consent forms will be stored separately from the questionnaire transcripts and destroyed after five years by shredding. Electronic data will be deleted once hard copies have been created and data analysis is complete. Written data (printed transcripts) will be stored for five years and then destroyed by shredding. Audiotape recordings will be erased after five years.

Interviews were administered in a private room. Some nurse participants interviews were conducted by telephone. The principal investigator conducted all interviews. I avoided probing questions or questions that might have been overtly upsetting. I was sensitive to emotional distress exhibited by participants and offered a break or the option of moving on to another, less upsetting, question if needed. I had available a list of local mental health counseling and crisis services to provide to participants who used opioids in case it was needed and also had with me public transit tickets to facilitate transportation to crisis services if needed. I also had available information on how to file a formal complaint to the various health professional regulatory bodies should any participant have wished to do so. Participants who used opioids were

reimbursed for their time with $20 cash after completing the first interview and $10 cash after the follow up interview (which was typically shorter in duration). The decision to provide cash rather than food vouchers or other non-cash reimbursements was made from the understanding that people having low incomes such as participants likely to be recruited from a harm reduction agency (that is, lacking sufficient personal resources to purchase the supplies they require) often have little choice in their day-to-day lives. As an example, they may eat in soup kitchens and have little choice about what they eat or when they eat. Providing cash would allow participants the autonomy to choose what they would do with the honorarium they receive for participation. Nurse participants were reimbursed for their time with a $10 coffee card as a token of appreciation.

3.3 Data Gathering

Prior to entering the field to begin data collection, I created a field notebook in which I recorded my background preconceptions and initial ideas about the study. I made notes to remind myself to be conscious of trying to shift from my persona of health care "expert" to the role of "curious learner" (Thorne, p. 130) and to avoid value-laden encouragement to responses which might inadvertently convey to participants that some information is "desired" and other types of information are not – although I did find this easier said than done once I had started interviewing people. It was helpful to keep track of those value-laden responses and other potential pitfalls using the field notes.

Using Benner's (1994) approach, interviews, observation and interpretation began simultaneously with recruitment. I recorded my reflections, observations, ideas and questions as well as things that surprised me and interpretations as they evolved (Thorne, 2008). Some of the questions I noted in the field notes journal prior to commencing interviews included: What if no

one agrees to be interviewed? Where else can I recruit? What if my presence in the harm reduction supply depot impedes people's use of the service? How will I use information gained from people who use opioids to inform the nurse interviews? I also noted points of interest which were not directly related to my research – such as the fact that some clients came in and took large volumes of supplies (such as clean needles and syringes) which I speculated may have been in order to conduct some informal "secondary distribution" to other people unable or unwilling to come in themselves.

I also noted in this journal my reflections after each interview if time allowed and after each day of interviewing. I noted, for example, my concerns about unconscious bias after the first interview that perhaps I had made encouraging nods and gestures during the telling of negative health care experiences, thereby encouraging more of these types of stories and fewer positive ones. I noted as well that I do have an underlying expectation that people will have negative experiences to share and was conscious of similarly trying to encourage the positive stories as well. I tried to be mindful of being, as Thorne (2008) suggests, "an encouraging and judgmentally neutral facilitator so that an individual can explain him or herself as fully as possible" (p. 129). I also noted that some participants had trouble understanding what I meant by "experiences of health care" until I elaborated with "good or bad," for example. I also came to the conclusion that asking the question about stigma related to ways to make money seemed rather self-evident when I asked it out loud. Notably, most people responded to this question referring to the experiences of other people and not themselves – perhaps a way of protecting themselves from disclosing their own participation in illegal activities? One of the surprises I noted early on was that some participants named opioids as the thing that improves their health – which helped me uncover my unconscious bias that compulsive substance use and the drug-

related harms accompanying it would be health impairing – which they may have been, but the perceived benefits of opioids outweighed the costs for some people.

Participants who used opioids. I arranged interview times at the harm reduction agency on consistent days of the week and advertised these in advance. I had planned to be present during the busiest times but soon discovered there appeared to be no consistently busy or quiet times. For the days I advertised that I would be on site, I left interview times with the agency staff so that people could return at a specific time rather than having several people show up at the same time and have to wait. Although I was uncertain if people would be able to adhere to specific times given the possible chaos of their lives, I did not find this to be the case. If someone did not arrive at their scheduled time, I did recruit eligible participants who had heard about the study and who dropped in to see if they might be able to participate. Second interviews were arranged for specific dates and times after allowing a sufficient time period for all of the first interviews to be completed and transcribed.

After determining eligibility (Appendix B) and obtaining informed consent (Appendix D), demographic data were collected using a short demographic form (Appendix E). This was followed by a semi-structured conversational interview loosely guided by a topic guide (Appendix F) which was used flexibly and departed from when "new or interesting ideas" were raised (Neale, Tompkins & Sheard, 2008). I borrowed a question from Merrill and Grassley's (2008) study of overweight women's experiences of health care. These researchers invited participants to tell them a story, "one you will never forget" about their experiences of health care as overweight women (p. 140). I found this a powerful prompt which I hoped would elicit meaningful stories and asked it of both groups of participants.

Participants were interviewed in a private room at the interview site, using communication intended to build rapport and "foster elaboration, clarification, and even correction of [my] initial understandings and interpretations" (Thorne, 2008, p. 129). Interviews were audiotaped with verbal permission. Participants were asked to choose their own pseudonym reflecting their gender to facilitate readers seeing them as individuals in any subsequent articles or reports (Drumm et al., 2003) although I found that many of them found this question difficult and could not think of a false name. Reflexive field notes were written immediately after each interview to record expressions and gestures which may not have been captured in the audio-recordings as well as my own impressions/reflections on the interview processes and content although on days when there were people waiting one right after another these notes became more point form than narrative.

Each participant was asked to return for a follow up interview on one of two specific dates. Of the ten participants included in the data set, seven returned for a second interview. After transcribing the first interviews, I conducted a preliminary thematic analysis of each transcript and then of all transcripts to determine common themes. In the second interviews, I attempted to review these preliminary interpretations with participants to assess interpretive validity. I anticipated that attendance by participants who use illicit opioids at the follow up interviews might be less than 100% due to attrition stemming from the inherent chaos in the lives of participants. I borrowed a strategy from Smye, Browne, Varcoe and Josewski's (2011) study which reviewed interpretations using a sub-set of participants. I drafted another interview guide for the second set of interviews which can be found in Appendix G. It incorporates the themes and issues to which I wished to return after transcribing all of the initial transcripts as well as points requiring elaboration or clarification pertaining to the details of an individual's specific

transcript. For example, in the first set of interviews participants sometimes alluded to leaving a care setting against medical advice, or leaving a health care encounter because of how they were made to feel, and I wanted to ask for clarity regarding the specific reasons. I wanted to check for accuracy and also for interpretive validity – is this what you meant by this? Because some participants in the first interviews expressed ideas to improve care, I also included a question about this as well as a question asking participants how they see themselves, as both of these topics came up in some of the first interviews and my curiosity was piqued.

Similar to the approach described by Harvey, Schmied, Nicholls and Dahlen (2015), I brought a respectful, humble demeanour to my interactions with participants who used opioids, mirroring my professional practice with similar people. In the recruitment flyer I had asked for people interested in telling their stories to someone who really wants to listen and my intention in the interviews was to convey this truth. Interviewing people in a location familiar to them was also intentional as a way to mitigate the unequal power dynamic.

Nurse participants. I arranged interview times with each nurse participant at a mutually convenient time. In hindsight, I realize I did not explicitly determine the eligibility of nurse participants aside from advertising for nurses who have worked with people who use illicit opioids in any setting – which allowed nurses to self-identify as such. Participants were interviewed in a private room at the interview site or over the telephone at a mutually agreed upon time. Interviews were audiotaped with written or verbal permission. Nurses interviewed by telephone had the consent forms emailed to them for review and to have a copy for their records. After obtaining informed consent (Appendix H), demographic data were collected using a short demographic form (Appendix I). This was followed by a semi-structured conversational

interview loosely guided by a topic guide (Appendix J). After the first two nurse interviews I changed the order of questions, asking question 2 (Can you think of a story – one you will never forget – about caring for someone who uses illicit opioids?) after question 5 because it seemed that nurses were prompted to recall more stories the longer they had to reflect and remember stories and anecdotes. As planned, I added some content to Question 5 after I interviewed participants who used opioids to reflect what I had heard as recurrent themes (see Appendix J). Similar to participants who used opioids, nurse participants were asked to choose their own pseudonym reflecting their gender. Reflexive field notes were written immediately after each interview to record expressions and gestures which may not have been captured in the audio-recordings as well as my own impressions/reflections on the interview processes and content. For example, I noted with some surprise that some nurses referred to sex work with language that might be considered pejorative, such as the phrase "selling herself" or "prostituting themselves" and that even nurses who appeared sympathetic to the issues experienced by people who use opioids used the language of "these people."

Similar to my intention to set a tone of respect and humility when interviewing people who use opioids, I also tried to set the same tone with nurse participants. Several were diploma-prepared and when stating this often framed it as "just" a diploma or let me know that they were working on their nursing degree. I tried to mitigate this dynamic, particularly as a nurse privileged to be in a Master's program, by emphasizing their extensive experience and expertise and the way in which I believed this would provide rich information to me.

3.4 Data Management and Analysis

The epistemology of critical hermeneutics recognizes that interpretation of meaning (knowledge) is influenced by subjective albeit dominant beliefs and ideologies which "mask, gloss over, ignore, or trivialize the realities" of marginalized people such as those using illicit substances (Lopez & Willis, p. 731). Given that participants who use drugs are likely to potentially be further marginalized by other factors such as poverty, homelessness and/or engagement in sex work, critical hermeneutic inquiry was used in an effort to surface the traditionally discounted knowledge of people who lack social privilege because of intersecting marginalizing factors. I attempted throughout to be cognizant of the ways in which my own dominant beliefs might conceal emergent themes by consciously attuning to what Thorne, Reimer Kirkham and O'Flynn-Magee (2004) describe as "preliminary theoretical scaffolding" and the need to distance myself from that as alternative themes and patterns emerge(d) (p. 5).

For example, I noticed that some participants who used opioids seemed reluctant to criticize health care providers, or would criticize health care providers but add a caveat such as "but not nurses – the nurses are okay" and it occurred to me that this may have been because I identified as a nurse. I am aware from my clinical experience that people who use substances are accustomed to not being believed, and so my encouragement as they began to tell stories of negative health care experiences became a challenging line to navigate between not only providing positive feedback for negative stories (the seemingly "correct" answers), but also to engender trust and the perception that I believed their stories so that they would continue to tell them. I also wondered if my underlying prediction that health care experiences might be negative might conceal the theme of participants who used opioids being effective self-advocates, or being open to believing the best of an individual nurse until proven otherwise. I found the

practice of recording these thoughts and reflexive questions essential to the process of "percolating" ideas which would potentially inform later theme and pattern recognition between interviews.

I transcribed each interview audiotape verbatim, beginning with first interviews of participants who used opioids. I then conducted second interviews of participants who used opioids and transcribed those prior to conducting and transcribing nurse interviews. I found it helpful to listen to the interviews and be reminded of the things people told me as well as how they told their stories – with emotion, or with matter of fact detachment, for example. After transcribing each interview, I noted comments and questions and impressions using the "comments" tool within each electronic document.

I borrowed preliminary analytic structure from Benner's (1994) analytic method which involves searching for paradigm cases, thematic analysis and exemplars. At the same time, I tried to be mindful of Thorne's (2008) advice to avoid rigid categorization of ideas too early in the process. I purposely avoided coding until many weeks into the process and even then, tended to code less narrowly than I had originally anticipated I would. I took note of similar themes and broad categories and tried to move back and forth from individual stories to larger patterns and themes to build my understanding of the data beyond "self-evident and superficial" groupings (Thorne, p. 149). I tried to intentionally attune myself to the more common pitfalls of a novice researcher such as premature analysis closure; misinterpreting the meaning of frequency of themes which may not be valid; and avoiding over-investing in metaphors in order not to be tempted to make the data "fit" the metaphors (Thorne, 2008). Due to work commitments I left the data for a few weeks and when I resumed analysis I found that having some time away to

contemplate themes had been extremely useful. Coming back to the data I found it much easier to "see" over-arching themes and sub-themes and I think this was more possible because of keeping the data as whole as possible for as long as possible and considering it in that manner rather than reduced to smaller pieces.

Once I had generated over-arching themes and sub-themes I drew upon Fontana's (2004) foundational processes of critique, context (historical, political, socioeconomic), politics (exposing unequal power relationships), emancipatory intent (looking for possibilities for change), democratic structure, dialectic analysis, and reflexivity to inform my thinking as I moved from analysis to thinking about potential explanations, conclusions and recommendations.

3.5 Rigour and Credibility

Lincoln and Guba (1985) articulated four components of trustworthiness in qualitative inquiry: credibility; transferability; dependability; and confirmability. Thorne (2008) suggests the evolution of a qualitative methodological credibility "gold standard" by which to evaluate qualitative research, which includes epistemological integrity; representative credibility; analytic logic; and interpretive authority (pp.221 – 225) and she goes on to argue for a broader, disciplinary and historical contextual critique of qualitative products. However, as a novice researcher, I have elected to use the more familiar trustworthiness measures stated above.

Credibility was established by reviewing all transcripts for similarities and constructing preliminary themes and patterns which were then noted in the field notes journal which, after leaving the field, evolved from a repository of questions and random thoughts and possible insights into a chronological audit trail where I recorded findings that surprised me, lists of

themes, areas of congruence and dissonance between the two groups of participants; and as time went on possible linkages and relationships between data. I also structured the project so as to build in the advantage of multiple perspectives through triangulation of data sources using the literature search; interviews with people who use opioids; and interviews with nurses to test relationships between possibly linked pieces of data.

Transferability was facilitated by collecting demographic data from both groups of participants to create a "dense description" of the study population as well as the geographic boundaries of the study (Thomas & Magilvy, 2011). This will allow determination of whether the study's conclusions may be transferrable to other similar populations in other jurisdictions and will also allow for comparability with existing research on similar populations.

Dependability was established through the creation of a detailed description of study decision making including the overall purpose; research questions; participant selection and recruitment; data collection; interview guides; as well as reflexive notes documenting my questions, concerns about pitfalls and my strategies to avoid them as much as possible; and a detailed chronological audit trail documenting analytical decision-making. Additionally, in order to be as transparent as possible, I have included in this report a detailed description of my personal philosophical lens through which I have interpreted the findings.

Confirmability was established through member checking via a follow up interview (for seven of ten participants who used opioids) during which I checked their individual first transcripts for accuracy as well as checking whether my preliminary analysis reflected what they had intended to convey. However I did keep in mind the reality that respondents have their own biases and agendas, including the desire to possibly see themselves in a certain way or to provide

a socially acceptable response (Armour, Rivaux & Bell, 2009). Confirmability was also supported through reflexivity including writing of field notes after each interview articulating my personal reactions, biases and insights and again following transcription of each interview in the comments pane. Carnegie and Kiger (2009) argue that researchers must analyze their political and ideological beliefs while conducting critical analyses which I have done and documented throughout the process in the field notes journal; in the audit trail; and in this document. I also debriefed regarding my concerns about my own biases with my supervisory committee.

Chapter Four: Findings – Participants Who Used Opioids

4.1 Demographic Information and Participant Description

Findings were derived from the transcripts of ten interviews with people who use illicit opioids. Five participants identified as female and five as male (see Chapter Three for a description of excluded transcripts). Ages ranged from 25 to 60 with the average age being 39.5 years. A summary of demographic data is presented in Table 1. Six participants identified as White/Caucasian and four identified as Indigenous (First Nations or Metis). Seven lived in an apartment and three (all of them women) lived in an emergency shelter. Five were receiving provincial disability benefits; four were receiving municipal social assistance benefits; and one was receiving federal disability pension benefits. One person reported a monthly income of less than $500; five people reported a monthly income between $501 and $1000; and four people reported a monthly income between $1001 and $1500. All of these incomes are below the Statistics Canada (2015) determination of Low Income Cut-off (LICO) for one person living in a community of less than 90,000 people.

Five people had been using opioids for more than ten years; three people for five to less than ten years; one person for one to less than two years; and one person for 6 months to less than 1 year. Six people reported daily opioid use in the previous 30 day period; three reported using opioids several times weekly in the previous 30 day period; one person reported using opioids several times in the past month; and one person report not having used opioids in the past 30 days. Nine people reported having ingested opioids orally as well as injecting opioids and five people reported having inhaled (snorted) crushed opioids. Eight people reported injection as their preferred method. One person preferred inhalation (snorting) and one person preferred oral

ingestion. Nine participants reported hydromorphone (long acting) as their opioid of choice if they could get it. Two people reported preferring oxycodone (long acting); one reported oxycocet; one reported hydromorphone (short acting) and one reported heroin although it was difficult to obtain in their community of residence. Some participants named more than one drug of choice in response to this question. Other substances used either currently or in the past thirty days were nicotine (reported by nine participants); powder cocaine (six people); benzodiazepines (five people); crack cocaine (four people); alcohol (three people); cannabis (two people); and one person each reported using methamphetamine; ketamine; MDMA (ecstasy); psilocybin (mushrooms) and Wellbutrin (bupropion). All participants are identified by a pseudonym of their choosing or mine.

Table 1. Participants who used opioids demographic data

Name	Age	Gender
John	58	M
Coreen	31	F
Steve	60	M
Joanne	55	F
Paul	52	M
Frank	53	M
Chase	26	M

Destiny	26	F
Casey	32	F
Cheryl	25	F

4.2 Reflections of Participants Who Used Opioids

Participants were asked to reflect on how they looked after their health, challenges to staying healthy, their experiences of health care, and what they might want to communicate to health professionals. In order to explore the issue of substance-use related stigma as fully as possible, participants were also asked to share their thoughts on non-traditional means of earning income. Additionally, participants were asked to share their ideas for improving care for people who use opioids and their reflections on how they see themselves. The headings below correspond to the content of each of the interview guide questions (see Appendix F).

I should take this opportunity to make note of the fact that although I interviewed nurses because this is a nursing study, many participants (both those who used opioids and nurses) provided information that was not always specific to nurses. Participants who used opioids, for example, sometimes gave examples of health care experiences involving non-nurses or interdisciplinary teams which sometimes included nurses; and nurses sometimes gave examples of experiences they had participated in or witnessed involving other health care providers. At times throughout this document I have used both the terms nurses (which for simplicity includes Registered Nurses and Nurse Practitioners) and health care providers when the data was not specific to or exclusively pertaining to nurses.

Looking after your health while using illicit opioids. One participant noted that looking after your health was relatively easy early on in one's opioid-using career before the health effects of regular use were apparent: "I kind of analogize it as possibly a grace period, of, there's nothing wrong, you're physically well, nothing happens, your veins can take a lot of abuse, and they come back, and you don't have to make a doctor's appointment…" [John, age 58]. However, most participants identified a number of challenges to looking after their health, including needing opioids every day; having to spend an inordinate amount of time trying to obtain drugs instead of looking after one's health; developing health issues related to drug use such as Hepatitis C infection; seeking care for acute and chronic health problems and experiencing discrimination and blame by health care providers; experiencing the presumption by health care providers that one is drug-seeking and not having one's health issue(s) addressed; not having pain associated with health issues adequately treated; and not attempting to obtain needed health care because of prior negative experiences.

Coreen identified that needing opioids on a daily basis was difficult because going without opioids caused her increased pain and withdrawal symptoms, which she described as interfering with even the most basic functions of daily living. Several participants noted that obtaining illicit opioids requires a lot of time and effort, leaving little time for other aspects of life including health care. Frank described letting health problems go without attending to them because of a singular focus on obtaining opioids:

> When you let things go for a long time, you go through a lot of sickness, because you're always looking for your next buck to get your next fix. You're always on the grind, you're always trying to do a con with somebody to get a better deal, or trying to find out

> who's got it, your whole time is spent finding out who's got opioids for sale, and who's got the better price, how many times you can hook up through the month, who you can avoid paying, it's a non-stop game like that. And then you find out – with me, 'cause I use the needle – eventually after a long time you're always getting abscesses and stuff like that [Frank, age 53].

Several respondents disclosed acute and chronic conditions related to their drug use including HIV and Hepatitis C infection. Casey reported having had a serious abscess in her arm that resulted from injecting which required intravenous antibiotics for several weeks as well as daily wound care. Destiny was awaiting test results for Hepatitis C infection when she was interviewed and she told me "I'm 90% sure I have Hep C." Joanne's Hepatitis C had led to Stage IV cirrhosis and a history of bleeding esophageal varices. John's HIV infection required him to take a complex regimen of anti-retroviral medications and to undergo frequent blood tests on a regular basis.

Prior to being asked explicitly about their experiences of health care, many participants spoke of being treated differently by health care providers once their opioid use was disclosed. This different treatment included being rude, uncaring and rough. Casey had an arm wound related to injecting and when she was asked whether it was self-induced, she noticed a distinct change in attitude: "…it would all depend on who the nurse and doctor was, they could be really just rough and snarky and not always very pleasant." Joanne described being treated differently than people not known to use opioids: "I don't go to the hospital like I should be when I'm, it's always too late by the time I get there, probably something could have been done, except for I

hate going there and the way you get treated. Like you're not part of the normal people – it's like you're just part of this – why worry about them? They're just drug users anyway."

Several respondents remarked that if you are known to be someone who uses illicit opioids, some health care providers assume that the only reason for seeking care is to obtain opioids. Paul described a time when he injected into a vein in his neck and "missed" the vein, causing the contents of the syringe to be injected instead into the interstitial tissue which caused airway-compromising soft tissue swelling in his neck. He told this story about the experience:

> I shot up here in my neck and I missed and it swelled up and I was an hour from dying. And they said 'you're just here to get painkillers' – really snobby and ignorant pigs…My throat was twice as big around…I was flat out for four days. Then I came to and I couldn't stand the pain and I was almost crying for something for pain – 'oh yeah, you just want (opioids)' they said. So I took the shit out of me (mimed removing IV catheter from his arms) and I left.

Paul was certain he was not being given pain medication because he overheard staff speaking about him: "Oh he's a junkie and he's flagged…(which) means don't give this person narcotics." The flag system refers to an alert on hospital computers identifying some people as known opioid users. In Paul's story, he was assumed to be drug-seeking and despite repeated requests for pain medication, he did not receive any and thus he left against medical advice in order to obtain illicit opioids for his pain.

Several respondents expressed reluctance to seek care when necessary because of having had negative experiences when doing so in the past. This included not getting care for health issues unrelated to substance use. For example, Joanne has diabetes mellitus and because her

physician assumed on three occasions, even after she corrected him, that she had been a heroin user, she has avoided returning to his care:

> Like even for my diabetes, I went to my diabetes doctor, and the first time I went to see him he said "so how long did you do heroin for?" and I said I've never done heroin. The second month he asked me the same thing – "how long did you do heroin for?" and I said I've never done heroin. The third month I went back he asked me the same thing – and I've never went back. I probably should be on two different kinds of pills for my diabetes, and I never went back again.

Challenges to staying healthy when using illicit opioids. Many participants expressed the opinion that it was very difficult to look after one's health when using opioids regularly. Paul stated: "There ain't no way to stay healthy – you don't care about it. You don't give a shit, once you're on that run [a prolonged period of using substances], (you don't care if you) live or die."

One of the findings which surprised me was that some participants equated staying healthy with having enough opioids. Several participants stated that not having enough opioids made them unhealthy. Steve said: "(Having opioids) helps you stay healthy. It takes care of your problems. But when you don't have that, everything's falling apart on you." Casey said that not having opioids made it hard to function: "Just trying to stay normal without it. Which is impossible right now. Because it's that constant need. Your body can't be without it. It just makes your life all about that."

Some participants noted that regular opioid use consumes all of one's resources, leaving little money or time to spend on other things. Destiny remarked that it can be difficult to take care of yourself because you spend all your income on opioids. Chase stated that spending all of

your income on opioids leaves little for food: “You don’t have the money to eat substantial meals and when you’re on social services they don’t give you nearly, nearly what they should for you to have a balanced diet and the foodbanks you’re basically getting candy and bread and maybe a can of soup if you’re lucky. You can’t sustain yourself on it.” Cheryl stated: “The hardest part would be, well, it takes all your money, right? So food, hydro, all of those kind of things become the back burner.”

Joanne stated that the hardest part of trying to stay healthy was trying to feel positive about your health after repeated negative experiences: “The hardest part is trying to have anything positive…about your health, because of the way you do get treated. Like you don’t want to get treated for anything, even something easily treated.” John felt that the hardest part was “just the monotony of life, like everybody else.”

How participants who used opioids saw themselves. After transcribing the first set of interviews, I realized that some participants had voluntarily offered their views on how they felt about themselves, often juxtaposed with the negative ways some health care providers saw them. This prompted me to explicitly ask people how they see themselves in the second set of interviews. Some participants indicated that they had come to see themselves less positively because of being repeatedly given negative messages. Others saw themselves as basically good people with a particular set of issues affecting them.

Several participants stated that they had come to see themselves as not being as good as other people because of receiving that message repeatedly from society. John sees himself as “a couple of notches below (people who do not use opioids).” Steve stated “you get to become what people mold you. You could call somebody stupid all their life, they’re gonna feel stupid.”

Many participants had positive views of their own qualities. Coreen said, "I see myself as well, as healthy…I'm not so much outgoing anymore because of my back, but I try to be as outgoing as possible. I'm fun, and funny, and I'm gentle…" Paul said that he sees himself as a "normal human being, just that I'm an addict." He does not see himself as lesser than other people: "No! I worked all my life. I didn't mean to be like this." Cheryl said, "On a good day I see a lot of potential. I have goals and recently I'm kind of realizing a lot of people just stop (trying), but I still want more." Casey said:

> On a good day, I see that I'm a good person – I know I am. I believe in karma. I'll never do anyone wrong – drug addict or not – I'm not someone who's going to screw you over. I have my faults, which I deal with on a daily basis, and sometimes you just kinda have to wake up, not think about it, not be so hard on yourself, and just try and carry on the best you can. On a good day I'm happy with myself. I know there's changes I have to make and I'm in the process of making them.

Experiences of health care. Some participants indicated that they had some experiences of health care which were positive. While some described very helpful relationships with health care providers who were aware of their opioid use and who were genuinely caring and supportive of them, all participants had experienced negative interactions with health care providers.

It's like a switch gets flipped. Several participants remarked on their experiences of interacting with health care workers who start off being friendly but whose attitudes change abruptly once they learn of a person's illicit opioid use, and in particular of their injection use.

Joanne said: “It’s just the attitude, like you’re not a person, they don’t talk to you, the conversation stops flowing, it’s a look that comes over them, you know? You’re taking up my time, right?” Casey said: “The attitude is just – even the way they look at you, it’s just kind of in disgust.” Cheryl remarked “Well, their answers are a lot shorter…they aren’t really rushing to help you.” Frank attributed this attitude switch to the discovery that he is an intravenous opioid user: “…as soon as they find out you’re an intravenous user they just – it’s like day and night with the attitude…they just go from night to day on you…they think you’re just a waste of time…(and) then you’re the scum of the earth.”

Multiple intersecting experiences of stigma. All participants had experienced stigma from some health care professionals which they believed was related to their opioid use. Steve described it as “all kinds of negative vibes.” Chase said: “Once they find out that you’re an addict, there’s automatically a negative stigma that’s thrown at you, they treat you like you’re the scum of the earth, and it really puts you off, and makes you not want to go to the hospital or a doctor’s office.” In addition, several participants who use injection opioids felt that injecting conferred additional stigma. Cheryl observed that treatment by health care providers was better when she was using drugs through non-injection routes. “Well once, say I smoked crack or sniffed, those were my first stages of drugs, obviously, I didn’t just jump to the needle, but I found when I was that way, they (health care providers) were still more understanding and helpful. It wasn’t until I started doing needles, that they were kind of like – don’t want anything to do with me, or whatever, right?” Chase echoed this: “…once they see your arms or wherever you shoot up, they give you that look that makes you not really want to be there.” He felt that health care providers were thinking “Basically that you’re a screw up and you’re less than them, you’re less of a person.”

Several participants had been on or were currently on methadone maintenance therapy, which is a treatment for opioid addiction. Coreen said: "I was on methadone for a while…and I was completely stigmatized because of that." Joanne, who is currently on methadone, said: "I don't go out because of the simple fact that what happens if the person finds out I'm on methadone?...So I have to live a secret life just because I'm on methadone." Destiny gave birth to a son while she was on methadone: "There was one nurse who talked to me disrespectfully, like (I was) lower than her because (I was) on methadone."

Cheryl described the experience of stigma related to being tested for Hepatitis C infection. She expressed surprise that nurses who she presumed would know how Hepatitis C is transmitted would treat her this way:

> As a health care provider you would know that it has to be blood to blood in order to get hep c, so like touching my arm doesn't make you have (infection) on your hand, you know?…I thought to be open and honest and assuming that…nurses won't judge and…when I got her reaction I just felt gross and embarrassed and wanted to leave and be around people who use so that there's no judgement.

Judgment, discrimination, and mistrust. Several participants felt that being judged for illicit opioid use occurred often and the consequences ranged from being blamed for one's own health issues to missed diagnoses. Steve and his partner have chronic health issues that necessitate regular hospital visits. He described consistently feeling judged by health care providers as responsible for their own health issues: "…going in there is just maddening. They know our history, they know (about) the drugs, and they just …(have) a real bad attitude toward opioid users, and well 'you got yourself in that position, and don't be crying to us, right?" Joanne

related a story about her friend who has a known opioid user who presented to an emergency room on three separate occasions with neck pain. She was presumed to be opioid-seeking and in fact had a cervical fracture requiring surgery at a tertiary hospital.

John told the story of a physician who slapped him in the back of his head. He felt that the doctor was trying to emphasize his point that John should stop using opioids and "smarten up." He knew that doing the same thing to the physician would not have been acceptable and agreed when asked if there is a power imbalance between doctors and patients which allowed this to be considered somehow acceptable. Some participants felt compelled to tolerate poor treatment in order to get needed care. They agreed that it is very difficult to advocate for yourself when you have been treated poorly by health care workers because they have more power than patients in that situation.

Several participants who use injection opioids described the experience of having nurses unable to successfully perform a venipuncture because of damaged veins. This often led to nurses becoming frustrated and blaming the patients for causing this damage: John described hearing two nurses speaking about his veins: "One nurse says to the other 'He's got veins like ropes' and 'he's one of those' and then continue when they're trying to [perform the venipuncture] say 'Oh, I can't get you – you've done too much damage.'" Joanne described nurses becoming "fed up" and Frank said "the nurse got pissed off 'cause she couldn't find a vein on me." Several participants also recounted being told by health care providers that in an emergency situation they might not be able to get intravenous access for life-saving treatment.

Paul described being given the suggestion that not receiving pain medications was acceptable because he had brought his health issues on himself: "They just say you brought it on

yourself, that's what they say to you." Cheryl had her reason for visit (Hepatitis C testing) announced in the waiting room. She expected more professionalism from nurses: "Don't engage in public humiliation, like when people are in the waiting room." [Cheryl] She also observed that not all people who use drugs are discriminated against in the same way: "There's people who hold high end jobs that are users and it's not fair…like how many lawyers have you heard of that sniff blow? A lot, right? but they're not frowned upon like a teenager junkie."

Several participants described not being believed by health care providers, such as not being believed when they said they had pain, for example. John described an experience of not being believed or trusted by health care providers. He recounted being advised in a hospital that he had a serious health issue and he told staff, because he knew he was going to be admitted, that he wanted to go home and collect some things for his hospital stay. Hospital staff did not trust him to return for care although he planned to do so and sent police to his home to escort him back:

> I wanted to go home and pack my bag because I knew they were going to keep me there for a while because of my other experiences, so I didn't go right away, and they actually sent the police department to my apartment to get me…if you're stuck in the hospital with no toothbrush or anything, it's always a pain, and I've learned this from experience, so I just wanted to get a change of clothes, and some sleeping pants and a t-shirt, instead of the gowns open at the back and stuff, that's all I wanted to do, and within an hour two policemen were at my door, saying we have to escort you to the hospital. I'm thinking this isn't your job, it's their job, and I have a choice in the matter…

John also wondered if some health care providers might prefer not to know about someone's substance use. He described a hospitalization during which he believed the physician looking after him knew he was a person who uses opioids but never asked directly about it. He stated that he thought this may have been because the physician did not want to take on the extra work that might be required: "I think now that the doctor probably…wanted to do the least amount possible that he had to do."

Several participants remarked that it can be challenging to avoid drug-related stigma and discrimination in a small community because you become known to the health care providers as someone who uses or who has in the past used illicit drugs and there are a finite number of health service options. Some noted that you may be judged as using substances no matter the reason you are there and the emergency room flagging system may label you forever even if you are no longer using. Participants noted that there is little anonymity: "And [this town] is so small, everybody knows everybody in the town, and that's where the bad service comes from…they don't know why you're on drugs – they don't know anything about my life at all, other than the fact they might have gone to high school with me, or they know my sister, 'cause my family's well known in town" [Steve].

Some health care providers lack knowledge. Most participants saw most nurses and other health care providers as lacking accurate knowledge about substance use including the fact that there are underlying causes and that substance use is not a choice. Several participants also noted that health care providers underestimated the pain of opioid withdrawal.

Several participants noted that many health care providers did not seem to have any understanding of the often-untreated mental health issues and traumatic experiences that were the

root causes of their substance use. Joanne, for example, had witnessed the particularly horrific death of her father; had also witnessed her mother's death; and had been sexually molested from age 9 to 13. She attributed her longstanding substance use to her attempts to cope with the aftermaths of these cumulative traumas.

Many participants related experiences of being told by health care providers that withdrawal was "not that bad" or likened withdrawal to a "bad flu." Participants were clear that this represented significant ignorance on the part of health care providers. Steve said: "There's nothing like withdrawal…It's nothing like a bad flu…if you're a serious opioid user…you can't drive properly, you can't function properly, you're in pain, you feel like you're going to die." Casey said: "Your whole body shakes, you sweat, you're hot, you're cold, you want to sleep, you can't sleep, you have headaches, it is the most excruciating pain that you'll ever go through and people are going through it every day, because they can't get what their body is needing now…they need to go through it themselves, because it is horrible. It is ridiculous."

Specialized programming can facilitate excellent care. Destiny had recently given birth to a baby boy while she was on methadone treatment. Although there were aspects of her experience that were difficult, she described very good treatment in the health care system at that time which she attributed to being in a special program for mothers who are on methadone. The team who cared for her and her son specialized in this care and Destiny reported not feeling judged or stigmatized except on one occasion where a nurse spoke to her disrespectfully. She had been encouraged to speak up if anyone treated her in this way and she did: "…I told them about it and they put an immediate stop because they said if anything happens, if you feel degraded or treated not fairly, tell us and we'll fix it and right away they did."

Unforgettable experiences of health care. Most participants had at least one story of an experience of health care that had a significant impact on them. Some had several stories. Typically these were stories in which the way participants were treated in the health care system led to significant consequences for their physical and/or mental health. Consequences of stigma, judgment and discrimination included feeling guilty and ashamed; being reluctant to seek care when needed; not obtaining needed care; and being misdiagnosed. Consequences of inadequate pain management included not getting needed care because of leaving against medical advice and turning to a less healthy alternative to manage pain.

Many participants shared stories of stigma from nurses and other health care providers which seriously affected their self-images. Participants characterized these experiences as recurrent rather than exceptional and the negative effects as cumulative. Steve remarked: "You get to become what people mold you. You could call somebody stupid all their life, they're gonna feel stupid…and after you leave there, whatever you went there for doesn't matter, you're so shell-shocked and feeling just as shitty mentally as the (physical) reason you went there for." Joanne said: "I think they've got their nose up in the air a lot of the times…it makes me feel very bad, very horrible." Casey agreed: "Sure, you do walk out of those situations feeling guilty, ashamed, whatever, but people don't understand. And then you know what? When you beat yourself up about it that's when you go use again! And you think you know what? I'm going to live up to what people think about me."

Participants' experiences of repeatedly being stigmatized and judged for their opioid use sometimes results in them avoiding health care when they need it. This has the effect in some situations of allowing a health issue to become worse because care was delayed. Casey put it this

way: “If I have something wrong I don’t go to the hospital now…because first thing they’re likely going to look in my file and see what happened before and come back and then I kind of get treated the same way.”

The experience of health care that Chase will never forget was when he had a serious infection in his hands from injecting opioids. His mother took him to the hospital. Once he was there, he was told that this infection could have serious consequences if not treated including death. IV antibiotics were started and he went to use the washroom. Because of opioid-induced constipation, he was in the washroom for a long time. This caused the nursing staff to believe he was using illicit opioids in the washroom:

> I had a blood infection and my hands swelled to the size of balloons. My mother took me to the hospital…and I went to the bathroom to use the washroom, and when you’re really heavy into opioids, it’s really hard for you to have a bowel movement, so I was in there for a bit, and the nurses came and grabbed me and they had just hooked me up to an IV for antibiotics…so they came up to me and said basically you’re being discharged from the hospital because you were using in the bathroom. They assumed that I was shooting up in their bathroom, so they told me basically I had to leave. I in turn kind of retaliated to that by putting up a front, like “what the hell?” like kind of being verbal with them, like kind of aggressive? Which I probably shouldn’t have done, but I felt very scared because they had just told me I could have died, and now they were telling me I have to take this antibiotic out of my body, and…I was scared, right? And I ended up pulling it out myself…so I pull it out and blood’s gushing everywhere and they were like ‘oh my god’ and so anyway I ended up leaving and they give me a prescription for oral

antibiotics but from my understanding I should have been on the IV antibiotics for at least a day.

Cheryl described a situation in which the attitude of being looked down on by a nurse caused her to walk out: "…I felt stupid and I didn't like the feeling and when I met with her and told her I do needles and stuff just the total attitude change and then going back in the waiting room, the anxiety was building up and I didn't like it so I got up and (left)."

Several participants shared stories about being judged or stereotyped as opioid users which led to incorrect assessments. Destiny was on methadone when she developed severe nausea and vomiting. She told staff she was on methadone and that she thought she might have stomach flu or food poisoning because she was vomiting so often. She was prescribed Suboxone as there was no methadone prescriber available at the time and she was discharged. In fact, she was experiencing nausea and vomiting of pregnancy: "(They) didn't do a pregnancy test, didn't do nothing. Just assumed that I was a junkie and I'd missed my drink [methadone]. And I explained to them I had been going through this and something was wrong."

Destiny also shared a positive story of giving birth to her son while she participated in a specialized program of care for pregnant women on methadone:

> (When I had my son) it was great. I was on methadone when I had him. The only reason they were good is because I was in a special program for mothers who are on methadone – a special withdrawal program, so I had Dr. Smith (a pseudonym) and she was awesome and her crew was awesome and they treated me very well. At the time I had all my carries [permission to take home one's daily methadone doses for a week], so we did very good there. There was one nurse who talked to me disrespectfully, like you were lower

> than her because you were on methadone. But there was just that one, and I told them about it and they put an immediate stop because they said if anything happens, if you feel degraded or treated not fairly, tell us and we'll fix it and right away they did. Dr. Smith (told me to do that) before I gave birth…I will never have a baby on methadone again. It wasn't a very nice experience. But the people, Dr. Smith was very good, but then there's other people with the stigma and looking at you badly and not treating you (right).

Coreen tore some ligaments in her knee and was advised to take acetaminophen for this. Her known status as a person who uses opioids meant that she was not prescribed a narcotic pain reliever. Because acetaminophen was not adequately treating her pain, she purchased acetaminophen with codeine over the counter. Because the over the counter codeine-containing products have a relatively small amount of codeine in them (8 mg per tablet) she took a huge number of them, including the acetaminophen they contain which was not safe for her hepatic function. Similarly, Paul started to use crack cocaine to manage his pain after being denied a narcotic analgesic: "They don't wanna give it? You self-medicate. They know it." Paul was admitted to a hospital for a serious health issue related to injection drug use. He was in and out of consciousness for several days. When he regained consciousness he requested pain medication and was accused of being opioid-seeking and no pain medication was provided. This caused him to leave against medical advice before he had recovered from his illness in order to obtain illicit opioids.

Steve often assumes the role of advocate for his partner who has several chronic health issues. He advocated on her behalf not to be discharged from a specialty clinic for missing appointments. He is of the opinion that without anyone to advocate she might not have survived

this long: “She hasn’t got the energy to make appointments…so they told her to eff off…she’s lucky to have one or two good days she can get up and go out. (Without an advocate) oh, she’d be dead by now.” However sometimes having an advocate made no difference. Chase was assumed by hospital nursing staff to be using opioids behind a closed door because he took such a long time in the washroom. His mother was with him and tried her best to advocate for him by informing staff that he had chronic constipation from his opioid use but this made no difference to how he was treated: “My mother was very upset about it, and tried to tell them ‘he has trouble using the bathroom’ and they didn’t care.”

Impacts of non-traditional ways of earning income. In order to better understand the effects of marginalization which might contribute to how people who use opioids are treated, I asked participants to reflect on non-traditional ways of earning income such as sex work, theft and panhandling.

All participants agreed that the non-traditional ways in which some people who use opioids make money can cause additional stigma or discrimination. In particular, sex work and selling drugs were identified as stigmatized ways of earning income. Coreen was of the opinion that many people look down on women who sell sex: “I think that a lot of people just look at them like, ew, gross.” Joanne recalled seeing sex working women at the hospital: “…if I am up at the hospital and happen to see people who have to do that…it’s like nobody wants to touch them because everybody thinks they’re dirty to begin with because of the way they’re dressed and the way they look…” Cheryl disclosed that she engages in sex work and sometimes she feels ashamed of it and other times she is pragmatic and thinks “I do what I have to.” She noted that sex work may lead to discrimination and not be seen as legitimate work for the purposes of having permission to be out after curfew while living in a shelter. She made the point that

someone working nights stocking store shelves would have permission to be out at night but that she as a sex worker would not.

Some participants had clear boundaries about what they would and would not do to obtain money. Neither Frank nor Chase would panhandle for money because of their sense of dignity and pride. Frank described being willing to steal from a store but not from an individual person: "…I would never go and rip some old lady off or do a B&E at someone's house. I don't believe in that at all. That's just right out rude."

What participants who use opioids want to say to nurses. Participants were asked what they would want to say to health care providers, including nurses, about how to provide care to them. Responses included exhortations to develop an understanding of the issues underlying opioid use; to avoid condescension; to avoid judging and stigmatizing; to manage pain better; and to be kind and empathetic.

Cheryl wanted to say to nurses that people who use drugs do not set out to ruin their lives but use substances for a reason:

> People who use drugs – we all use for a reason. We don't wake up to our perfect lives and be like 'let's destroy it!' [laughs] Right? So I just want (nurses) to maybe have a one weekend kind of meeting, like a learning thing for them, to understand addiction. Before I would be grossed out by needle users. I'd be like 'oh my god – I would NEVER do that' right? And so maybe it's just not understanding? So like maybe they could have…part of their program have one module on addictions.

Destiny wanted to tell nurses "That everybody has different stories in their lives, and that everybody's raised and grown in their own way and if there's somebody who is in active use, not

to treat them any differently…" Steve thought that some nurses might judge people who use drugs because they do not know about the underlying issues affecting each person:

> They don't know why you're on drugs – they don't know anything about my life at all, other than the fact they might have gone to high school with me, or they know my sister…and it's not that at all. They don't know nothing about sexual assault, they don't know anything about my life…They are not in my shoes. But they think they do (know me) and they categorize (me) and that's what you get. And after you leave there, whatever you went there for doesn't matter, you're so shell-shocked and feeling just as shitty mentally as the (physical) reason you went there for…you just feel like you've just been demoralized. And that's a bad feeling.

Coreen echoed the sentiment of other participants regarding inadequate pain management. She wanted to say, "Not just to me, but to everyone, they need to be more aware of how much someone is in pain, and they need to do something about it; they need to be more lenient in prescribing painkillers." John wanted to say "I'd like to tell them to do it with some kind of humour, like the nurses have seen a lot, eight hours a day, well the average addict has seen it at least eight hours a day too, so you don't have to be condescending to me…I know that they're not supposed to be condescending, they're supposed to be helping." Chase said "Basically I'd just say that you can't judge someone solely on their addiction. I'm not a bad person just because I was addicted to opioids. It didn't make me a bad person. Yeah, I did sell drugs which – that wasn't me though, it was my addiction coming out and manifesting in that way. I'd just tell them don't judge a book by its cover." Steve said, "Don't be judgmental…Most of (the local health care providers) know I'm a drug addict, but they don't know why. They don't know that I've never hurt anybody." Joanne said "I'd say give the person a chance before you

presume what the matter with them is, and let them tell you and give them that chance to them, without friggin' diagnosing them just because you looked at them." Destiny would want to ask nurses to be open-minded and not treat people differently because they may be actively using opioids:

> That everybody has different stories in their lives…and if there's somebody who is in active use, not to treat them any differently, as if you were going to treat a 30 year old woman who's not used a single drug in her life. So basically you have to look at everybody the same instead of jumping to a conclusion that this person's a bad person because they've used drugs, or, you know, for all you know they're clean…So it's all stigma and what everybody thinks of people who are on them. I just think be more, I don't know how to put it, just be more open to everybody and the way you treat them.

Frank wanted to remind nurses that anyone can be using drugs: "Just remember, that could be their kid going in there being treated like that. They may not be on duty and their kid could be going in there on drugs and someone treats their kid like that." Casey would want to remind nurses that part of the nursing role is to have empathy: "What I would say is you're in a health care profession, you're supposed to be empathetic, so be empathetic for every person that comes in because we all have our own issues. Yours may not be the same as ours, but we're all struggling, so, just take it easy on us." She also remarked that anyone could one day find themselves in the situation of being addicted to opioids. Casey would also say to nurses: "Just be nice! Be kind. Like you never know – people don't know where life's going to take them. They could be in that spot one day." Steve would encourage nurses to "Be a nurse. I don't know if you still have an oath or whatever – but follow that oath."

Improving the care of people who use opioids. Participants had several ideas for strategies that could be used to improve their care and also to improve the lives of people who use illicit substances more generally.

Provide more education to nurses on substance use. Many participants believe that nurses lack understanding of addiction and thought that education would help. Cheryl remarked "People who use drugs – we all use for a reason…So I just want health care providers to maybe have a one weekend kind of meeting, like a learning thing for them, to understand addiction. Before I would be grossed out by needle users. I'd be like "oh my god – I would *never* do that" right? And so maybe it's just not understanding? So like maybe they could have like part of their program have one module on addictions." Casey commented: "Education would work, but then not just reading a book – not just reading a text book. The empathy thing is huge. Basically read the words that you're studying and apply them into real life situations." Joanne suggested that education about addictions ought to be part of basic nursing education.

Learn from people who use opioids. Several participants stated that creating safe learning situations where nurses could learn from people who use opioids would be beneficial. Casey stated that "(hearing) from addicts…would be fantastic. Or even go to an open NA [narcotics anonymous] meeting, where people are getting up and talking – listen to the stories – 'cause it'll be like – you don't understand what people go through – it's an everyday struggle just to stay alive." Cheryl thought that if nurses could sit down with people who use opioids it could result in a huge attitude change: "…if I had a chance to sit down how me and you are, with the lady taking my blood, I'm sure it would be 110 percent different. But because she's thinking I'm out prostituting on the corner at night…and doing needles in stairwells – like you think of the

worst? When you think of junkies. And, well, that does happen, I'm not going to lie, but it's not everybody's situation."

Create a position in hospital emergency departments to connect with patients who use drugs. One participant suggested perhaps having someone in a hospital emergency room whose role would be to greet and connect with people who use substances in order to help them feel more comfortable.

Provide more drug treatment resources. One participant stated that more funding ought to be dedicated to drug treatment services, especially in smaller communities.

Create more harm reduction housing. Frank stated that one of the most cost efficient, high impact interventions would be to provide harm reduction-based housing for people who use substances:

> I'll tell you the biggest thing they should do, if they really want to save money and help people in Ontario, all these slum lords go and buy all these houses, why don't the government start buying houses, and use them for people on welfare, so that they just don't get kicked out of their rooming house, you know what I mean? They can organize different houses for the kinds of, the way people live their lives, so if someone's an alcoholic, they can have a rooming house that's just for alcoholics, and literally – the money goes right into their hand to pay the rent, and then it goes right back to the government, 'cause it's the government that owns that place. Instead of these slumlords making all this money off people, you know what I mean?

4.3 Reflections on Findings From Participants Who Used Opioids

Participants who used opioids provided insights that were frank and detailed. Some of the experiences they shared were difficult and painful to relate. I was humbled by their trust in telling me, a nurse, these stories. Their experiences of stigma, discrimination and judgment largely mirror those found in the literature. What was reflective of their experience of these issues in a smaller community were their comments on the harmful consequences of being known to be, or to have been, a person who uses opioids within a relatively small pool of health care providers – meaning that one never has a "clean slate" and the stigma lasts forever. Their ideas for improving care were insightful and practical. I found their comments extremely useful to take into the nurse interviews in order to reflect those experiences back to nurses for their perspectives on what people who use opioids had to say. In Chapter Five I will describe what nurse participants had to say.

Chapter Five: Findings – Nurse Participants

5.1 Demographic Information and Participant Description

Four female and two male Registered Nurses or Registered Nurses (Extended Class) were interviewed. One had practiced from 5 to 10 years; one from 10 to 15 years; one from 15 to 20 years; and three had practised more than 20 years. The average length of time in nursing practice was 21.8 years. A summary of demographic data is presented in Table 2. The primary practice setting for four participants was an emergency department; one worked in a primary health care setting; one worked in a specialty clinic and one participant had a part time inpatient/critical care practice setting in addition to their primary practice setting. Participants had practised in their current setting from three to nineteen years. Three had Registered Nurse diplomas; two had baccalaureate degrees in nursing; and one had a Masters' degree in nursing. Four were Registered Nurses and two were Registered Nurses (Extended Class). All participants are identified by a pseudonym of their choosing or mine.

Table 2. Nurse Participants Demographic Data

Name	Years in Nursing	Gender
Brian	15	M
Sue	26	F
Mabel	32	F
Jennifer	31	F
Lorraine	7	F

James	20	M

5.2 Reflections of Nurse Participants

Nurse participants were asked to reflect on what it is like to care for people who use illicit opioids; whether they had witnessed nurses or other health care professionals expressing difficulty caring for people who use opioids; and what it is like to care for women who use opioids. They were also asked to reflect on what participants who used opioids had told me about attitudinal shifts by health care professionals on discovering someone's illicit opioid use, and were invited to share an unforgettable story of caring for someone who uses opioids. The headings below correspond to the content of each of the interview guide questions (see Appendix J).

Caring for people who use illicit opioids. Some nurse participants described enjoying caring for people who use illicit opioids. Many nurse participants described numerous challenges associated with caring for people who use opioids including sometimes challenging behaviours, comorbid mental health issues; and being unsure if people using illicit opioids can be considered trustworthy. Nurses also reflected on frustration related to the notion that some health issues are brought on by illicit opioid use; that people who use opioids may have no idea how dangerous their use can be; that some people attend for emergency care repeatedly; and that there are insufficient resources available to assist people who use illicit substances. Nurses also shared that it can be difficult to watch people's health decline over time and in some cases eventually lead to their death.

Some nurses pointed out that not every encounter, even in an emergency room, is with someone who needs resuscitation. Being able to interact with people who use opioids can be satisfying and rewarding. Jennifer said: "I tend to be very open with them. I enjoy caring for them. Not all of them are coming in in a crisis that we have to resuscitate." Mabel worked with people with addictions who also had Hepatitis C infection and described it as one of the most rewarding practice settings of her career.

Challenging behaviours. Every nurse interviewed described having experienced some challenges associated with caring for people who use illicit opioids. Nurses had many examples of the ways in which people who use opioids demonstrate behaviours that make providing nursing care challenging, particularly in an emergency room setting. Some nurses understood that nurses often see people who use opioids when they are quite unwell. James commented: "They're not nice people generally. Because we tend to see them at their absolute worst – so either they're coming down or they're super high or they're with the police or something – or we're intubating them because they've overdosed or something – so they're generally not a nice population to deal with." Sue remarked that behaviours such as being paranoid or agitated can make it difficult to care for other patients in an emergency room as well: "we're trying to actually save people's lives that are having traumas, heart attacks, (and) everything else too." Some nurses noted that people who use illicit opioids frequently have mental health comorbidities that may complicate their treatment such as personality disorders and bipolar disorder. James noted: "…because they generally don't just come with addiction problems but they also come with mental health problems…so they're certainly hard to deal with."

Mistrust. Nurses described wanting to believe their patients but being aware at the same time that sometimes people are reluctant to disclose their use of illicit opioids as well as the fact

they may be on methadone or have Hepatitis C or other blood-borne infections. Brian stated: "I even found that amongst my patients who were getting help and treatment with methadone, they didn't even want to tell you that…" Nurses also worried that people who did not disclose their opioid use might have other opioids in their system that would have implications for the treatment they were being provided. Lorraine remarked that it is important to nurses to ensure patients' pain is well managed: "[it's] not that we don't believe they're in pain, but maybe we're a little more cautious because maybe they have other narcotics on board, so we may be less quick to jump on the stronger narcotics to treat their pain initially."

Additionally, some nurses spoke of the concern that injection opioid users might use venous access devices to inject illicit opioids and this would not be safe for them: "When I was doing general nursing practice…[we would] watch them like a hawk once their IV port was in, because you never knew what they would do when they leave the unit" [Brian]. Sue echoed this sentiment when describing plans of care utilizing safer routes of medication administration than intravenously: "we're not leaving the IV in, because he's only an IV drug user anyway, so let's give him an IM injection, because how can we safely send him home…so I think [we're] thinking about the patients then…not allowing them to go out and get it through our IV, with their cellulitis – (we) are thinking about the patient's safety."

Frustration. Jennifer recalled having seen nurses express frustration, especially towards people whom they have seen frequently for the same reasons: "They just get angry, frustrated, 'you brought this on yourself' – and I do hear that." Some nurses thought there might be a disconnect between people's use of opioids and the most serious consequences of that use because they are unconscious prior to being resuscitated. Sue said:

> I honestly don't think they realize the dangers that go along with it, because they don't see their behaviour, they don't see what we had to do for them, basically, to save their life. Whether it's giving them Narcan [opioid reversal agent], whether it's intubating them, I find that basically they continue with the abuse to themselves because they have no recollection of it!"

Several nurses mentioned the frustration of seeing the same people over and over for the same opioid-related issues – which James and others referred to as "frequent flyers." They noted that none of the care provided seemed to make any difference to people's opioid use. Sue described how difficult it can be to see someone repeatedly returning with the same issues: "wow, you're here again, doing the exact same thing, we've tried to get you help, we're sending you to [the addictions agency], what else can we do, you've gotta help yourself, and here you are again, you're disturbing our unit, again, when – you know, what, what do you need me to do?"

Some nurses were aware that addictions and mental health resources were significantly lacking in the community and this sometimes made them feel frustrated as did not having any resources at their immediate disposal to support people who use opioids. Jennifer said: "I am more frustrated…because we don't have…any resources to help them."

Witnessing declining health. Nurses stated that it is difficult to care for people over time and watch their health fail and sometimes die because of opioid use. Some nurses felt quite powerless to do anything to change the outcomes. Jennifer said:

> [It is] difficult because we see these people declining all the time, and difficult because we also see them die. So that's very hard…there's a point where they just become terminal and they are past whatever help you can give them, and you have to respect

them for what they've been through because first of all we don't even know what their lives were before, and I've learned that probably in the last decade myself – the person that we're seeing now, and where they came from – if we knew that, wow - it just changes your whole perspective. It is difficult.

Reflections on suboptimal care. Most nurse participants endorsed that they have at times experienced personally and witnessed other nurses having conflicting emotions when caring for people who use illicit opioids. Sometimes this is because they feel that people bring about their own health issues through their drug use, or because they see them as "drug seeking," or because they do not follow through on treatment advice. Some health care professionals may avoid caring for people who use illicit substances.

Mabel stated: "I have seen my colleagues treat people with addictions in ways that – I want to be politically correct, but at the same time I think it's really important to convey – with disgust." James had also had experience of witnessing health care providers, including nurses, treating people who use opioids disrespectfully: "…there are people who are very offended to look after them almost because some of them are drug-seeking and they tend to pigeon-hole them and stereotype them as that."

Lorraine had observed some nurses expressing judgment towards people attending an emergency room in order to obtain narcotic prescriptions: "I would say it's mostly nurses that are maybe a little more judgmental towards that…we've really tightened up saying to people at the front that we don't renew narcotic prescriptions."

Some nurses had noticed that there are health care providers, including nurses, who may try to avoid having to provide care to people who use opioids. Jennifer thought this might be

positive: “I see nurses that don’t even want to deal with them – which you would think that would be terrible, but I think that’s good that they are able to recognize that in themselves – to be able to pass it on to someone who can deal with them in a more respectful manner.”

Nurses’ reflections on the attitude shift noted by people who used opioids (the switch being flipped). Some nurses described experiences of their own attitudes changing towards people who use opioids and most had witnessed this by other nurses and health care providers. Some nurses had witnessed patients being treated rudely, being undertreated for pain and being blamed for their health issues. Some nurses disputed this and felt that patients tend to be treated the same regardless of their opioid use although “same treatment” may refer to the type of care provided and not necessarily the attitude with which that care was provided. Some nurses had a very different perspective on the “switch being flipped” metaphor mentioned by people who use opioids. Other nurses remarked that knowing someone’s opioid-using status might result in a more comprehensive diagnostic work-up. Some nurses reflected on the conflict they experienced between wanting to ensure patients receive optimal pain management yet worrying about the effects of providing narcotic analgesia to people with a history of opioid addiction.

Some nurses stated that people who use opioids are not subject to attitude changes from nurses. Lorraine said: “I don’t think they get treated any differently than another unresponsive patient would be. We treat them symptomatically and they get treated the same, treated urgently.” It may be that she was interpreting the question more narrowly in terms of stating that patients get the same intervention rather than the same attitudinal treatment by nurses.

Although some nurse participants endorsed that their own attitudes may change when they become of aware of illicit opioid use, and particularly of injection use, this might be related

to increased vigilance around occupational health and safety. Lorraine attributed this in part, for example, to the need as a nurse to be more careful to avoid blood contact: "I think when somebody says that they do use IV drugs my reaction might be to just be a little more careful because you don't want to end up contracting something that they are more at risk to carry like a blood-borne infection."

Some nurses did agree that during some interactions with people who use illicit opioids a change in perspective might occur, similar to what participants who used opioids described as a switch being flipped. However nurses had a different vantage point of this switch, such as considering that confusing pieces of past encounters began to make sense, knowing now that someone was using illicit opioids, or perhaps someone was articulating a request for help: "the light switch, it kind of explains how they were acting those other times, those other appointments, I'll bet that time I saw them they were probably inebriated, okay this is starting to make sense, now that I know this or they told me this they must want help so sometimes the light switch kind of goes off for other reasons" [Brian].

One nurse was of the opinion that knowledge of a patient's illicit opioid use, especially injection opioid use might increase the comprehensiveness of their assessment because the list of differential diagnoses is broadened to include potentially life-threatening conditions for which they are at risk such as endocarditis or osteomyelitis: "…I think also as far as the IV drugs there are other things to look at as far as what could be going on…there could be endocarditis and stuff like that, so to me I would think that if they had let that come out in an emergency assessment that we would potentially do more bloodwork and more treatment and more of a work up" [Lorraine].

Nurses described feeling conflicted about pain management for people who use opioids. On one hand, they want to believe their patients and ensure pain is well managed but they could also see the position of physician prescribers who might be reluctant to prescribe narcotic analgesics to patients with a history of illicit opioid use. Some nurses working in an emergency room setting felt that a blanket policy against prescribing narcotics might at times prevent people from getting needed treatment. Nurses noted that being denied narcotic analgesics sometimes caused an escalation in disruptive behaviour in some patients. Jennifer remarked that the computer system which flags patients as being known to have used illicit opioids was sometimes problematic because it judged people before they were even assessed: "I find it difficult, when people are on methadone for example, and they are labelled drug-seeking because they came in with abdominal pain – you see it all the time. Sometimes the doctor is right in doing that, but…sometimes I think these people are in pain, and you try and advocate for them, Patients *are* under-treated for pain. Patients *are* stigmatized for their drug use."

Caring for women who use illicit opioids. Most nurse participants agreed that caring for women who use illicit opioids is different than caring for men, and that the possibility of pregnancy for reproductive-aged women who use illicit opioids conferred a heightened level of concern for women and fetuses in utero as well as an increased potential for judgment of the woman. Some nurses remarked on the particular ways pregnant women who use opioids may be discriminated against. Others spoke of their "suspicions" that women may be involved in sex work; may have sexually transmitted diseases; or may be victims of past and current male violence.

One nurse noted that women may not be able to get comprehensive prenatal care. Some nurses expressed conflicting feelings of not wanting to judge someone but having judgmental feelings nonetheless: "I mean it ups the ante, right?...as a health practitioner, you'd like to say you never judge anyone, but honestly you kinda do, but I mean if somebody's on methadone, I'd see that more as a strength" [Brian]. Jennifer recalled how some nurses adopt an attitude towards a pregnant woman using opioids of "how dare you" do this to your unborn child. Lorraine remarked: "…we do see the babes coming in that are on the withdrawal protocol, and I don't think there's really enough research on that to really – I don't know...I try not to be judgmental about that in my practice, but it's always in the back of your head what's happening to baby…"

One nurse stated that, if addiction is considered a disease, then we ought to consider pregnancy in addictions similar to how we think of implications for pregnancy in other disease states, such as diabetes. She argued that there may be a double standard applied to pregnant women with addictions in that some health care providers are quick to report them to child welfare agencies:

> We treat women who have diabetes very specifically. We send them to …a tertiary centre, so their diabetes can be very well controlled, but when these people become pregnant and they have an addiction, they're ostracized. And I find this such – the opposite end of the spectrum from where we should have these people. We should be coddling these pregnant addicted women. And some do – some health care practitioners do – but obstetricians they will…(get) children's services involved – but why wouldn't we have children's services involved with a woman who is diabetic and not managing her blood sugars? [Mabel].

Some nurses suspected that some women earn money for opioids through sex work:

> Well I think it's very, very sad…we assume that they're getting their money and their drugs from selling themselves…you're like, man, there's help out there, what are you doing? I know that, I think with women in particular…you think what kind of person would be with this girl? It's so sad…and they're so thin, they're always so thin, their teeth are bad, they're unkempt, they smell bad, and I know that they got diseases, like they need to see women's health and get pap smears but they're just ashamed…[Sue].

Some nurses noted that they often suspect a history of past abuse and current male violence affecting the lives of women who use opioids. They observe men who accompany women during hospital visits or appointments and suspect that these men may be forcing women to sell sex; may be controlling them; and may be violent towards them. Lorraine suggested that this ought to be part of a more routine comprehensive nursing assessment: "I think being aware of the other factors you need to look for. I think of one woman who we see often…and we didn't for the first few visits even consider sexual abuse as a factor as well but in fact she had been prostituting herself to get money or drugs, so I think once we became aware of that we were able to treat her as a whole…" James noted: "Well I think they come from a world of violence. It's constant. Just anecdotally speaking, from what I've seen, they're involved with assholes who beat them, abuse them, so they come from that kind of background." One nurse observed that women may be more challenging to de-escalate than men and hypothesized that this might relate to a preponderance of male police officers and security guards in the context of likely history of trauma and male violence among woman.

An unforgettable experience of providing nursing care. Nurses told compelling stories from their nursing practice that affected them profoundly. Themes included connecting on a human level with patients; the potential for grave consequences from non-disclosure of illicit opioid use; and the emotional devastation of witnessing someone's decline and eventual death, particularly if that person seemed a lot like them.

Nurses shared stories of connecting with patients who use illicit opioids which were meaningful and emotionally satisfying. Sue described a recent encounter with a woman whom she had known for several years who visited to express her gratitude for Sue's help:

> I dealt with a girl that was my age, and she had been in drugs for a long, long, time, and she just really thanked me because every time she comes in I was always really nice to her and always seemed to talk to her and care for her, And she sat down with me and we had a talk about…where she's been, and how she felt like she had really accomplished a lot, because she was no longer doing the stuff she used to do…she just made a big impact on me because she made me realize that I really do try to treat these people just like everyone else, with respect, like they have an illness, and…her being my age, it just kind of made me go "wow"…because I hadn't seen this girl in a little while…and we had a good…talk… (and) she seemed to confide in me then."

Jennifer recalled a similar story of caring for a young woman on many occasions over time. She remarked that each time she saw her she seemed more unwell and in fact Jennifer concluded that she was in the process of slowly dying. She made a decision to have a frank discussion with her about the end of life:

> Every time you saw her she was worse and worse… and I said to her "you're going to die." And she said "they've been telling me that for years." So I printed off her blood work results …and we went through what was normal and abnormal, and hers were like through the roof. And we talked about liver failure and…how death would be – and I thought maybe I'm going too far, but she seemed to absorb it – and so we kept going, and…then she left, with the pieces of paper with her lab results. Three weeks later I [saw] her again. She [came] in very intoxicated, and the papers [were] still in her pocket, okay? And she saw me and she said "I still have these papers and I look at them every single day." So – two months later, she still had the papers in her knapsack. Now they're getting very ratty! But – wow.

One of the concerns nurses mentioned was their worry that if someone did not disclose opioid use, and they were given an opioid during their treatment, there could be serious consequences. Lorraine told a story she will never forget about this very scenario:

> We had one young girl…[who] had been addicted to narcotics…and ended up on methadone, but obviously did not disclose that because she didn't want to be judged when she came in through the emergency department, so despite asking her multiple times, you know "no, no" – so she came in for a fractured wrist and we had to set it, so we did a conscious sedation and again she denied being on medication, so we gave her medication to put her to sleep and she went completely out, more so than what she should have for the medication we gave her and then we gave her Narcan [opioid reversal agent] to wake her up and reversed everything that was in her system and she went, you know, wild. Pupils dilated, aggressive, thrashing on the stretcher, pulling her IV out, pulling the cardiac electrodes off, cracking her cast open – and again we still didn't really know what

was going on. When she came around, at that point, she said well I'm on methadone. It was very eye opening for many reasons. For one thing, she obviously didn't feel comfortable exposing her history, which is unfortunate – and also her care was compromised and she was potentially put in a dangerous situation because of it. So I think that was an eye-opener just to try to make people feel as accepted as possible. I don't think initially we gave her any reason to think she couldn't tell us that but obviously she had that feeling.

One nurse told an emotionally wrenching story of a young woman for whom he had cared over several years. He described this young woman as a "normal kid" from a "normal" family. He had met this patient's family and related as a parent to the young woman's mom whom he described as "normal." The young woman he described as "horrible" when she was using but also credited the experience of caring for her as "the keystone to changing how I viewed these people." Each time she came in she would be sicker and sicker and the nurse felt he was watching her slowly die over time and she eventually did die of drug-related causes: "And she was just a normal kid. And you could talk to her, and when she wasn't on the stuff she'd get the desire to use and then she'd leave and she'd come back and she'd be sicker. I remember talking to her mom and I remember her saying "I had to kick her out, I had to let her go" – and it affects us…I never forgot her" [James].

Other reflections on caring for people who use illicit opioids.

Experience matters. Mabel disclosed that she did not particularly like caring for people with addictions when she was a less experienced nurse. Looking back, she expressed some shame at what she described as callous or judgmental treatment of some patients: "[caring for people] that

had overdosed on opioids…when we gave the antidote of Narcan [opioid reversal agent], when they came out of their bad trip, I'm gonna say – swearing and belligerent – and I remember saying to someone after he, you know, "blank-ity blank blank why did you do that?" And I said, very callously, 'we just saved your life.' I'm not proud of that." James also remarked on his own evolution as a nurse providing care to people who use opioids:

> Absolutely – all of that's true. They are stigmatized and there are certain nurses that will avoid them. They will make them wait. They will judge them and talk down to them rudely. That's not my philosophy, certainly. Like I say – I think there was a time in my career when I did that. But I think over the…years…I've kind of matured I think and come back around to 'they're human beings.'

Some nurses credited what they had learned while practising as nurses as helping them provide better care to people who use opioids. James remarked that what he had learned from nursing experience helped him treat people who use opioids with more compassion: "I think a lot of them come from – both men and women – from bad homes, from bad lives, I think they grew up and they never had a chance."

Education on substance use is lacking. Many nurses observed that neither their basic nursing education nor their ongoing professional development prepared them to care for people who use illicit opioids or other substances. Those who felt that they had learned what they needed to know typically described having learned from experience or self-directed learning. Mabel stated: ": Well I can honestly say that it was not taught to me in my nursing education when I first became a nurse, nor did it really change when I acquired my BScN. It really changed when – probably midway through my experience as an RN working in the emergency room."

The impact of viewing addiction as a disease. Mabel felt that understanding how addictions alters the brain and understanding addictions as a disease had made her less judgmental: "So I can for certain say that my experience has softened my approach to these people, and I have a greater understanding of how the brain actually is altered in any addiction and not just opioids. My response to people is like any other disease in that it can be heart disease, it can be diabetes, it can be addictions."

Substance use is not a "normal" path. Some nurses described drug use as a departure from the "normal" path of life and a choice of behaviour in which to engage. Sue remarked on a young woman patient who was the same age as her: "her being my age, it just kind of made me go "wow" – I'm really glad I went down the right path in life…" Sue also recognized that while she felt empathy for the difficult situation people who use opioids are in, she also struggled with being unable to understand why they would continue: "I think there's a lot of empathy, but also you're like, man, there's help out there, what are you doing?"

Even "normal" people may use opioids. Some nurses referred to people who use opioids as being just like "normal" people or as coming from "normal" families. Lorraine told a story of a young woman who did not disclose her opioid use and was in fact on methadone. She suggested that the young woman's middle class status contributed to not suspecting she might be on opioids: "…she was a 20 year old girl, she went to university, she – you know – was middle class – we had no reason to suspect that."

5.3 Reflections on Findings From Nurse Participants

Nurse participants shared important views, insights and stories, some of which were difficult to tell. Some nurses' views in many ways mirrored the findings seen in the literature. The nurses' unforgettable stories of caring for people who use opioids belied their initial expressions of frustration, blame and mistrust and were for the most part stories of connecting emotionally to care for patients who had made a significant impact on the nurses, sometimes after many years. I believe that all the nurses really wanted to connect emotionally in a caring way with their patients who use opioids but there were some significant areas of disconnect between the two groups. In Chapter Six I will explore more fully the meaning of the findings.

Chapter Six: Interpretive Analysis

The purpose of this study is to better understand how the experience of being a person who uses illicit opioids in a smaller community affects one's experiences of health care, including access to health services and treatment within the health care system. Further, I wanted to explore the perceptions of nurses working in smaller communities about what it is like to care for people who use opioids. The overarching findings that really stood out for me were two-fold: people who use opioids want to be treated with respect and kindness by nurses; and nurses want to connect with their patients and provide excellent care to them. Myriad factors contribute to a significant disconnect between the two groups which has negative consequences for nurses and for people who use substances.

Nurses may experience frustration, helplessness, reduced role fulfillment, moral distress, compassion fatigue and burnout. People who use substances may experience frustration, inadequate care, lack of care, and misdiagnosis. They may leave the health care setting feeling worse than they did on arrival and may delay or avoid seeking care in the future. Many of the findings of this study are supported in the international and Canadian literature on the health care experiences of people who use substances, such as the prevalence of stigma, discrimination and judgment by health care providers including nurses. Also supported were findings that some nurses find people who use substances challenging to look after and feel they lack sufficient education on substance use.

There were some surprises, which may have occurred because of my long tenure working from a harm reduction perspective which has led me to forget that not everyone approaches substance use using a harm reduction lens. Just to keep me humble were some findings which

surprised me and which, in hindsight, ought not to have! When I asked people who use opioids about their challenges staying healthy, I was surprised when several responded by stating that not having enough opioids impaired their health. I think I was applying my primary care nurse lens, seeing only the visible health consequences of daily substance use, and especially of injection use, such as cellulitis or sepsis or ignored chronic conditions resulting in, for example, poorly-controlled diabetes. I understand that daily substance use is about self-medicating untreated psychological pain, so of course not having one's pain medication would impair health, as would the dreadful experience of opioid withdrawal.

When considering the responses of nurse participants, I was surprised at the prevalence of the belief that addiction was either a disease or an individual choice – and further, an "abnormal" individual choice made by someone who might also not be considered "normal." Several of the nurse participants expressed surprise when someone they considered "a normal kid, from a normal family" struggled with substance use; or when they discovered that a middle class young woman was on methadone – and further, had withheld that information from them with serious repercussions. I was surprised that, although nurses expressed helplessness and frustration with their inability to help people who use opioids, so few nurses made any mention of harm reduction as an approach or as a set of practical strategies which might be offered. Also surprising to me was the disconnect between some nurses' observation that substance use might be related to adverse early life events, but little understanding of the robust epidemiologic relationship between trauma and substance use. I was also surprised to discover a fairly pervasive use of language that separates people who use illicit opioids as "others."

It is these standout findings as well as the surprises that provide the framework through which I will now distill the overarching themes and concepts. The key analytical points I will highlight now include a detailed elaboration of the metaphor articulated by several participants who used opioids of a "switch being flipped" once their substance use was disclosed or discovered or even if it was merely assumed that they were using substances. I will explore what triggers the switch to be flipped; how people who use substances can recognize when the switch has been flipped; and its consequences. I will explore possible reasons for flipping the switch including the desire of nurses to minimize risks to themselves; lack of knowledge about substance use and harm reduction; the replication of sociocultural beliefs about substance use and compassion fatigue.

Other key points of analysis include nurses' lack of accurate knowledge of substance use, which ranged from minimizing the severity of opioid withdrawal symptoms to wrongfully characterizing substance use as a choice to failure to understand the etiology of substance use in adverse early life experiences. Here I also explore the findings of reciprocal mistrust between nurses and people who use opioids which can operate much like an endless feedback loop. Additionally, although some nurses felt experience enabled them to more confidently care for people who use substances, being self-taught was not always helpful as nurses sometimes learned either inaccurate information or they simply learned how to adopt a façade of "professionalism" to conceal their true feelings about patients who use substances. One of the surprises for me which I explore further was the idea that nurses often characterized people who use substances as being different from themselves and of being different than "normal" people. Nurses also described the distress caused by witnessing the declining health of people who use substances and feeling helpless to intervene; and they articulated that caring for women using

substances was different than caring for men. Participants who used opioids suggested that stigma lasts forever in a small community which has implications for access to care. Finally, I explore some hopeful findings such as nurses who enjoyed caring for people who use substances and participants who used opioids who described some positive health care experiences and their optimistic belief that if nurses had the opportunity to learn from people who use substances they might find it easier to be compassionate towards them.

6.1 It's Like a Switch Gets Flipped…

Both participants who use substances and nurse participants identified numerous negative emotions, attributions and attitudes that characterize many nurse-patient encounters and which impede caring and serve to thwart the development of a therapeutic connection. These negative feelings and attitudes caused distress for both groups and were perceived by some members of both groups as inevitable. One of the prominent themes articulated by participants who used opioids was that of an abrupt attitudinal change by some nurses on discovery of someone's opioid use. Some participants who used opioids likened this to a switch being flipped. Frank described it as "it's like day and night with the attitude…they think you're just a waste of time." Chase echoed the sentiments of other participants who used opioids in identifying how they knew when the switch had been flipped: "…they give you that look that makes you not really want to be there."

Initially I was thinking that the switch was one which turned on attitudinal discrimination, but the more I have reflected on it the more I think that a more apt interpretation is that nurses' creation of authentic caring relationships (which usually defaults to the "on" position) is switched off. It may be that the polarity of "on/off" is a bit overstated or simplistic.

Perhaps this switch behaves more like a dimmer switch, with gradations of reduced caring or greater disengagement from patients depending on nurse and patient factors and the particular health care context. Regardless of how far the switch is turned down, the result is the provision of care which may be more aptly described as a series of disengaged nursing tasks.

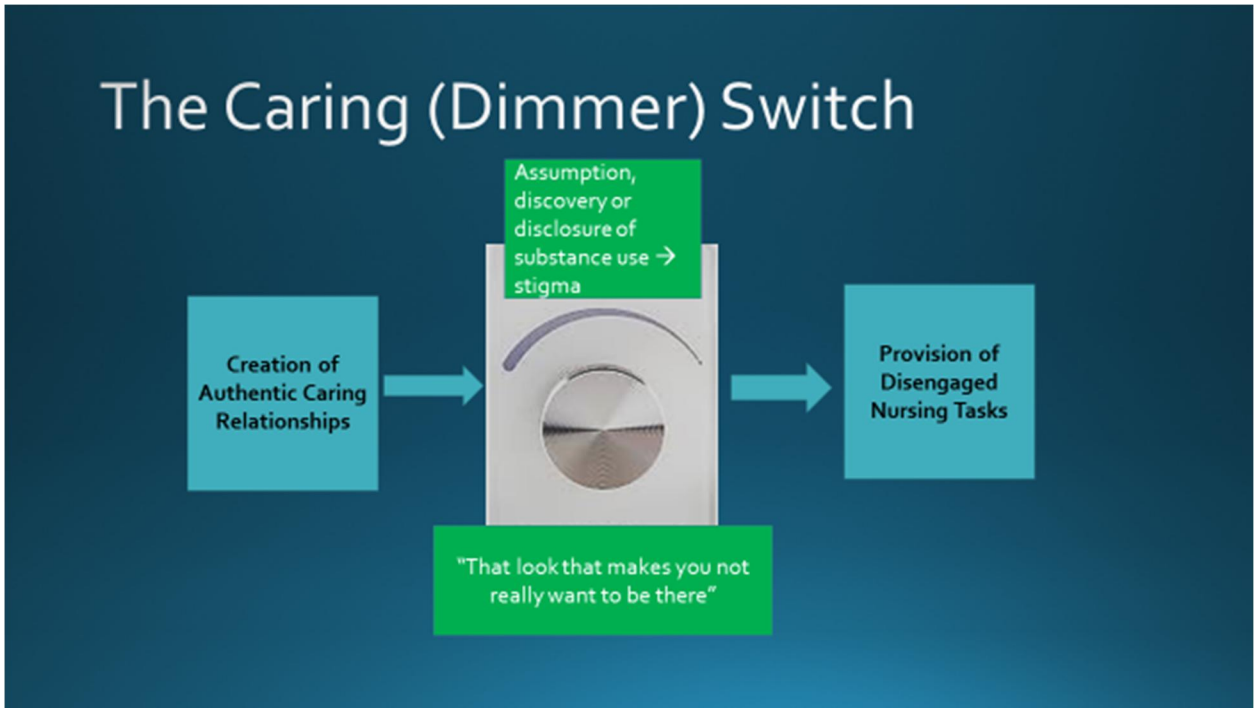

Figure 1. The Caring Switch

What triggers the switch to be flipped? My nursing practice with people who use substances over several decades has influenced me to understand the pervasiveness of stigma as a barrier to care. Participants who used opioids identified a vast array of intersecting potentially stigmatizing issues in addition to being a person who uses opioids. Also stigmatizing were having HIV or Hepatitis C infections; being seen to be at risk for contracting and transmitting HIV or Hepatitis C infections; being tested for these infections; being on methadone; engaging in non-traditional ways of making money such as sex work or selling drugs; having a health issue

that arose as a direct consequence of drug use such as an abscess or an overdose; and, widely perceived as the most stigmatizing of all, being someone who injects opioids. These findings are consistent with those from other international jurisdictions (Ahern et al. 2007; Butt, 2008; Day et al., 2003; Harris, 2009; Martin et al., 2006) and from other Canadian jurisdictions (Gustafson et al., 2008; Jackson et al., 2010; Lang et al., 2013; McCutcheon & Morrison, 2014; Sallman, 2010; Whitaker et al., 2011; Wise-Harris et al., 2016).

Disclosure by participants who used opioids of any one or more of these issues to a nurse or other health care provider frequently resulted in an abrupt attitude change by some nurses which can be described as flipping off the (caring) switch. Notably, this theme of experiencing stigma related to one's substance use arose repeatedly, regardless of what question I posed and even when I was not specifically asking about it. It appears that the primary trigger for the switch to be flipped is stigma – related to one or more of the intersecting stigmatizing attributes which may characterize people who use opioids.

Although some nurses had witnessed other nurses treating people who use opioids with disgust, anger or avoidance, the nurses' perceptions of the switch being flipped were generally quite different than those of participants who used opioids. Some nurses disputed the existence of the switch, suggesting that everyone received the same treatment regardless of their drug use status. I wonder if these nurses were referring to patients receiving equivalent interventions, but perhaps being unaware of differences in attitude towards people who use opioids. One nurse suggested knowing about someone's opioid use could expand the diagnostic evaluation to encompass a broader set of differential diagnoses. Another nurse remarked that learning that someone was using opioids helped one to make sense of confusing past encounters.

Nurse participants identified that caring for people who use illicit opioids was frustrating, difficult, and challenging because of their sometimes perceived disruptive and otherwise "bad" or "not nice" behaviour including agitation; because of sometimes co-occurring mental health issues manifesting symptoms such as paranoia; because of not being sure if such patients were trustworthy; and because of feeling helpless to meaningfully intervene. As well, nurses expressed frustration and judgment at repeat visits to an emergency department for the same issues over and over; for being seen to bring on their own health issues as a result of their drug use; for being assumed to be narcotic-seeking; and for taking time and attention away from other patients. These findings are also consistent with those in the studies referenced above.

"The look" – how you know when the switch has been flipped. Casey remarked, "…the way they look at you, it's just kind of in disgust." Several participants described experiencing a "look" from nurses, which they described as conveying disgust. This unmistakeable look made them feel "like you're not a person" [Joanne] or like "you're the scum of the earth" [Frank]. Chase noted "…once they see your arms or wherever you shoot up, they give you that look that makes you not really want to be there…basically that you're a screw up and you're less than them, you're less of a person."

Participants who use substances identified that once this switch was flipped, they experienced discrimination, judgment, frustration and blame for their health issues by health care providers including nurses. Participants often had incorrect assumptions made about them by health care providers and felt ignored when they tried to correct those assumptions. John, who had a lengthy opioid-using history and countless health care experiences over decades remarked that discrimination was a standard expectation for him upon entry into a health care setting.

Participants who used opioids described being made to wait longer for care, being given less information ("the conversation stops flowing" [Joanne]), and being admonished and blamed for having damaged veins. The desire to avoid negative health care experiences was given as the reason they sometimes avoided seeking care and/or hid their substance use. These findings of negative health care experiences are similar to those of Gustafson et al., (2008); Harvey et al. (2015); Jackson et al. (2010); Lang et al. (2013); McCutcheon and Morrison (2014); McLaughlin et al. (2000); Pauly (2008b); and Pauly et al. (2015).

Consequences of the switch being flipped. Similar to the international and Canadian studies referenced above, some participants reported feeling guilty and ashamed of their drug use as the result of negative health care experiences which made them feel worse than they did when they arrived in the setting (which would seem to be at odds with the goals of any health care agency). Others reported avoiding or delaying getting care in order to avoid subjecting themselves to negative experiences. This sometimes resulted in worsening of health issues or people leaving hospital against medical advice. Sometimes it resulted in people turning to a less healthy alternative means of treating health issues such as using street-purchased medications. Some people endured negative experiences in order to get needed care, which is consistent with the findings of Neale et al., (2008) who found that people who use injection drugs in a small city in the United Kingdom tolerated hostile attitudes from primary care providers because they believed no other providers would accept them. Similarly, the Canadian Mental Health Association (2009) found that in rural and remote regions of the country some primary care providers screen out individuals with complex mental health or addictions issues.

Why flip the (caring) switch off? This notion of a switch which can turn off empathetic caring begs the question – why have one? What could be the purpose? In what circumstances would it be used? The following are some posited explanations.

The desire to minimize risks. The nursing literature suggests that nurses may distance themselves from patients who use substances to protect themselves from perceived risks to their safety and the desire to reduce disruptive behaviour. Peckover and Chidlaw (2007) found that British home visiting nurses working with people who use substances dealt with fear for their own safety by reducing visit duration and focusing solely on the specific tasks to be performed at the visit. Ford's (2011) study of Australian nurses caring for people with substance use issues found that some identified challenges in interacting with patients related to perceived manipulative and irresponsible behaviours. Monks et al. (2012) found that nurses working on an inpatient unit minimized contact with and implemented a detached manner of providing care to patients who use substances to minimize the risks of disruption and violence.

Lack of knowledge about substance use and harm reduction. Ford (2010) described constrained nursing care of people who use substances when nurses lacked adequate knowledge about substance use and when they had limited institutional support for their role. Although these researchers identify the phenomenon of thwarted therapeutic relationships between nurses and people who use substances as well as contributing factors, hypotheses about the reasons remain theoretical. Ford (2010), for example, suggests that nurses' beliefs may mirror stereotypes held by the general population – a finding also reported by Harling and Turner (2011) with respect to Australian student nurses and Lang et al. (2013) in Saskatoon, Canada. Some may see substance use as a choice (whose solution lies in the criminal justice system) while others may see it as an

illness or a moral failing which would justify forced abstinence. Morgan (2006) suggests that nurses' lack of understanding of substance use may negatively affect the quality of nursing care, especially regarding pain management.

Ford (2010) found that a sample of Australian nurses lacked knowledge of and belief in the efficacy of harm reduction strategies. Ford also found that some nurses had trouble reconciling acceptance of ongoing substance use required by harm reduction approaches (2011). In the Canadian context Smye et al. (2011) suggest harm reduction strategies may provide nurses a means to understand intersectional experiences of oppression while Pauly (2008a, 2008b) suggests harm reduction strategies might provide nurses with practical interventions allowing them to avoid moral judgments and move away from stigmatization.

As stated previously, although Canadian and some provincial nursing organizations advocate harm reduction as an important strategy, there is a paucity of nursing literature on harm reduction which represents a significant gap for nurses and patients who use substances.

Replicating sociocultural beliefs about substance use. Pauly et al. (2007) observed that nurse-patient therapeutic relationships were hindered when people who use substances were characterized as irresponsible or undeserving of care. Morgan (2014) suggests, like Ford (2010), Harling and Turner (2011) and Lang et al. (2013) that nurses may be subject to the general socialization processes at work that cause them to unwittingly perpetuate societal labels which stigmatize and marginalize people who use substances, placing them in the category of undeserving of care.

Compassion fatigue. First described by Joinson (1992), compassion fatigue describes situations in which nurses and other caring professionals "turn off" their feelings or experience helplessness and anger in response to the stress they feel caring for patients in a range of challenging circumstances. Valent (2002) theorized that compassion fatigue may be related to an inability to rescue the patient or improve their situations. Yoder (2010) interviewed 106 nurses from a variety of settings in a small Midwest American community hospital and found that common situations that triggered compassion fatigue include caring for patients whose behaviour was challenging (such as angry or demanding patients) and being involved in care that was or seemed futile. Nurses typically coped using two very disparate strategies: either by disengaging from the patient, or by intensifying their focus on the patient's needs.

Nurse participants articulated the frustration they felt dealing with the sometimes challenging behaviours of people who use opioids. They also spoke of the difficulties they experienced witnessing patients decline and feeling helpless to intervene to change the outcome. It would seem that turning off the caring switch could be considered a coping strategy nurses might use in the context of compassion fatigue triggered by frustration and helplessness associated with caring for people who use opioids. Figure 2 outlines risk factors contributing to the switch being flipped; strategies used by people who use opiates to prevent it being switched; and consequences of the switch being flipped for both groups.

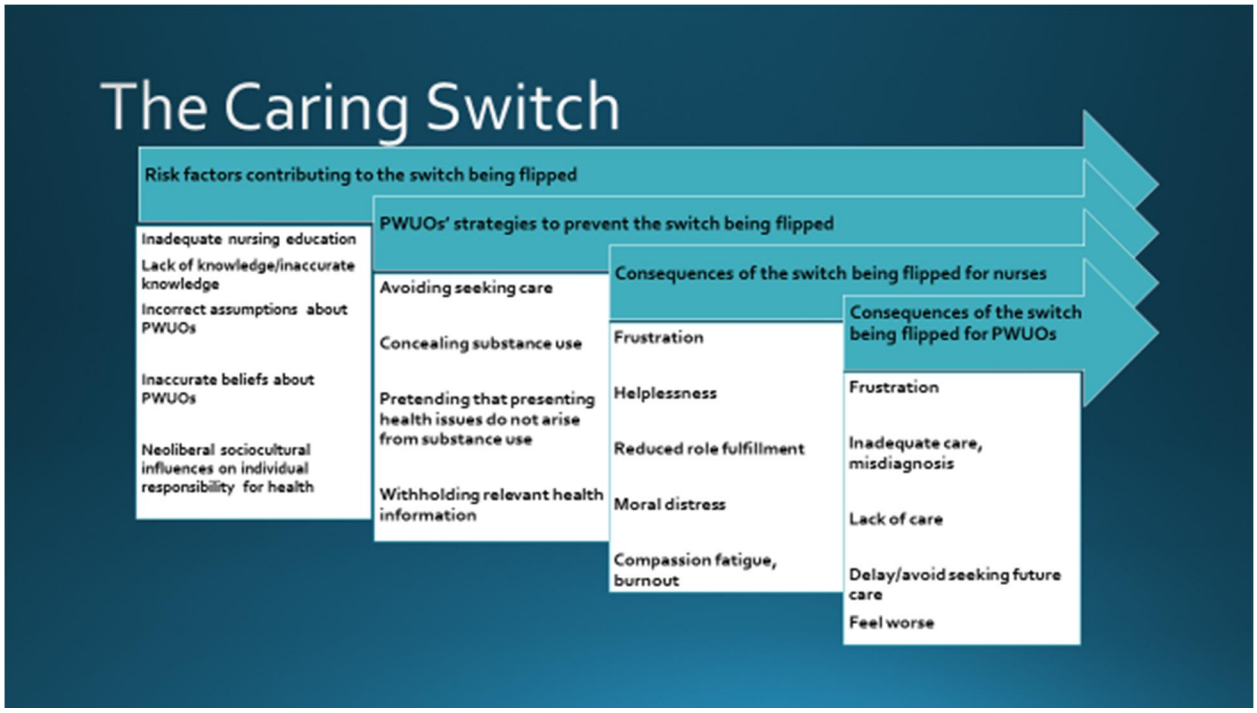

Figure 2. The Caring Switch – Risk Factors, Strategies, Consequences.

6.2 Nurses Lack Accurate Knowledge about Substance Use

An area of overlap between participants who used opioids and nurse participants was the observation that nurses have huge knowledge gaps around substance use. Participants who used opioids frequently commented that nurses did not understand substance use or people who use substances. Nurses reported that neither their basic nursing education nor their ongoing professional development provided sufficient education on substance use. Participants who used opioids noted that these gaps included significantly minimizing the severity of the symptoms of opioid withdrawal, not understanding the presence of underlying mental health issues in people who use substances; and not being aware of the role of trauma in the etiology of compulsive substance use.

Nurses may minimize the symptoms of opioid withdrawal. Participants who used opioids had numerous experiences of being told by health care providers, including nurses, that withdrawal was like "a bad flu" or "not that bad." Casey described withdrawal this way: "Your whole body shakes, you sweat, you're hot, you're cold, you want to sleep, you can't sleep, you have headaches, it is the most excruciating pain you'll ever go through….it is horrible…" Steve described withdrawal as "(feeling) like you're going to die."

When nurses minimize the severity of withdrawal symptoms, it conveys several messages to people who have experienced opioid withdrawal: that they may be viewed as catastrophizing or malingering; that they may be using these symptoms as a (false) rationale for obtaining opioids; or perhaps that they deserve this suffering. As Steve said, he has heard this message from health care providers numerous times: "you got yourself in that position, and don't be crying to us, right?" The premise on which methadone replacement therapy for opioid addiction is based is that avoidance of withdrawal symptoms is the primary motivation of people whose opioid receptors have become sensitized to opioids. It is so powerful a motivation that the primary treatment for opioid addiction involves providing a long acting opioid to prevent withdrawal symptoms – yet nurses and other health care providers typically minimize its severity in a manner which could be described as dismissive and insensitive.

Nurses may believe that substance use is a choice. Some nurses did not endorse the "addiction as disease" theory but rather held the view that substance use was a "choice" which could be made or not made. John, for example, told a story of being smacked on the back of the head by a health care provider to convey the message that he ought to "smarten up" or "get over it" and quit using opioids. Sue was of the opinion that when patients have overdosed and require

resuscitation because they are unconscious, that this lack of awareness of how close they had been to death supported their ongoing substance use: “I think that basically they continue with the abuse to themselves because they have no recollection of it!” This implies that knowing, or being made to see the negative consequences of one’s substance use would have the effect of “smartening up” a person who would then, presumably, make the rational choice to stop using.

Nurses may not understand the etiology of opioid use. Another important knowledge gap identified by participants who used opioids is the lack of understanding of the underlying reasons for substance use. People who use opioids observed that nurses frequently had no idea why they had started using opioids and why they used every day. Some participants disclosed to me that they used opioids because of untreated anxiety or depression and to manage emotional pain related to grief and past trauma – which was sometimes profound, repetitive and cumulative. Some nurses remarked that patients who use opioids sometimes had remote and recent experiences of assault and violence but mostly stopped short of articulating a direct cause and effect link between a history of trauma and substance use.

The Adverse Childhood Experiences (ACES) study is one of the largest research projects investigating childhood abuse and neglect and its relationship to adult health and wellbeing. Beginning in the United States in 1995, the 17,000 person sample revealed that two thirds reported at least one Adverse Childhood Experience (ACE) and more than one in five reported three or more ACEs. Eighteen ACES were studied including emotional, physical and sexual abuse; emotional and physical neglect; household substance use; household mental illness; witnessing violence against one’s mother; and living with a household member who was incarcerated. The effects of ACEs are cumulative and dose-dependent, meaning that the more

ACEs experienced, the greater the negative impact on morbidity and mortality. Participants who had experienced four or more categories of childhood exposure, compared to those who had experienced none, had a 4-to 12-fold increased risk for alcoholism, compulsive daily substance use, depression, and suicide attempt and a 2- to 4-fold increase in smoking (Felliti et al., 1998). Since then numerous ongoing studies built on the original study have consistently reported a robust relationship between ACEs and adult substance use and mental health issues (Anda et al., 2006; Dube et al., 2001; Dube et al., 2002; Dube et al., 2003; Dube et al., 2006; Remigio-Baker et al, 2014; Strine et al., 2011) – to list but a few articles from the extensive body of research on this subject. Figure 3 provides a visual representation of the epidemiologic mechanism by which these relationships are thought to occur (Centres for Disease Control and Prevention, 2016).

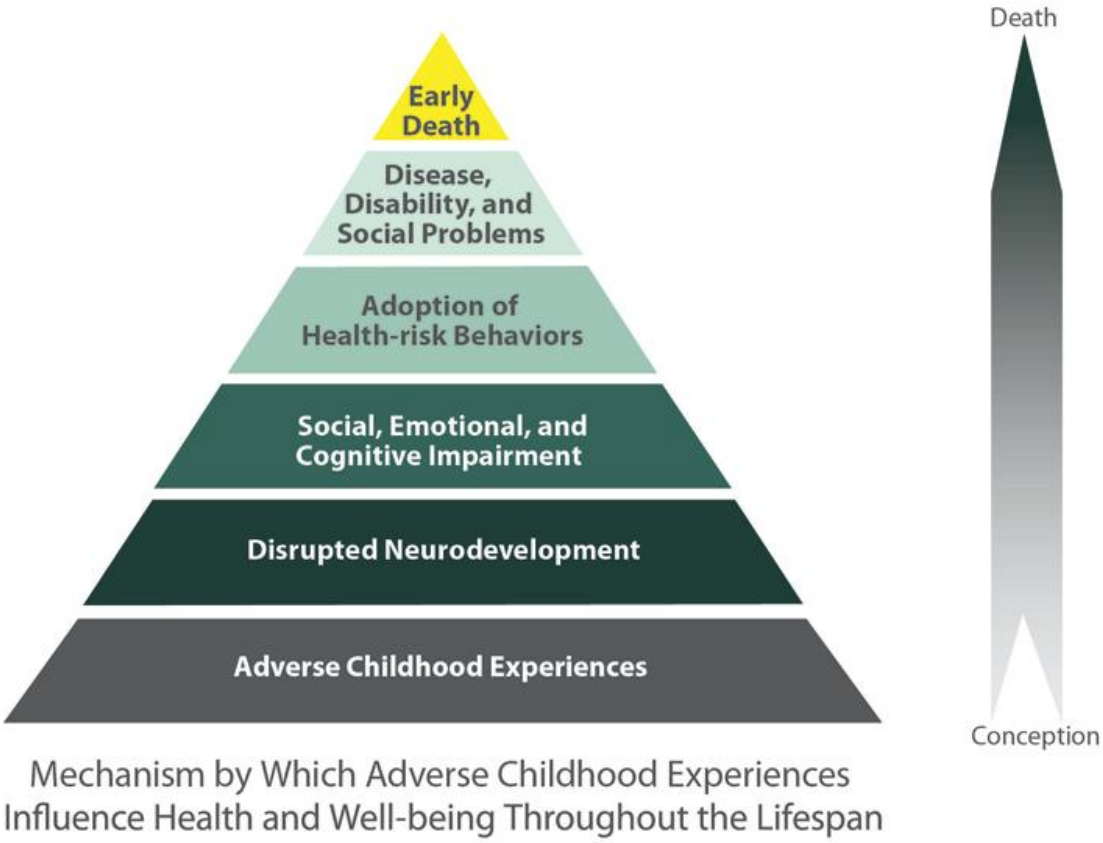

Figure 3. The adverse childhood experiences (ACE) pyramid.

Christensen et al. (2005) assessed men and women enrolled in substance use/mental illness treatment and found that 100% of the women and 68.6% of the men had a history of trauma. Wu, Schairer, Dellor and Grella (2010) assessed 402 adults in residential substance use treatment program and found that 95% had experienced at least one childhood traumatic event and 18.1% had experienced six or more. Sandford, Donahue and Cosden (2014) found that participants in a drug treatment court program experienced an average of four traumatic events during childhood. Cosden, Larson, Donahue and Nylund-Gibson (2015) found statistically significant gender differences among men and women in substance use treatment with women

reporting more sexual abuse than men and further 69% of the women had experienced physical abuse. Giordano, Prosek, Stamman, Callahan, Loseu et al., (2016) surveyed a sample of adults in outpatient substance use treatment program and found that 85.12% had experienced at least one traumatic event in their lifetime with women reporting more sexual abuse and more men reporting witnessing violence.

Nurses would appear to lack basic knowledge having to do with opioid addiction, such as the realities of withdrawal symptoms. Further, the apparent lack of understanding by nurses of the epidemiologically robust relationship between physical, sexual and emotional abuse or other kinds of trauma, and untreated mental health issues and substance use, represents a huge, fundamental gap in nursing knowledge.

6.3 Reciprocal Mistrust – An Endless Feedback Loop

One of the largest areas of overlap between the two groups of participants was pervasive lack of trust of the other. Participants who used opioids told me that they were often not believed by health care providers when they said they were having pain, for example. Another example of mistrust was when John went home to pack a bag for his hospital admission and staff did not trust him to return so sent the police to escort him back. Chase described taking a long time in the washroom because of opioid-induced constipation and being accused of using opioids in the washroom and discharged abruptly as a result – even though it was not true. Disclosing one's opioid use often led to not being believed by health care providers, even when telling the truth, and as such some participants who used opioids concluded they might be better off not disclosing their illicit opioid use. Further, participants who used opioids described past negative

experiences of health care which resulted in mistrust of nurses from whom they feared judgment, admonishment, blame and stigma.

Nurses described wanting to believe their patients but were cognizant of some people's reluctance to disclose illicit substance use. Nurses were concerned that non-disclosure of opioid use might lead to dire consequences for patients if additional opioids were administered. This fear is consistent with that expressed by a cohort of Australian nurses (Ford, 2011). One nurse's unforgettable story was of this very scenario in which a young woman who was on methadone had to be resuscitated when she was administered conscious sedation to set a fracture. Nurses were also concerned that people who use injection opioids might use intravenous (IV) access devices to inject their illicit drugs and believed that this would not be safe. One nurse recalled the need for enhanced surveillance by nurses of patients known to be opioid users once a venous access device was inserted, especially if those patients left the unit. Brian described feeling the need to "watch them like a hawk…because you never knew what they would do when they (left) the unit."

This experience of mutual mistrust becomes in some regards an endless feedback loop. Patients may not trust that they will not be stigmatized for disclosing their opioid use, so they may withhold this information. Nurses suspect patients of non-disclosure and then, when they discover opioid use through, for example, a urine toxicity screen, feel they are correct to mistrust patients. Nurses also did not trust that people who inject opioids would not use venous access devices to inject illicit substances. There are two notable issues illustrated in this example. First, it implies that nurses assume that people who use substances are more likely than other people to risk compromising their health care treatment by improper use of a medical device. Second, it

exemplifies the harm reduction knowledge gaps of some nurses who would seem to believe that injecting illicit substances through a medical device is a bad idea. Through a harm reduction lens, it makes perfect sense to teach a patient safe use of a device inserted by a health care professional under clean conditions to inject illicit drugs. Nurses are in fact injection and intravenous access experts. Who better to teach lay people who inject themselves with drugs how to do this safely?

6.4 Experience Matters – But Self-Taught May Not Always Be Helpful

Some nurses indicated that they compensated for their lack of education on substance use by learning how to provide care to people who use substances on their own or through their nursing experience. Nurses also reflected on the fact that the distaste they may have felt when caring for people who use substances while they were novice nurses diminished over time as they accumulated more experience.

Beginning to understand the context of individual substance use. Some nurse participants indicated they had developed skills and understanding they lacked when they were novice nurses. Both James and Jennifer remarked that experience had helped them develop a better understanding of the difficult life stories of some of their patients who use substances. James said, "I think they grew up and never had a chance." Jennifer said: "…I've learned that probably in the last decade myself – if we knew (what their lives were before)…it just changes your whole perspective." This is in keeping with the findings described by Morgan (2014) who interviewed nurses caring for people who use substances on an inpatient unit. These nurses also indicated a gap in nursing education around substance use. They identified that after some years of experience in nursing they had more patience and confidence to deal with patients having

challenging behaviours than they did as new nurses as well as more perspective on the difficult life experiences of people who use substances.

Developing a professional façade. Mabel recalled as a novice nurse having been more "callous" toward a patient who had overdosed and described feeling ashamed of having done so. James also reflected on how differently he approached caring for people who use substances now that he had more experience. He recalled nurses who were avoidant, rude or judgmental towards patients who use substances and noted: "…there was a time in my career when I did that. But I think over the…years…I've kind of matured…" He described having developed the ability to "put on a façade of professionalism so that the patient does not know what you think of them." This may be a means to cope with the challenges of caring for people who use substances for nurses who would use a different way of relating if they had the skills, knowledge and institutional support to do so.

Addiction as a disease. Several nurse participants told me that they believed that addiction was a disease, "like any other disease" in the words of Mabel – who attributed this understanding to her "softened" approach to patients with substance use issues. Does characterizing addiction as a disease entity relieve patients of the burden of being considered responsible for having made some unfortunate lifestyle choices? In the same way nurses care for smokers with lung disease, or obese people with diabetes, does seeing addiction as a disease allow nurses to provide care with less judgment or perhaps to provide care with a familiar degree of judgment that nurses are used to, as one does with smokers and obese people? Pauly et al. (2015) found that some nurses in Vancouver, Canada characterized addiction as a disease process that takes over patients' lives, rendering them unable to exercise control over it.

Interestingly, some of the patients interviewed in this study disputed this notion and took exception to the idea that they were helpless victims of their substance use.

It is reflective, perhaps, of a significant lack of substance use education available to nursing students and practising nurses that nurses must rely on conclusions they draw from their nursing experience and presumably from their nursing and other health care professional colleagues. Sometimes this self-taught knowledge can be useful but in some cases, the understandings may be inaccurate or incomplete and impede the ability of nurses to form authentic relationships and to provide the highest quality of care possible.

6.5 The Myth of Normal – People Who Use Opioids Are Not Like Me

Several nurses articulated the idea that drug use was not "normal" nor something that "normal" people engaged in. The unforgettable story James recounted was of a young woman whom he had cared for over a long period of time, who eventually died of drug-related complications. James described this patient as a "normal kid" from a "normal" family. He had met the young woman's mom and related to her and to the young woman who seemed much like James and James' family. Sue told a story of connecting with a young woman who was her age who struggled with addiction. The similarities between this young woman and Sue prompted Sue to be grateful she had gone down "…the right path in life," having made the correct "choice" not to use drugs. Lorraine's unforgettable story was of a young woman who did not disclose her methadone use prior to being given conscious sedation drugs which affected her adversely. Lorraine said "…she went to university, she…was middle class – we had no reason to suspect (she was on methadone)." This would seem to indicate that some nurses believe the following:

a) Drug use indicates a deviation from the normal life path;

b) People who use drugs can usually be visibly identified;

c) People who use drugs are not usually middle class;

d) People who use drugs are not usually a lot like me.

What this suggests is that nurses tended to separate people who use substances from themselves – a process referred to in the literature as othering. MacCallum (2002) applies the concept of othering to psychiatry and specifically its role in separating the "mad" from the "sane." She notes that this is problematic because it results in misrepresentation of patients. She considers othering inevitable in nursing practice but suggests strategies to bridge the gap between nurses and patients. Reimer Kirkham (2003) explored how the construction of the "Other" within health care contexts serves to reproduce sociopolitical forces of the broader society in which they exist. Peternelj-Taylor (2004) argues that othering can have a detrimental effect on the therapeutic relationship and ultimately on the quality of care received. Canales (2010) notes that othering often results in members of non-dominant groups being judged against "a mythical norm" (p. 26) and argues that identifying differences is easier than seeing what makes us similar and thus vulnerable; and easier than looking at our own roles in creating and maintaining boundaries that exclude.

Nurse participants frequently referred to people who use opioids using terms such as "these people" – sometimes in counterpoint to "normal people" – and also made stereotypical assumptions such as the suspicion that women who use opioids must be engaging in sex work and must have sexually transmitted infections. Such stereotypes and the use of language which separates patients who use substances from so-called "normal" patients can have the effect of

creating an "other" or of distancing patients from nurses. It may be helpful at this point to recall what participants who used opioids had to say about "the look" from nurses once the switch was flipped. They interpreted this look as conveying "disgust" [Casey]; "like you're not a person" [Joanne]; like "you're the scum of the earth" [Frank]; that you're a screw up and you're less than them, you're less of a person." [Chase]. Language used by nurses to describe people who use opioids as well as the experiences of participants who used opioids who described being made to feel distinctly "less than" after receiving an unmistakeable look conveying disgust or contempt suggest that "othering" dynamics influence health care experiences of people who use opioids.

Nurses may engaging in othering in order to protect themselves from their own vulnerability. When nurses construct some groups of patients as the "Other," they suppress recognition of themselves in others which prevents the creation of authentic relationships and allows them to avoid seeing their own vulnerability. Daniel (1998) explored the notion of vulnerability in nursing and concluded that the choice for human beings is not whether we will be vulnerable, but whether we will be authentic in our vulnerability. She concludes that authenticity requires of nurses an awareness of our own vulnerability, recognition of ourselves in others, and the willingness to "enter into mutual vulnerability" (p. 191). Failure to do so increases the risk of dehumanizing other people and compromises the central premise of nursing which is caring. Gastmans (2013) argues that responding to vulnerability is the essence of nursing care but further, and importantly, this requires that nurses engage in a dialogical interpretive process of communication, interpretation and understanding, in a relational context, with each patient. Wright and Schroeder (2016) argue that authenticity can be considered the "catalyst" for a therapeutic nursing relationship (p. 221) and posit that relationship building is the essence of nursing work. They suggest that nurses caring for patients who may be considered

challenging (using the example of patients with anorexia nervosa admitted to a speciality hospital unit) are themselves vulnerable to harm arising from inauthentic and nonreciprocal relationships. They suggest a set of recommendations designed to protect nurses from these harms which I will return to in Chapter Eight.

6.6 Witnessing the Decline, Feeling Helpless to Intervene – Does This Cause Moral Distress?

Some nurses remarked on how difficult it is to witness the declining health of someone who uses opioids and to feeling helpless to intervene or make any difference to that trajectory. Several nurses expressed frustration with seeing the same patients repeatedly for the same issues related to their opioid use and not being able to offer any resources or help. Partly this frustration was related to the lack of mental health and addictions resources in a small community and partly because of being unable, as an individual nurse, to offer any immediate practical assistance. It was also articulated that it was emotionally difficult to watch people get more and more unwell and eventually die: "…there's a point where they just become terminal and they are past whatever help you can give them…" [Jennifer].

Varcoe, Pauly, Storch, Newton and Makaroff (2012) interviewed 292 Canadian nurses about their experiences of situations they considered morally distressing. Participants identified a range of situations including providing care that compromised one's values; witnessing unnecessary suffering; and negative judgments about patients. In response, nurses related that they felt incompetent and tried to distance themselves from patients in order to cope. Interestingly, nurses questioned their competence in situations where patients were discharged without appropriate care or resources in place and expressed their feelings of helplessness to

change those situations. Even more interesting, they framed systemic or situational constraints, such as lack of community resources, in the context of individuals' lack of competence.

Also distressing to nurses was when they felt frustrated having to care for patients they perceived negatively, such as people who use substances who were disruptive and perceived as taking time and resources away from other patients; but also when they were witness to negative judgments made by colleagues about marginalized patients, such as people who use injection drugs; and in some cases, what was described as morally distressing was the stress arising from their own judgments about certain patients. Strategies nurses used in these situations included avoiding patients and distancing themselves from patients. These are also strategies that helping professionals use when they are experiencing compassion fatigue (Yoder, 2010).

Nurse participants frequently stated that they felt frustrated and helpless when caring for people who use opioids. Some expressed negative characterizations of people who use substances and some expressed disgust with nursing colleagues who made disparaging remarks about people who use substances. It could be argued that caring for people who use opioids may cause nurses to experience moral distress on several levels: not feeling competent in their knowledge of substance use; not having any interventions to offer that would make a difference; not being able to link patients to resources that do not exist in smaller communities; feeling badly about judging pregnant women who use substances; and caring for patients they perceived negatively.

6.7 "How Dare You?" – Caring for Women is Different

When asked about their impressions and experiences of caring for women who use opioids, several nurses agreed that women's reproductive potential conferred an additional layer of expectations on women which were not conferred on men who might be parents. They expressed concern and in some cases judgment related to possible in-utero fetal effects. Nurses spoke of trying not to be judgmental but finding it difficult not to think about what maternal opioid use might be doing to a fetus. Nurses also spoke of their "suspicions" that women who use opioids may be involved in sex work; may have sexually transmitted infections; and may be victims of past and current male violence. Again, I found here a hint that nurses might be thinking about links between violence and trauma and substance use, but mostly this was interpreted as a circumstance accompanying substance use but not directly linked epidemiologically. It would seem that some nurses are unaware of the robust evidence linking physical and sexual abuse to substance use with a statistically significant higher prevalence in women (Christensen et al., 2005; Cosden, Larson, Donahue & Nylund-Gibson, 2015; Giordano, Prosek, Stamman, Callahan, Loseu et al., 2016), I will return to this disconnect in the next chapters.

It was noted that access to comprehensive prenatal care might be challenging. One nurse remarked on the possible double standard applied to pregnant women with addictions in that some health care providers are very quick to report them to child welfare agencies but might not do the same in the case of a pregnant woman with poorly controlled diabetes. Notably, one participant who used opioids had delivered a baby while on methadone and enrolled in a

specialized program which enabled her to get comprehensive antenatal care delivered for the most part with compassion and without judgment.

This additional set of issues for reproductive aged women is consistent with the findings of Carriere (2008) who concluded from her study of young Indigenous women in a smaller British Columbia community that not only is there more stigma attached to women's substance use but also that this leads to women having less access to harm reduction and treatment services. The women in this study were also determined to be more vulnerable to abuse and coercion than men; and more at risk for sex and drug-related harm such as HIV infection. This represents a disproportionate burden of excess risks for women in the context of higher stigma leading to poorer access to services for those who arguably need it the most.

6.8 In a Small Town the Stigma Lasts Forever

Several participants who used opioids described the challenges inherent in living in a small community because the pool of health care providers is small and you become known as someone who uses or who has used illicit opioids in the past. This label becomes one's primary identifier and may stick to a person forever, even if someone is no longer using opioids. Being labelled as a person who uses illicit substances may last a very long time and this information, whether accurate or not, may get communicated informally from provider to provider and be applied to one's family members, appropriately or not (Hardill, 2011). The number and range of health care options are limited (Neale et al., 2008) and some primary care providers may screen out people with addictions from their practises (Canadian Mental Health Association, 2009).

Clay (2007) has noted that the effects of stigma may be more significant in small and rural communities because of rural sociocultural norms including an emphasis on self-reliance,

pervasive conservative values and intense religiosity which may make it more difficult for rural people to acknowledge their need for assistance with substance use, regardless of where on the continuum of harm reduction they may be. Some participants who used opioids noted that if you are known to be someone who uses illicit opioids, some health care providers assume the reason for every visit is to obtain opioids, even when this is not true. There is little anonymity as Steve noted: "…and (Forest) is so small, everybody knows everybody in the town…(but) they don't know why you're on drugs – they don't know anything about my life at all, other than the fact they might have gone to high school with me…" Having limited options for health care locally means that the impacts of stigma and judgment which may cause people to avoid or delay seeking care may be intensified as there are few health care options, as Gustafson et al. (2008) found in small urban communities in Newfoundland. As well, Wardman and Quantz (2006) noted lack of transportation as a significant barrier for rural people who use substances. When a new health care service opens, such as a walk-in clinic, some people may seek care and decide not to disclose their opioid use in order to avoid stigma and judgment. This is consistent with the findings for Jackson et al. (2010) who found that some rural people in Eastern Canada hide their drug use to avoid stigmatization.

6.9 Glimmers of Hope

Although experiences of inadequate and discriminatory health care were pervasive in the lives of the participants who use substances, some of them reported having had positive experiences with health care providers including nurses. Casey had a family physician who had a close relative with substance use issues, and Casey felt this helped her doctor be more understanding and less judgmental of her. Monks et al. (2012) found that a small number of

nurses who expressed that they enjoyed caring for people using substances disclosed personal experiences of family or friends who used drugs which apparently allowed them a way to connect with those patients.

Some of the nurse participants described enjoying caring for people who use opioids. Mabel had worked with people having substance use issues and Hepatitis C infection and described it as one of the most rewarding practices of her career. Four out of six of the unforgettable stories told by nurse participants were about the powerful emotional impact of connecting to patients who use substances. Some of the stories described rewarding, professionally satisfying encounters where nurses felt they had possibly made a difference. This is consistent with nursing literature demonstrating that nurse role satisfaction is enhanced by rewarding patient interactions and connectedness with patients (Morrison & Korol, 2014) and by psychological empowerment which includes perceived impact and meaning (Manoilovich & Laschinger, 2002; Laschinger, Nosko Wilk & Finegan, 2014; Purdy, Laschinger, Finegan & Olivera, 2010).

Some participants who used opioids thought that if nurses understood better the underlying reasons behind opioid use they would find it easier to be compassionate. Some were very excited about the potential of peer involvement in the education of nurses. Casey suggested nurses consider attending an open Narcotics Anonymous meeting, to listen to the stories of people who are addicted: "…'cause…you don't understand what people go through – it's an everyday struggle just to stay alive." Cheryl thought it would be beneficial for nurses to have the opportunity to sit down one-to-one with people who use opioids: "…if I had a chance to sit down

how me and you are, with the (nurse) taking my blood, I'm sure it would be 110 percent different…"

Participants who used opioids were remarkably generous in their optimism describing nurses' potential to learn what we need to learn and to become more compassionate towards people who use substances. Nurse participants were in agreement that substance use education was glaringly absent from basic nursing education and professional development offerings and many would welcome it. The longer some nurses worked with people who use substances, the more they began to understand the context of substance use. This leads me to believe that nurses want to create authentic caring relationships with people who use substances and many are open to learning.

6.10 Summary: Two Sides of a Divide

Many issues were identified by both groups of participants as being problematic. The explanations and conclusions of each group were quite different. Juxtaposed above, one can see how they represent a deep divide in understanding between the two groups with significant potential to impede therapeutic connection. For example, each group had divergent perspectives on the switch being flipped, with participants who used opioids identifying stigma as the drivers, and nurses being more or less unaware of the pervasiveness and effects of stigma, attributing the switch being flipped to other factors, such as the need for greater vigilance regarding occupational health and safety risks or concerns about mistrust and the possibility of not being told the truth. Both groups experienced mutual mistrust of the other, which was both real and perceived. Nurses lacked understanding of many facets of substance use, including the causes. Some nurses erroneously saw opioid use as an illogical choice patients were making. What some

nurses learned through experience was neither accurate nor helpful. Nurses sometimes distanced themselves from patients who use substances for a variety of reasons and participants who used opioids were able to recognize these behaviours as common, familiar and expected. Nurses felt helpless to intervene meaningfully as they watched patients' health deteriorate, sometimes to the point of death. Nurses experienced distress and grief as a result.

One analogous finding I found regarding such profoundly divergent views between patients and health care providers was a study conducted by Harris (2000) in the United Kingdom looking at the health care experiences of women who engage in deliberate self-harm in emergency departments. The women understood that physicians and nurses viewed their self-harm as irrational and illogical. They described being treated with impatience, frustration and hostility. The women experienced humiliation and were berated for wasting time and resources. Not surprisingly, such treatment made the women feel worse than before they went for care and resulted in them avoiding care. Harris notes that there were widely divergent views between health care professionals and patients which impeded the development of therapeutic relationships. The women were exercising control in one of the only ways they felt they could, in the social context of their oppression as women with mental health issues. Health care providers' inability to bridge the divide between the two perspectives contributed to their suffering. Harris suggests contextualizing deliberate self -harm within broader social themes of oppression in order to make seemingly irrational behaviour make sense. This approach could assist nurses to better understand the systemic and relational contexts of substance use.

Nurses did describe greater challenges caring for women of reproductive age because it was harder for them not to judge women's behaviour in the context of potential fetal harm or

harm to children. I do not think that they would have necessarily characterized this as greater stigmatization although this effect can be found in the literature (Carriere, 2008; Harling & Turner, 2011; Harvey et al., 2015). Finally, the effects of stigma and negative health care experiences of people who use illicit opioids in small towns and rural communities have significant potential impacts because stigmatizing labels last a very long time; there are usually few other health care options; and people who are stigmatized may avoid or be denied access to care.

In the next chapter I will look at some aspects of the particular social context of substance use in Canada in order to consider why this divide exists and ways in which it might be bridged so that nursing care can be improved for this group rendered vulnerable by intersecting oppressions and stigma. Further, it will be important to consider ways for nurses to improve their knowledge and efficacy to better enable their ability, as suggested by Doane and Varcoe (2005, 2015) to "nurse across the differences" that separate them from people who use substances. This will in all likelihood result in greater satisfaction and fulfillment for nurses in their caring role by enabling the creation of authentic caring relationships that will result in people who use substances in need of health care being treated with dignity and respect.

Chapter Seven: Discussion

In this chapter I will examine the key analytic points highlighted in Chapter Six using the lens of Paolo Friere's (1970) critical social theory framework to consider how ideologies have influenced and continue to influence health systems and the people who work and receive services in them. I will explore the role of health care systems in defining normalcy and deviance. I will then describe the rise of neoliberalism and its impacts on the global drug trade, on health care systems, on nursing, and on individuals. I will place Canadian drug policy in the context of the pervasive influences of the global War on Drugs and in particular the ways in which this has created a context which exacerbates the stigmatization of people who use drugs and which is hostile to the introduction of harm reduction policies and strategies in Canada.

Following the delineation of each of these contextual influences, I will place into these larger sociopolitical contexts the key findings of this study - in particular, stigmatization; reciprocal mistrust between nurses and people who use substances; the ways nurses used experience and self-learning to cope with the lack of education on substance use; the ways nurses invoked a false notion of normalcy to "other" people who use substances; the experiences of moral distress nurses described when they felt helpless to intervene meaningfully; and the divide in understanding which separates nurses and people who use substances. I will show how the powerful sociopolitical and economic global forces of neoliberalism profoundly affect nursing relationships at the micro-level.

7.1 The View through Friere's Critical Social Theory Lens

A fundamental concern of nursing is compassionate, whole-person care of human beings. Thorne's interpretive description requires nurse researchers to place research interpretations back

into the context of nursing practice which is characterized by complex sociopolitical and ideological influences in order to change the perspective through which the phenomena are generally viewed (Thorne, 2008). I used the epistemological lens of Friere's (1970) critical social theory framework to learn how the health care experiences of people who use illicit opioids in small towns and rural communities were influenced by sociopolitical, economic, cultural and ideological contexts which shape what is perceived to be real. Further, using the epistemology of critical hermeneutics, I sought to explore how interpretation of meaning (knowledge) might be influenced by dominant beliefs and ideologies which might render inaudible the voices of marginalized people – in this case, people who use illicit opioids who are marginalized in multiple, intersecting ways (Lopez & Willis, 2004).

Friere's framework posits that it is in the wisdom of oppressed groups that one will find the most appropriate strategies to improve the conditions of their lives. The information I have gleaned through the process of learning from people who use opioids in small communities has been illuminating and instructional. They outlined for me the particular challenges of being labelled and stigmatized as people who use substances in smaller communities where choices are limited and health care access can be difficult. They also made the point that in small communities stigmatizing labels may last forever. At the same time they had interesting ideas for improving their care including drug user-led education to help nurses understand substance use more accurately. Some thought this education should be based on real life examples from people who use drugs to increase nurses' empathy and one woman suggested nurses could attend an open Narcotics Anonymous meeting where people who use substances stand up and tell their stories to the group (open meetings allow anyone to attend, not only people who use drugs and alcohol). Another interesting idea was to create a staff position in areas such as hospital

emergency rooms whose role would be to help people who use substances feel more comfortable while they wait and advocate for their needs. This is similar to a role suggested by Wen and Hwang (2016) in the context of health care settings serving homeless and other marginalized people. They suggest a "Marginalized Patient Advocate" whose role would be to advocate for the needs of such patients, replicating the role played by family or friends for other patients. Participants who used opioids also made thoughtful suggestions which interpreted health more broadly such as highlighting the need for harm reduction housing.

Numerous nursing scholars have advocated using critical social theory in nursing research in order to consider the broader socioeconomic and political influences which affect the health of oppressed groups (Carnegie & Kiger, 2009; Crowe, 2005; Lopez & Willis, 2004; Parlour & McCormack, 2012; Stevens, 1989). Relevant to this research project is Friere's central argument that oppression and its resultant dehumanization must be identified and transformed. Using Friere's (1970) framework, I will now turn to a broader, contextual analysis which searches for the effects of dominant ideological and sociopolitical structures which may influence the health care experiences of people who use illicit opioids in small and rural communities in Ontario, Canada.

7.2 Health Care Systems as Agents of Social Control

It is important to situate health care systems within the complex ideological and sociopolitical systems in which they operate. Rather than viewing them as benign purveyors of health and wellness within which all people apparently have similar health-promoting experiences, a broad socio-political analysis enables us to see how those complex influences create inequitable access and outcomes for non-dominant groups of people. Volinn (1983)

describes the historical shift in social control from religious institutions to law enforcement organizations to medicine as one in which "badness has become sickness" through the "medicalization of deviance" (p. 386). Using the examples of leprosy and alcoholism, Volinn notes that illness is socially constructed by the people who take care of the ill, and thus health professionals become "stigmatizers and destigmatizers" of diseases (p. 385). Stereotypes are developed by health care professionals, often physicians, who are characterized as having unique skills and scientific knowledge that allows them to dominate interactions with patients and shape concepts of illness. Cooper's (2004) historical analysis of medical theories of opioid addiction in the late nineteenth and mid-twentieth century in the United States found that health professionals typically attributed opioid addiction to individual pathology among poor, working class and non-white people; and to external factors among affluent, white people. Cooper places these characterizations within eras experiencing sociopolitical turmoil which threatened the established (white, capitalist) order. Again, physicians 'diagnosed' the underlying cause of opioid addiction among poor people of colour as related to "innate degeneracy and vice" while attributing its cause among white, affluent people to either painful illness or the "stresses of living in modern society" (Cooper, p. 442).

Aggarwal et al. (2012) argue that North American drug policy and medical definitions of substance "abuse" have been politically motivated to allow governments to control ownership of psychoactive substances. Use of those substances without state sanction may lead to legal sanctions which may lead to a diagnosis of "substance abuse" by health professionals whose collective thinking has "acquiesced to what could be called 'drug war diagnostics'" (Aggarwal et al., p. 7). Applying the medical word "narcotic" to the legal descriptions of a wide range of diverse psychoactive plant materials, even those that do not have narcotic properties, such as

cocaine or cannabis, "gives the illusion of a scientific basis to legal policy and...acts as a legitimation and a defense of government intervention…[so] we see the power of the language…to construct a reality" (p. 13). This causes us to see certain substances as dangerous because the so-called scientific evidence "proves" it. Dodd and McClelland (2016) describe the efforts of Canadian and international political movements of people who use drugs to critique the conceptualization of drug use as "addiction" noting that this term has been used to "pathologize, medicalize and criminalize" people who use substances resulting in a false understanding of all drug use as problematic and in need of corrective expertise through recovery programs, criminal courts, criminal sanctions and medical rehabilitation (Dodd & McClelland, p. 4).

7.3 Health Care Systems as Agents of Social Control: Contextualizing Study Findings

Volinn (1983) describes health professionals as potential stigmatizers who may develop stereotypes that shape concepts of illness. One of the most prominent findings of the study was that of the significant burden of stigmatization experienced by participants who used opioids. They were stigmatized by nurses for using illicit (illegal) psychoactive substances, for injecting substances, for being on methadone, for having Hepatitis C or HIV, for being at risk for those infections, for being tested for those infections and for earning income in non-traditional ways, such as sex work. They powerfully described an abrupt attitudinal change by nurses after disclosure or discovery of their drug use – the switch that gets flipped – and I would argue that stigma is the primary trigger. Participants who used opioids described being looked at by nurses with disgust and being made to feel very uncomfortable and not wanting to stay in the health care setting. They described feeling discrimination, judgment, admonishment and blame for their

health issues and their drug use. They reported that the labels that stigmatized them could never be shaken in a small town.

Nurse participants did not necessarily agree there was a switch at all, although some did. Some nurses disputed the existence of the switch by suggesting that all patients received the same treatment regardless of their drug use status, which led me to speculate that perhaps these nurses were referring to the provision of equivalent interventions while remaining unaware of differences in attitude towards people who use opioids. Those nurses who agreed there was a switch did not have the same interpretation of why the switch gets flipped, tending to attribute it to the need to be more vigilant about protecting oneself from blood-borne infections, for example, than to stigma. Although this vigilance is a reasonable consideration from an occupational safety standpoint, it is also inconsistent with the principles of infection control routine precautions which recommend that health care providers assume all patients are infectious whether we think they are at risk or not. Could this possibly hint at a subconscious characterization of people who use substances as particularly unclean and perhaps dangerous?

Some nurse participants had witnessed stigmatizing behaviour from other nurses and even themselves when they had less experience. Overall, though, nurse participants did not see their behaviours or approaches to patients who use substances as being rooted in stigma. When asked about their experiences providing care to women, some nurses agreed that women's reproductive potential conferred an additional layer of expectations on women which were not conferred on men who might be parents. They expressed concern and in some cases judgment related to possible in-utero fetal effects of maternal substance use which is consistent with the literature suggesting that women who use substances are more likely to experience more barriers

to care and more stigma (Carriere, 2008; Mehrabadi et al., 2008) than men who use substances. However nurse participants did not interpret these differences as being based in stigma.

Consistent with the view through this lens is the finding that for many nurse participants substance use was not considered a "normal" activity engaged in by "normal" people. Some nurses expressed stereotypical assumptions about patients who used substances such as the belief that women must be engaged in sex work and likely had untreated sexually transmitted infections. Nurses expressed surprise when people they considered "normal" and middle class were found to use substances, suggesting that some nurses replicated social constructions of the visibly-identifiable person who uses drugs as deviant. Canales (2010) noted that othering sometimes leads to members of non-dominant groups being judged against a "mythical norm" (p. 26). Nurses tended to "other" people who use substances as different from themselves, sometimes through the use of language such as "these people." Recall Reimer Kirkham's (2003) exploration of how the construction of the "Other" within health care contexts serves to reproduce sociopolitical forces of the broader society in which they exist. These experiences of stigmatizing and othering by nurses which made people who use opioids feel distinctly inferior or "less than" suggest that these dynamics not only reproduce societal norms but also negatively influence the health care experiences of people who use opioids.

Finally, some nurse participants stated that considering addiction as a disease helped them to be able to care better for people who use substances. Mabel described her "softened" approach to patients once she considered their substance use a disease "like any other." Recall the disconnect noted by Pauly et al. (2015) who found that while some nurses in Vancouver, Canada characterized addiction as a disease process that takes over control of patients' lives,

some of the people who use drugs interviewed in this study disagreed and took exception to the idea that they were helpless victims of their substance use. The lack of contextual understanding of the role of substance use in the lives of people having experienced trauma leads to some nurses medicalizing substance use using a fairly narrow biomedical lens which ultimately excludes from view the pain, grief and loss experienced by so many people who use substances. This simplistic decontextualized view precludes meaningful understanding by nurses and impedes the development of authentic caring relationships as has been argued by others (Daniel, 1998; Gastmans, 2013; Wright & Schroeder, 2016).

7.4 The Rise of Neoliberalism

The 1970s marked the beginning of the rise of global neoliberal economic policies as successive Western countries elected conservative governments (Ronald Reagan in the USA, Margaret Thatcher in the UK and Helmut Kohl in Germany, for example). Coinciding with the burgeoning world debt crisis the International Monetary Fund (IMF) and the World Bank gave loans to heavily indebted countries on the condition that they privatise state assets, liberalize taxation to benefit foreign investment and loosen tariff restrictions to rapidly facilitate globalization of trade. Central to these policy changes were reductions in social spending by governments which led to global increases in poverty and inequality. Deregulation of financial markets led to the 2008 financial crisis which has justified the promotion of ongoing austerity measures to reduce public debt and boost economic recoveries (Labonte & Stuckler, 2016). As I will now argue, the effects of neoliberalism are pervasive and continue to influence the global drug trade, health care systems and health services, nursing, and individuals who use illicit substances.

7.5 Neoliberalism and the Global War on Drugs

It is no coincidence that the rise of neoliberalism was accompanied by the dawn of the War on Drugs, a term infamously coined by former American President Richard Nixon in the 1970s. Increased emphasis on deterrence during the rise of what Corva (2008) calls the "penal state" required a neoliberal risk management approach including an intensification of state power to incarcerate – heralding, for example, reinstatement of mandatory minimum sentences for drug-related offenses in America (p. 178). Corva places this in the context of deindustrialization as part of the transition to global capitalism and the apparent need to incarcerate "racialized, classed and gendered" individuals – that is, those seen as threats to the social order (Corva, p. 181). Although sometimes thought of as a primarily American policy, the War on Drugs is unmistakeably global. As the Global Commission on Drugs (which includes in its membership former Canadian High Commissioner for Human Rights, Louise Arbour) concludes, the War on Drugs has been a failure with devastating consequences for individuals and societies world-wide including fueling of the HIV/AIDS and Hepatitis C epidemics and contributing to punitive, marginalizing, and stigmatizing treatment of people who use drugs (Global Commission on Drugs, 2011; 2012; 2013).

In the Canadian context, Gordon (2006) characterizes the War on Drugs as an important feature of Canadian neoliberal policies. He places it in the historical context of a state policy of drug criminalization and racialized class relations in Canadian capitalist society with antecedents dating back to railroad building in the late 19th century. Gordon argues that drug prohibition was less about specific drugs and more about the communities that sold and used them. For example, opium was first criminalized in 1908 in direct response to Chinese immigration which provided a

source of extremely low cost labour considered "pivotal to the growth of industrial capitalism" in Canada (Gordon, p. 63). Chinese immigrants' use of opium was seen as a threat to this labour pool. Later similar approaches were applied to the legal status of cocaine and cannabis which were associated with racialized Caribbean immigrants. Gordon points out that the link between substance use and the labour force continues to exist in Canada as the state continues to monitor and publicly announce annual lost productivity due to drug use.

Adherence to the War on Drugs philosophy has posed some challenges to the political and social acceptance of harm reduction in Canada. As pointed out in the Canadian Medical Association Journal by Elliot, Csete, Palepu and Kerr (2005): "The prevailing emphasis on law enforcement in drug policy has failed to produce its purported benefits, yet many countries insist on enforcing prohibition and resist the implementation of evidence-based measures to reduce the health-related harms of drug use" (p. 655). Former Canadian Prime Minister Stephen Harper's government launched a National Anti-Drug Strategy in 2007 and infamously fought all the way to the Supreme Court of Canada to have a British Columbia supervised injection harm reduction service permanently closed. All nine Supreme Court judges ruled that to do so would contravene the Canadian Charter of Rights and Freedoms by threatening the lives of people who use injection drugs (Small, 2012).

One of the most serious consequences of the decades-long War on Drugs has been the stigmatization of people who use substances. Phelan, Link and Dovidio (2008) concluded that stigma and prejudice perform three functions: exploitation and domination (for example, racial prejudice that allowed support for the practice of slavery); norm enforcement (such as criminal behaviour or substance use norms that identify the boundaries of acceptable behaviour and

consequences of non-conformity); and disease avoidance (such as mental illness or HIV/AIDS). Hatzenbuehler, Phelan and Link (2013) argue that the role of stigma is so important to the stigmatizers that as one method becomes outmoded, another will take its place. For example, people having mental illness were once housed in asylums in order to segregate them. Deinstitutionalization then resulted in the "construction of psychiatric ghettos" comprised of dense clusters of boarding homes and rooming houses which offered a degree of physical separation. Friedman et al. (2001) argue that politicized attacks against people who use drugs as scapegoats intensify in periods of economic and social unrest in order to quell potential opposition and also to gain support from middle class people.

7.6 Neoliberalism and the Global War on Drugs: Contextualizing Study Findings

Clearly the War on Drugs has been profoundly successful in stigmatizing people who use drugs. These pervasive effects were hugely apparent in the small town setting of this study. Stigma was a prominent finding in the study and highly consistent with many other Canadian and international sources including Gustafson et al., (2008); Harvey et al. (2015); Jackson et al. (2010); Lang et al. (2013); McCutcheon and Morrison (2014); McLaughlin et al. (2000); Pauly (2008b); and Pauly et al. (2015). Some participants who used opioids remarked on their expectation of discrimination in health care settings. Others reported waiting longer for care, receiving less information from nurses and admonished and blamed for bringing on their own health issues. The desire to avoid negative health care experiences was given as the reason they sometimes avoided seeking care and/or hid their substance use.

It can be argued that Canadian policies which criminalize the use of many psychoactive substances create a climate within which substance use is considered a deviation from social

norms. People who use psychoactive substances frequently have criminal records which further entrenches their characterization as deviant and contributes to stigma as well as creating practical limitations on factors such as movement between legal jurisdictions and on employability, for example. Incarceration further marginalizes people and in the case of those with significant histories of trauma serves to destabilize their lives and interrupt any meaningful consistent health care relationships and ability to receive health care. I have seen and continue to see these effects on a consistent basis in my primary care practice.

Further, these legal policies and discriminatory enforcement practices uphold the status quo and the hegemony of dominant groups by targeting low income people, Indigenous people and other people of colour and have been tied directly to Canada's embrace of the War on Drugs (Lawrence & Williams, 2006). As one example of discriminatory enforcement practices we see that while Indigenous people made up only 4.3% of the Canadian population in 2011, Indigenous women comprise 63% of all the women incarcerated in Canada (Canadian Association of Elizabeth Fry Societies, 2015). Of note, four of ten participants who used opioids in this study were Indigenous people. As the sampling strategy was purposive and not randomized, this fact ought not to be over-interpreted. However, given what is known about the devastating effects of colonization, inter-generational trauma and systemic racism, particularly in Canadian health care systems, the need for culturally safe, trauma-informed approaches to health in general and to substance use in particular is crucial (Allan & Smylie, 2015; Klinic Community Health Centre, 2013).

Finally, the ongoing legacy of the War on Drugs in Canada includes a sociopolitical climate which is hostile to harm reduction (Carter, 2013). Although major urban centres in Ontario have some harm reduction programming there is little available in small towns and rural

communities. This has serious health consequences for people who use drugs because they may not have access to supplies, equipment and education to help them reduce the risks of using drugs. I would argue it also has consequences for nurses because of their feelings of frustration and helplessness at not having any practical assistance to offer people who use substances. This helplessness was accompanied by what I think was suppressed grief and loss when nurses spoke of witnessing the declining health of people who use substances in their care. As Pauly (2008b) argues, harm reduction may provide a range of practical interventions for nurses who struggle when they experience frustration when they feel unable to "fix" patients who use substances. If there were widespread funding and uptake of harm reduction services and education across the province of Ontario including in small and rural communities, these strategies might well become normalized. This would provide front line nurses with a practical form of assistance to their patients that not only provides needed supplies but also creates a profound dynamic of care which conveys to a person so familiar with stigma, judgment and discrimination that she is worthwhile, that she matters, that her health matters, and that you as her nurse are also her ally.

7.7 The Impact of Neoliberalism on Health

The health care consequences of neoliberal policies have been far-reaching and include rising poverty rates, increased homelessness, increased consumption of "obesogenic" food as food costs rise, and rising unemployment (Labonte & Stuckler, 2016, p. 314). Ongoing austerity-driven budgets in Canada have led to increasing inequity in the distribution of the social determinants of health (Ruckert & Labonte, 2016). As poverty increases so does morbidity and mortality as we have seen in the Canadian context (Bierman et al., 2009; Conway et al., 2008; Fryers et al., 2003; Lightman et al., 2008; Shack et al., 2008; Smith et al., 2007; Statistics Canada, 2014). Canadian Doctors for Medicare (2016) warn of the dangers of neoliberal

globalization agreements and argues that the Tran-Pacific Partnership (TPP) has the potential to negatively impact Canadian health care through pharmaceutical patent strengthening (which will mean reduced access to and affordability of medications) and further weakening of state regulatory powers. Austerity-driven reductions in health care spending by the provincial government of Ontario, Canada have resulted in lower Registered Nurse to patient ratios; fewer hospital beds; cancelled surgeries; early patient discharges; the highest hospital readmission rates in Canada, ambulance delays and understaffing (Ontario Health Coalition, 2016).

7.8 The Impact of Neoliberalism on Nursing

Neoliberal, austerity-driven economic policies have contributed to a reduction not only in health care services generally but specifically in nursing positions through cutbacks in provincial health care spending. These cuts are often achieved by laying off nursing staff and limiting the creation of full time permanent employment. The Registered Nurses' Association of Ontario (RNAO) (2016-b) reported that during the 1990s in Ontario nursing employment fell drastically through lay-offs. It warned that nurse-patient ratios have been eroded significantly as Ontario's population ages and needs more nursing care – a finding which it attributes directly to austerity-driven "spending restraints announced in October 2008 as part of the government's attempt to deal with a recession-driven deficit" (p. 22). Owing in part to provincial government targets to increase RN positions, the province saw some growth in nursing employment between 2012 and 2015 although many of these positions were in part time jobs. RNAO argues that the rising incidence of nurses having multiple employers potentially provides evidence that many nurses are "cobbling together" part time and casual jobs to make up the equivalent of full time work (p. 3). Further, RNAO (2016-a) argues that declining Registered Nurse positions is accompanied by

the rise of team-based organizational models of nursing care delivery which fell out of favour in the 1970s because of their ineffectiveness but which hospitals argue they are forced to resurrect due to budget constraints.

There is evidence that reduced nursing staffing and higher workload volumes are stressful and difficult for nurses. Varcoe, Pauly, Storch, Newton and Makaroff (2012) interviewed 292 Canadian nurses about their experiences of situations they considered morally distressing. Participants identified a range of situations including providing care that compromised one's values; witnessing unnecessary suffering; and negative judgments about patients. In response, nurses related that they sometimes tried to distance themselves from patients in order to cope. Interestingly, nurses questioned their competence in situations where patients were discharged without appropriate care or resources in place and expressed their feelings of helplessness to change those situations. Even more interesting, they framed systemic or situational constraints, such as lack of community resources, in the context of their own lack of competence – a finding which mirrors what some nurse participants expressed in this study. Varcoe et al. (2012) identify that this type of moral distress occurring in the context of health care cutbacks, higher workload volumes, less staffing and nurses' relative power positions in health system hierarches led to some nurses attempting to rectify situations for individual patients but these were usually isolated and not related to identifying systemic patterns of problems affecting many patients.

7.9 Neoliberalism – Blaming Individuals for Their Problems: Contextualizing Study Findings

An important feature of liberal and thus neoliberal ideology is the notion that individuals freely make choices in their lives. It assumes an egalitarian "level playing field" environment

where everyone has equal opportunities. There has been a rise in preventative medicine and health promotion campaigns endorsing "healthy lifestyles" wherein people are encouraged to quit smoking, reduce saturated fat intake, exercise more and follow guidelines for low risk alcohol consumption. Health care "consumers" can choose health although as Moore and Fraser (2006) point out, there is no acknowledgement that choice may be constrained nor is there a discourse that questions the epidemiologic validity of the idea that healthy choices even matter, in the context of inequitable access to the social determinants of health. Importantly, using the example of people who inject illicit substances, Moore and Fraser (2006) note that people marked by stigma may be seen to behave in irrational (non-health promoting) ways by continuing to make 'unhealthy choices.' Health promotion becomes a means of "self-regulation and self-care that is central to the government of conduct in neoliberal societies" (Moore & Fraser, 2006, p. 3037).

In a health care system influenced by neoliberal beliefs, if a person is constrained by social or economic structures such as high unemployment or low wages, the goal of health care professionals is to support how people cope with those constraints or assist them to make healthier choices (Reimer Kirkham & Browne, 2006). For example, discourse analysis of public health messaging related to childhood obesity in Canada and Australia found neoliberal values underlying much of the content, particularly around attribution of parental/guardian responsibility for their children's bodies which failed to consider the inequitable distribution of resources which support physical activity such as time and money (Alexander & Coveney, 2013). An important consequence of individualization of blame for health problems is that the focus of attention and interventions are all aimed at individuals and not the dominant power structures that create those problems in the first place. For example, a homeless woman who has

a venous stasis ulcer that will not heal may be advised to keep her leg elevated as much as possible, which if she had a home might be a realistic intervention. Someone who attends an emergency department with an abscess caused by injection drug use may be characterized as a person who has caused her own health issue because of a poor choice she made, rather than be seen as a courageous survivor of horrific and recurrent male violence perpetrated against her as a child who is coping the best she can.

People who use opioids are making unhealthy choices. Consistent with the neoliberal belief that individuals are responsible for the choices they make, some nurses held the view that substance use was a "choice" which could be made or not made. Sue, for example, thought that if patients who had overdosed and nearly died could see how close to death they had been, this knowledge would help them make the (presumably more rational) choice to stop using. Sue also recognized that while she felt empathy for the difficult situation people who use opioids are in, she also struggled with being unable to understand why they would continue: "I think there's a lot of empathy, but also you're like, man, there's help out there, what are you doing?" This lack of understanding was common among nurse participants. Pauly et al. (2015) found similar results and argue that viewing illicit drug use as an individual shortcoming is a common belief arising out of dominant neoliberal perspectives on substance use in Canada and North America. Further it is underpinned by the belief that people who use drugs do not deserve care because they have chosen to continue to engage in so-called irresponsible behaviour.

Nurses do not understand why people use opioids. Also consistent with the decontextualized neoliberal view that people freely choose to use opioids is the corollary finding identified by participants who used opioids that nurses lacked knowledge of the underlying

reasons for substance use. People who use opioids observed that nurses frequently had no idea why they had started using opioids and why they used every day. Some nurses remarked that patients who use opioids sometimes had remote and recent experiences of assault and violence but they stopped short of articulating a direct cause and effect link between a history of trauma and substance use, despite the robust body of evidence which exists (Anda et al., 2006; Christenson et al., 2005; Cosden et al., 2015; Dube et al., 2001; Dube et al., 2002; Dube et al., 2003; Dube et al., 2006; Giordano et al., 2016; Remigio-Baker et al, 2014; Sandford et al., 2014; Strine et.al., 2011; Wu et al., 2010).

People who use opioids are to blame for their problems. The next logical conclusion reinforced by neoliberal thought is that if people make unhealthy choices which are interpreted in a manner which completely excises them from any personal or historical context of trauma, racism, colonization, male violence, pervasive sexism and structural poverty and inequity, then they are to blame for their problems and they deserve what consequences they experience. Nurse participants identified that caring for people who use illicit opioids was challenging for a variety of reasons including: frustration at repeat visits to an emergency department for the same issues over and over; for being seen to bring on their own health issues as a result of their drug use; for being assumed to be narcotic-seeking; and for taking time and attention away from other patients (implying that they were less deserving of care). Pauly et al. (2007) observed that nurses sometimes characterized people who use substances as undeserving of care and this compromised nurse-patient relationships. As we have seen, several other authors suggest that nurses may be influenced by socialization processes which cause them to perpetuate stigmatization and marginalization of people who use substances, rendering them undeserving of care (Ford, 2010; Harling & Turner, 2011; Lang et al., 2013; Morgan, 2014). I would argue that

these macro-level processes are steeped in pervasive neoliberal influences which are acted out in individual nurse-patient interactions at the micro-level.

Nurses feel helpless to meaningfully intervene. Several nurse participants remarked on the difficulty of witnessing the declining health of someone who uses opioids and to feeling helpless to intervene or make any difference to that trajectory. In part nurses expressed frustration at the lack of mental health and addictions resources in a small community and in part they were frustrated at being unable to offer any practical assistance that might change the outcome. Varcoe et al. (2012) suggested that nurses may experience moral distress in situations such as these including witnessing unnecessary suffering, the lack of appropriate resources for patients and feeling helpless to intervene. One of the most interesting findings in this study is the fact that nurses interpreted structural constraints, such as lack of community resources, in the context of their own lack of competence. This would seem to me to be additionally influenced by neoliberalism which influences nursing practice in myriad ways: health system service cuts; reduction in nursing staff; higher workloads; more overtime; less time to provide care to each patient; less time to learn about community resources. Further, a harm reduction-hostile political environment means that nurses working directly with people who use substances often have little practical assistance or education to provide.

Varcoe et al. (2012) also found that nurses experienced distress when they felt frustrated having to care for patients they perceived negatively and when they heard negative judgments made by colleagues about marginalized patients. In some cases what was described as morally distressing was the stress arising from their own judgments about certain patients. Strategies nurses used in these situations included avoiding patients and/or distancing themselves from

patients. These are also strategies that helping professionals use when they are experiencing compassion fatigue (Yoder, 2010). Study nurse participants often stated that they felt frustrated and helpless when caring for people who use opioids. While some of the nurses interviewed expressed negative characterizations of people who use substances, others expressed disgust with nursing colleagues who made disparaging remarks about people who use substances. It could be argued that caring for people who use opioids may cause nurses to experience moral distress on several levels: caring for patients they perceive negatively; not feeling competent in their substance use knowledge; lacking interventions to offer that they believe would make a difference; and being unable to link patients to resources that do not exist in smaller communities.

It is a characteristic of neoliberal influences on health care systems that employees are expected to do the same amount of work with fewer resources. When they fail to do so, they may be blamed for inefficiency. We hear about organizations 'right-sizing' and 'trimming excess fat' which often incorrectly implies that they have not been efficient rather than not correctly staffed. This is a neoliberal strategy designed to conceal service cuts. Several nurse scholars importantly point out that it is not fair to expect nurses working in structurally constrained settings to provide adequate care without optimal role support (Ford, 2011; Ford, Bammer & Becker, 2008; Monks et al., 2012). There is a very real risk of blaming nurses for inadequacies in care which are created by neoliberal funding cuts to health care services. This is not dissimilar to the way that some nurses blame patients who use opioids for causing their own health problems. This is the legacy of neoliberalism.

7.10 Two Sides of a Divide Required by Neoliberalism

As we have seen, many issues were identified by both groups of participants as being problematic and each had divergent views of those issues. People who use opioids may not trust that they will not be stigmatized for disclosing their opioid use and therefore may withhold this information. Nurses *suspect* that they cannot trust patients and if, for example, they discover opioid use through a urine toxicity screen, feel they are justified in their mistrust. Each group had divergent perspectives on the switch being flipped or even the belief that the switch existed. Nurses had significant knowledge gaps in the area of substance use, including the causes. Some nurses characterized opioid use as an illogical choice patients were making. What some nurses learned through experience was neither accurate nor helpful. Nurses felt helpless to intervene meaningfully and experienced distress and grief as they watched patients' health deteriorate along trajectories some saw as inevitable

Hearkening back to Friere (1970) who reminds us that "…the oppressor minority…cannot permit itself the luxury of tolerating the unification of the people" (p. 141), we can see through this critical social theory lens that neoliberalism does not merely create divisions between people, it requires them. They are intentional – reinforced by pervasive misinformation messaging about the deviance, irrationality, dangerousness and difference of others. Health care systems provide a microcosm for the replication of social relations of power (Neale et al., 2008) which represents one of countless bricks in the neoliberal foundation. Thus the analytic finding of the experience of the divide between nurses and people who use opioids begins to make sense when we understand this context.

7.11 Discussion in Summary

Looking through Friere's critical social theory lens allows us to see the myriad ways neoliberal beliefs and policies influence health, health care systems, nurses and patients. These influences occur at the macro-level and are then acted out in individual nurse-patient interactions at the micro-level. In order to see completely, one needs a broadly-encompassing view such as one would get using a wide angle lens. To understand what happens at a micro-level, one needs to closer view, such as one would get using a zoom lens. Figures 4 and 5 provide conceptual diagrams of both macro- and micro-level neoliberal influences on the nursing care of people who use illicit opiates in small and rural communities. Figure 4 represents the widest angle lens, describing structural constraints from the global level to the small community level.

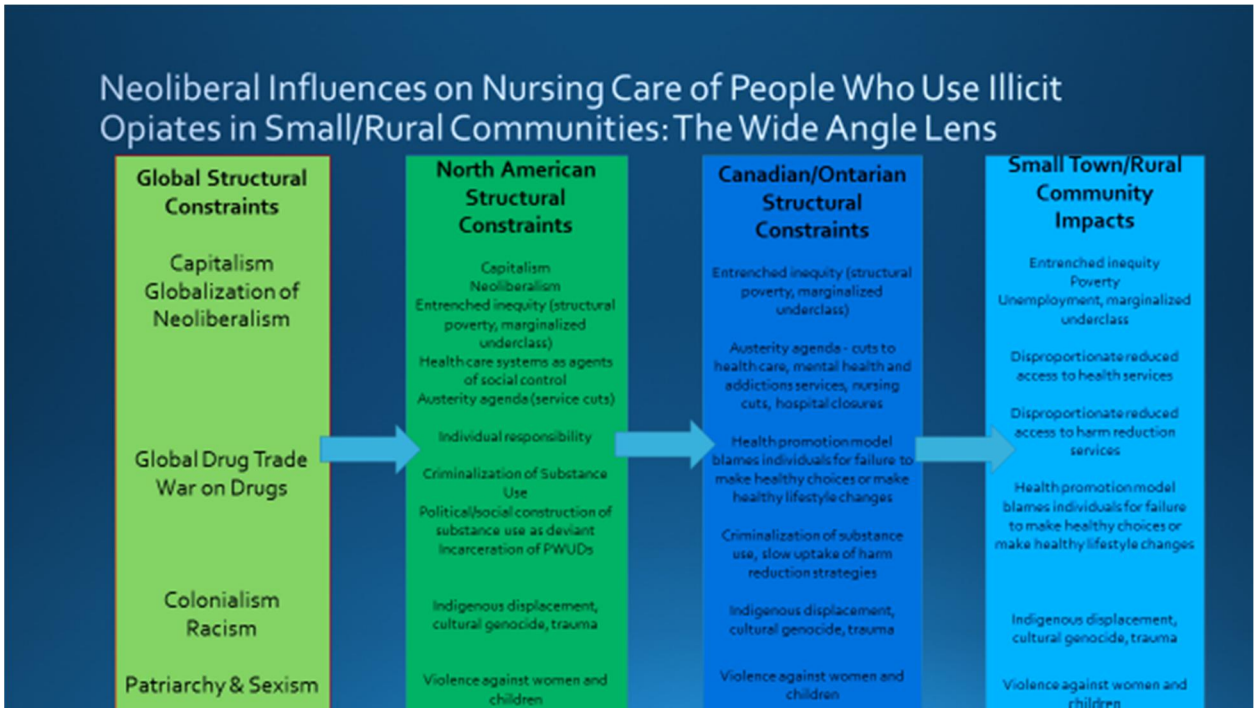

Figure 4. Neoliberal Influences on Nursing Care of People Who Use Illicit Opiates in Small/Rural Communities: The Wide Angle Lens

Figure 5 zooms in to the effects on nurses and people who use substances in those small communities.

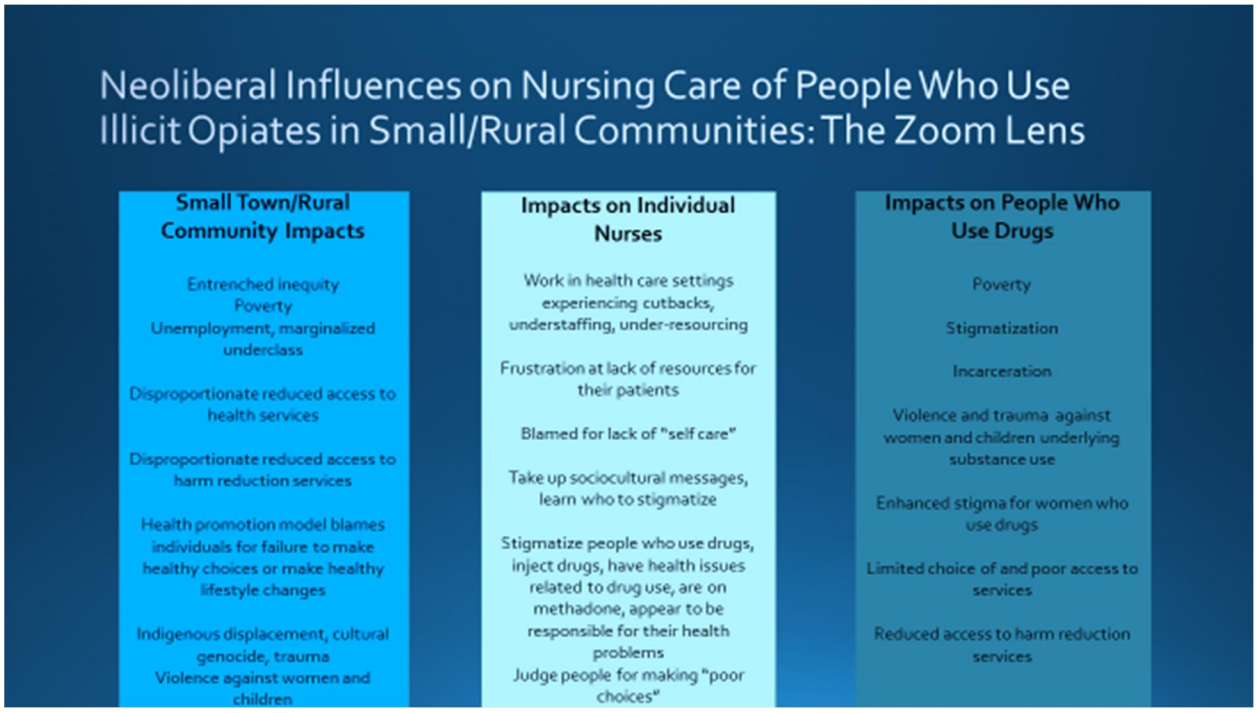

Figure 5. Neoliberal Influences on Nursing Care of People Who Use Illicit Opiates in Small/Rural Communities: The Zoom Lens

I return now to the questions I considered throughout the development, conduct and analysis of this study:

- Might neoliberal beliefs focusing responsibility exclusively on individuals for their substance use be replicated in health care settings, and if so, might this focus actually obscure underlying health concerns which then remain untreated?
- Might mainstream ideological beliefs about drug use among nurses in some way encourage or condone discriminatory treatment by nurses?

- Might adherence to the so-called "war on drugs" ideology be reflected in the manner in which some nurses treat people who use drugs?
- Does the illegality of many substances contribute to the harm related to substance use?
- What types of power dynamics are embedded in health care systems in general, and in small community and rural health care systems in particular?
- What roles do nurses play in their entrenchment?

While the purpose of the study was not to explicitly answer these questions, revisiting them at this point may help us understand how seemingly unconnected dots are interdependent. There is a compelling argument to be made that the lens of critical social theory allows us to see that the intersectional effects of pro-capitalist, pro-globalization neoliberal political and economic policies create numerous problematic issues affecting people who use substances, health care systems, and the people who work in those systems. There is some historical evidence that health care professionals, mostly physicians (as representatives of the upper class; white race dominance and male privilege), have been complicit in creating pathology and stigma where it once did not exist. Neoliberalism creates and requires the existence of a wide range of stigmatized "others," including low income people who use substances – who are widely perceived as morally suspect, untrustworthy, potentially infectious criminals who may engage in reprehensible activities to make money to enable themselves to continue to make terrible choices. Even the most caring of nurses, as members of society, take up and internalize these messages. Nurses also work in systems affected by neoliberal policies which make that work challenging and difficult and constrained by powerful structural forces of which they may be

unaware. In Chapter Eight, I will turn to the implications and recommendations for nurses to mitigate the effects of such forces.

Chapter Eight: Implications and Recommendations

8.1 Resisting the Impacts of Neoliberalism Using Contextual Responses

It can be argued that the pro-capitalist forces of neoliberalism require that human beings be divided into disparate groups that keep us separate from one another in intentional and pervasive ways – rich from poor; middle class from poor; People of Colour from White people; Indigenous people from settlers; newcomers from settlers; people with mental illness and HIV and Hepatitis C and other stigmatized conditions from others; criminalized from those who are not; people who use illicit substances from those who do not. Friere (1970) says, "…the oppressor minority…cannot permit itself the luxury of tolerating the unification of the people" (p. 141). The suggestion by Neale et al. (2008) that interactions between health care providers and patients replicate social relations of power, giving health care providers the power to marginalize or exclude clients they deem 'difficult' or 'disruptive' and to facilitate access to those they deem 'normal' or 'deserving' or 'compliant' is instructive when exploring the health care experiences of people who use opioids in small communities. The divide between people who use illicit opioids and the nurses who care for them is caused by powerful structural dynamics. While working to dismantle oppressive structures is an important pursuit, and one which is appropriate for nurses to engage in, for the purposes of the next section I will focus on the ways in which nurses can begin to bridge the divide in nursing practice, education, research and policy by using a range of contextualizing strategies.

8.2 Implications and Recommendations for Contextualized Nursing Practice

As Thorne (2008) reminds us, interpretive description requires that research interpretations be brought into the context of nursing practice, characterized as it is by complex

sociopolitical and ideological influences, in order that we might alter the perspective through which the phenomena are generally viewed. This perspective-altering is necessary given what this study has revealed about the impact of negative health care experiences on the health of people who use illicit opioids in small communities, particularly given possible limited access to health services in many small and rural communities in Ontario. Additionally, we have seen that nurses also experience negative experiences providing care to people who use illicit opioids and that this can contribute to moral distress, compassion fatigue and burnout.

Contextualized nursing practice supports seeing each patient through a social determinants of health lens which considers where they have come from and where they are returning after leaving the health care setting. It is patient-centred and pragmatic. It creates a climate of acceptance and compassion which supports honest disclosure by patients. Further, contextualized practice settings support nurses to engage meaningfully with their patients in ways which are trauma-informed, culturally safe, based on relational inquiry to enable nursing across difference and which understand the value of a harm reduction philosophical approach. What follows are recommendations for nurses and managers of nurses to improve the care of people who use substances.

Embrace the concept of trauma-informed nursing. Nurse participants did not have a solid understanding of the epidemiologic relationship between trauma and substance use. Numerous studies, enumerated in detail in Chapter Six, have documented the astonishing prevalence of trauma among people who use substances. The Adverse Childhood Experiences Study provides robust and compelling longitudinal evidence for the epidemiological relationship between substance use and trauma. Many have called for the integration of trauma approaches

and trauma-based interventions with people who use substances (such as Christensen et al., 2005; Giordano et al., 2016). Improved understanding and care can result from trauma-informed practice, policies and procedures, which are based on the core principles of acknowledgement of the pervasive nature of trauma; safety; trust; choice and control; compassion (including self-compassion); collaboration; and a strengths-based approach (Canadian Centre on Substance Abuse, 2014; Klinic Community Health Centre, 2013). Importantly, being trauma-informed profoundly shifts the perspective from asking patients "What is wrong with you?" to asking "What has happened to you?" (Klinic Community Health Centre, 2013, p. 16).

Embrace a cultural safety model. Originally developed by Indigenous nurse scholars in New Zealand as a means of providing more respectful care to Indigenous populations (Kearns, Dyck & Robinson, 1996; Papps & Ramsden, 1996; Ramdsen, 2000), cultural safety has been embraced by some in Canada (McNeil, Kerr, Pauly, Wood & Small, 2015; Pauly et al., 2015) as a way to move beyond cultural sensitivity or competence to consider structural inequities and power imbalances and their roles in creating inequitable access and treatment within health care settings. Further these Canadian scholars have suggested the model can be applied to mitigate the effects of stigma, discrimination and inequity affecting the lives of marginalized people who use substances. As we have seen in this study, participants who used opioids consistently articulated negative experiences of health care due to stigma, discrimination, judgment and blame which caused them to delay or entirely avoid seeking care. Additionally, participants who used opioids and nurse participants were frequently separated by a wide gap in understanding of the issues.

Pauly et al. (2015) propose a model of cultural safety to bridge the gap between people who use illicit drugs (who characterize the health care system as unsafe due to stigmatization) and those caring for them. They argue that a cultural safety model helps nurses reflect on the

structures, discourses and assumptions that frame health care and how to mitigate power imbalances by examining their power and privilege and how their values and perspectives can affect the development of therapeutic relationships. McNeil et al. (2015) advocate for the adoption of a cultural safety model also on the basis that it supports patient-centred care which "structurally vulnerable" groups such as criminalized or racialized people and including people who use illicit drugs do not receive equitably (p. 686).

Embrace a relational inquiry practice model. One finding of this study was that nurses believed that experience helped them provide nursing care to people who use substances. A strategy that some nurses used was to develop a "professional façade" to conceal their judgmental attitudes towards patients who use substances. Although it may be better for people who use substances if nurses' judgmental attitudes are hidden from them, it would ultimately be best for patients and for nurses if conditions conducive to a truly therapeutic, authentic relationship could be fostered. Doane and Varcoe (2005; 2007; 2015) have described the concept of a relational inquiry practice model to help nurses navigate the increasingly challenging contexts of nursing relationships and enactment of nursing values. A relational inquiry practice model requires nurses to interrogate personal and contextual factors which shape nursing relationships and is posed as an alternative to nursing relationships historically understood in the context of liberal individualism and separated from any broader social or interpersonal context. Further they argue that when nurses are unaware of the relational elements (personal and contextual) influencing their actions, they are less likely to exercise effective clinical judgment and are more likely to be practicing in "relational oblivion" which makes key nursing obligations such as the obligations to be reflexive and intentional; to "open the relational space for

difficulty;" and to act at all levels to maximize health and healing impossible to meet (Doane & Varcoe, 2007, pp. 199-200).

Embrace the principles of harm reduction. The Canadian Nurses' Association (2011) argues that nurses have an ethical responsibility to promote health and to base their practise on available evidence. As such they argue that harm reduction strategies are essential for nurses to implement to mitigate the health-related harms associated with illicit substance use. Becoming knowledgeable about harm reduction and using harm reduction strategies is beneficial for nurses and patients. It can provide nurses who may feel helpless to intervene meaningfully with their patients who use substances options for providing assistance, such as providing harm reduction education, including safer injection education; providing clean needles, syringes and other injection equipment; providing safer crack cocaine inhalation kits; and providing overdose prevention kits containing naloxone, for example. Ford (2011) argues that harm reduction is a pragmatic response for nurses. Pauly (2008b) argues that harm reduction shifts the contextual perspective for nurses from the goal of "fixing" individuals to reducing harm and this can assist nurses to navigate values conflict and increase role satisfaction. As an example, study nurse participants articulated their frustration at repeatedly assisting in the resuscitation of people who use opioids in the hospital setting. Being able to provide overdose prevention education and naloxone (the antidote) to those patients for peer or family member administration in the community would not only reduce the risks of opioid-related death from overdose but also has the potential to provide nurses with the opportunity to meaningfully intervene in improving the health of their patients and to begin to create trust-based authentic relationships with them.

Managers of nurses must provide role support to nurses. It is important to note that individual nurses, particularly in the context of neoliberal, austerity-driven health system cutbacks, must have the organizational support of managers and administrators to implement any practice recommendations.

Ensure there are workplace strategies in place to support nurses in working with people who use substances. Several studies have indicated that education about substance use is necessary but insufficient without organizational role support (Ford, 2011; Ford, Bammer & Becker, 2008; Monks et al., 2012). This support includes having a resource person readily available to assist with clarifying professional responsibilities and formulating approaches to patients as well as having ready access to peers for rapid debriefing after experiencing difficulties in providing care. Development and/or implementation of standardized protocols and clinical practice guidelines in practice settings can also increase knowledge and confidence as can explicit referral pathways for management of withdrawal and detoxification (Kelleher, 2007; Keller & Cotter, 2008). Also important is the support of nursing practice by managers at the policy level including policy support for education about and implementation of trauma-informed care, cultural safety, relational inquiry models and harm reduction policies in all practice settings.

Ensure there are workplace strategies in place to mitigate the risk of compassion fatigue and burnout. Chana, Kennedy and Chessell (2015) as well as Wright and Schroeder (2016) suggest that to cope with the demands of working in settings with regular exposure to challenging behaviours and situations that taking part in regular clinical supervision is important to support insight and resilience. Chana et al. (2015) argue that regular clinical supervision

reduces compassion fatigue and burnout and also provides an opportunity to intervene early when nurses are experiencing psychological distress and to promote coping strategies to improve nurses' well-being. These sessions ideally are built into regular work plans and budgets.

Regular multidisciplinary rounds (different than traditional medical rounds) have also been proposed as a strategy to support caregivers to discuss challenging social and emotional issues arising while caring (Chana et al., 2015). This could have the effect of normalizing and making transparent discussions of challenges which arise while caring for people who use substances which may transform the way nurses who may be left largely to their own devices obtain collegial support.

Ensure that nurses have access to ongoing professional development opportunities related to substance use including education by people who use substances. Nurse participants clearly identified that they lacked knowledge of substance use both in their primary nursing education and as practising nurses. Although it must be connected to high role support, workplace in-service education on substance use can be effective (Ford et al., 2008) as can workplace-offered skills training based on identified learning needs (Kelleher, 2007; Kelleher & Cotter, 2008). Small and rural community nurses may have additional barriers to participating in continuing education including time, travel from remote communities to large centres and associated costs (McCoy, 2009; Penz et al., 2007). Paid workplace education is one strategy that might assist rural nurses to overcome these barriers and increase uptake of those offerings by nurses.

8.3 Implications and Recommendations for Contextualized Nursing Education

Nurse participants identified that their primary nursing education curricula did not provide them with education on substance use or how to care for people who use substances.

Provide substance use education grounded in trauma-informed principles and harm reduction to nursing students and practising nurses. It is imperative that nurses be exposed to substance use education which is rooted in harm reduction and trauma-informed principles in undergraduate nursing curricula, practicum settings and as a core competency in ongoing professional development. There is little in the literature about the specific value of harm reduction and trauma-informed education, although there is some evidence supporting the value of education for improving knowledge, confidence and comfort levels in providing care to people who use substances (Kelleher, 2007; Kelleher & Cotter, 2008; Silins, Conigrave, Rakvin Dobbins & Curry, 2007; van Boekel et al., 2013).

Provide user-led substance use education to nursing students and practising nurses. Some participants who used opioids in this study suggested creating safe spaces for nurses to learn from the experience of people who use substances would be beneficial. There is some evidence to support the efficacy of user-led education (Livingston, Milne, Fang & Amari, 2011; Lloyd, 2013; Monks et al., 2012). An Australian study found that contact with people who use illicit drugs in small group settings was associated with more positive attitudes by first and fourth year medical students (Silins et al., 2007). Nursing students in the U.K. were able to engage in open discussion during a small group session with a volunteer who used opioids who gave an account of their experience with opioid withdrawal and the challenges of avoiding drugs after detoxification. This was reported to have resulted in a wide-ranging discussion of drug use, class

biases and criminalization and may have provided a less-threatening environment for students to ask questions (Harling et al., 2006).

8.4 Implications and Recommendations for Contextualized Nursing Research

The literature review for this study identified some significant gaps in nursing research, and in particular a glaring absence of research on substance use by rural nursing research organizations. The gaps around substance use research of any kind in rural Canada are also very large, as are the gaps on research related to harm reduction in rural areas.

Given the prevalence of substance use in rural Canada, it will be important for rural nursing research chairs to give attention to it. There are many issues worth exploring around rural substance use, including issues related to access to health care; access to harm reduction supplies and education; the potential role of nurses in providing harm reduction supplies and education in rural areas; the prevalence of rural peer helpers and secondary distribution of harm reduction supplies; the experiences of women who use substances in small and rural communities; the particular experiences of racialized groups; and optimal strategies for knowledge transfer to nurses around substance use and trauma and harm reduction in rural areas.

Some nurse participants noted that they came to like caring for people who use substances later in their professional life. It would be interesting to explore the type of nursing experiences that help nurses change the way they feel about caring for people who use substances. Could this be related to generic nursing experience which leads to having more confidence generally? Or could it be related to particular experiences of working with people who use substances? What would be the effects on practising nurses of contact with people who use substances enacting the role of expert educators? How effective might this be with regard to

mitigating the impacts of neoliberal individualization of blame or on the notion that substance use is a choice?

Also interesting would be research looking into factors that support the uptake of education on trauma-informed care, relational inquiry models of practice and harm reduction philosophies in rural health care settings. What is required to adopt such models in small community primary care settings and in small community hospital settings? What is the role of nursing education? What are the institutional policy and practice implications? How could one measure the effects on patient outcomes and on nursing role satisfaction? What would be the role of nursing managers and other health setting administrators in the successful implementation of these models? What would be the effects of universally-implemented harm reduction strategies on opioid-related morbidity and mortality in Ontario?

Given the dearth of research currently available on rural substance use, there are myriad research questions waiting to be asked and answered.

8.5 Implications for Policy

Friere (1970) argues that humans are "beings of praxis" who may work to maintain oppressive structures or who may work to change them (pp 100 – 101). Numerous nurse scholars argue that nurses have an ethical responsibility to advocate for individual patients and improved access to health services. Although these advocacy activities are necessary, they are not sufficient, as nurses much also advocate further upstream for policy changes that would improve the health of marginalized groups (Anderson et al., 2005; Bekemeier & Butterfield, 2005; Browne & Tarlier, 2008; Carnegie & Kiger, 2009; Reimer Kirkham & Browne, 2006). The Canadian Nurses' Association (CNA) (2011) suggests that nurses understand Canadian policy

development through the lenses of gender inequity, colonization and racism and invites nurses to consider the ways these have created inequities for people who use drugs. CNA calls on nurses to challenge harmful policies which are neither consistent with harm reduction principles nor with the CNA Code of Ethics (2008). The International Council of Nurses (ICN) Code of Ethics states that nurses share with society responsibility for "initiating and supporting action to meet the health and social needs of the public, in particular those of vulnerable populations" (ICN, p. 2). There are numerous policy implications arising from the findings of this study. Below are several "upstream" policy issues which would improve the health and health care of people who use substances in small and rural communities.

Implement trauma-informed care principles across the Ontario health care system. The Ontario Ministry of Health and Long-Term Care (MOHLTC), which funds most health care in the province on Ontario, should require and financially support all health care organizations receiving provincial health funding to transform their organizations from trauma-unaware to trauma-informed organizations. Ongoing funding should be contingent on full implementation.

Implement harm reduction policies across the Ontario health care system. The Ontario MOHLTC should require and financially support all health care organizations receiving provincial health funding to adopt a policy of evidence-based harm reduction strategies and principles. McNeil et al. (2015) found that adopting harm reduction strategies such as supervised drug consumption services could help improve retention in hospitals and reduce adverse outcomes among people who use drugs. Pauly et al. (2015) note that it is insufficient for individual nurses to adopt harm reduction strategies in their practice settings when the institutions in which they work may have policies which are premised on zero tolerance for

substance use and lack harm reduction policies. An expectation by the provincial health system funder (MOHLTC) that harm reduction policies be implemented across the health sector and tied to ongoing funding would allow for availability of a much broader range of strategies beyond the provision of opioid substitution therapy (methadone or buprenorphine) to include provision of a range of safer drug use supplies; provision of harm reduction education; widespread provision of overdose prevention strategies including naloxone provision (which is in the process of being liberalized in Ontario as of this writing) and supervised drug consumption services such as those suggested by McNeil et al. (2015).

Expand harm reduction services funding to small and rural communities. The Ontario MOHLTC should invest public health funds towards the goal of rapidly expanding harm reduction services funding in all Public Health Unit districts across the province, including rural and remote regions, to enable the provision of robust harm reduction services in small and rural communities.

Decriminalize illicit psychoactive substances. The Government of Canada should move immediately to decriminalize the use and possession of all currently illicit substances. A significant proportion of the stigmatization affecting people who use illicit substances arises from their criminalization. The impact of decriminalization in Portugal in 2001 has included reduced drug deaths, reduced rates of arrest and incarceration, reduced rates of HIV infection, reduced problematic and adolescent drug use and no major increases in overall substance use (Drug Policy Alliance, 2015). Further, the Global Commission on Drug Policy (2011) reports that decriminalization, in combination with alternative health-based therapeutic responses to people struggling with substance use, has reduced the burden of drug law enforcement on police,

courts and prisons and reduced the overall level of problematic substance use. Reinerman, Cohen and Kaal (2004) determined that Amsterdam's liberalized policies on cannabis, which they refer to as de facto decriminalization, did not increase the use of cannabis. Similar findings were also seen in Western Australia (Fetherston & Lenton, 2007).

8.6 Limitations of the Study

As in most studies, there are limitations that must be acknowledged. I acknowledged at the outset that the issue of opioid use in Canada was a serious public health crisis resulting from a number of contributing factors. I made a decision not to explore the important role of the pharmaceutical industry and prescriber practices around opioids that have been linked to the rise of the prescription opioid crisis. Although I am aware of these issues I believe that including them in this study may have served to deflect attention from the core issues of substance use, stigmatization and nursing care. I also focused less deeply on the context of rural geographic place than I might have, choosing instead to characterize a smaller number of rural issues such as access to health services, the particular implications of stigma in smaller communities, and issues for rural nurses such as having less access to professional development opportunities. A comprehensive analysis of substance use within, for example, the particular cultural or religious contexts of rural communities might provide interesting insights in addition.

Arising from my clinical nursing practice experiences over almost thirty years as a Registered Nurse and then as a Primary Care Nurse Practitioner, I opted to privilege the concept of stigma in the conduct of this study as well as to consider the issues using the lenses of the social determinants of health, health care access, harm reduction and trauma-informed care. This clearly leaves space for the future exploration of other considerations such as the role of

pharmaceutical companies, of prescriber education and controls (including nurse practitioner prescribers), and strategies such as provincial opioid monitoring systems.

Further, in this study the demographics of participants who used opioids were less heterogeneous than they might have been using different sampling strategies with race being limited to either White or Indigenous origins. These participants' experiences may not be reflective of those from racialized or other racialized groups. It may reflect even more pronounced stigma affecting other racial groups in small communities that they were not strongly represented in the harm reduction service where interviews occurred. Others not represented were transgender people whose experiences may also have been different. I did not inquire about sexual identity which may have had some further independent impact on participants' experiences of stigma and discrimination. Although I explored some issues related to women who use substances, I did not fully explore gender as an issue as I did not look at the experience of men who are parents or of the gender role influences on and implications of male substance use, for example.

As well, all of the nurse participants were working in a small city in either a small community hospital, primary care clinic or specialty clinic although some of them may have lived in more rural locations. I did not gather data on race or sexual identity or income of nurse participants. None were recruited from a rural or remote setting which might have resulted in differing perspectives.

8.7 Conclusion – Beginning to Bridge the Divide

Both groups of participants identified numerous problematic issues in nurse-patient interactions. The explanations and conclusions of each group were quite different and represent a deep divide in understanding between the groups with significant potential to impede authentic connection. Although each group had divergent perspectives on the switch being flipped, the consequences for both were significant and negative. Participants who used opioids experienced frustration, inadequate care or lack of care, misdiagnosis, reluctance to seek care because of previous negative experiences and often felt worse after a health care encounter. Nurse participants experienced frustration, helplessness, reduced role fulfillment, moral distress, compassion fatigue and burnout.

Regardless of their beliefs about substance use, I believe that most nurses want to provide excellent care based on authentic caring relationships with patients. Although experiences of stigma and inadequate health care were pervasive in the lives of the participants who used opioids in this study, some of them reported positive experiences with nurses. Some of the nurse participants stated that they enjoyed caring for people who use opioids. Most of the unforgettable stories told by nurse participants were stories of powerful emotional connections to patients who use substances, describing rewarding encounters where nurses felt they made a difference. Participants who used opioids were remarkably generous in their optimism describing nurses' potential to learn what we need to learn and to become more compassionate towards people who use substances. Some were very excited about the potential for drug user involvement in the education of nurses.

The late psychologist Alice Miller (1991) wrote: “What is addiction, really? It is a sign, a signal, a symptom of distress. It is a language that tells us about a plight that must be understood.” The gap between nurses’ understanding of substance use and the role it plays in the lives of people who have survived trauma is wide but therein lies the transformative potential of the recommendations – to learn to see substance use as a sign or a hint of what lies below the surface and not as a disease or unhealthy choice or moral failing. I am hopeful that this research will become part of a roadmap guiding nurses along a journey that resists powerful neoliberal influences towards deeper, more humane understandings of people who use psychoactive substances in their care.

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Appendix A: Recruitment Flyer for Participants who Used Opioids

Do you use opioids?

Do you want to talk about your experiences with health care with someone who really wants to listen?

I am a nurse researcher and harm reduction advocate interested in finding out what it is like to get health care as a person who uses opioids in small or rural communities. If you are willing to do a confidential interview with me, please contact me in one of these ways to find out if you are eligible to participate:

- By email at khardill@yorku.ca
- By dropping in to the Town of Forest Harm Reduction Agency at 100 Forest Street, Suite 100 during the times marked on the calendar

Appendix B: Eligibility Screening Questionnaire for Participants who Used Opioids

1. Have you received nursing care from me in the past two years?

   Yes ____ No ____ [If yes, NOT ELIGIBLE]

2. What is your age?

   Record in years: _____ [If less than 19 years of age, NOT ELIGIBLE]

3. On average, how often do you use illicit opioids?

   Daily _____

   Weekly _____

   Monthly _____

   Less often than monthly _____ [NOT ELIGIBLE]

4. If you are not currently using opioids, have you used opioids in the past year?

   If "no" [NOT ELIGIBLE]

   If "yes" – how long did you use opioids in the past year?

   One month or less _____ [NOT ELIGIBLE]

   More than one month but less than six months _____ [NOT ELIGIBLE]

   More than six months _____

5. How long have you been using illicit opioids?

   One month or less _____ [NOT ELIGIBLE]

   More than one month but less than six months _____ [NOT ELIGIBLE]

   More than six months _____

Participants will be eligible if they are 19 years of age or older; are currently using illicit opioids by any route at least once monthly; and have been using illicit opioids for at least six months (or have done so in the past year). If not eligible, explain to the person that they are not eligible to participate and thank them for their time.

Appendix C: Nurse Participant Recruitment Flyer

Have you provided nursing care to people who use illicit opioids?

I am a Forest area nurse practitioner conducting community-based research as part of my Master's program at York University's School of Nursing.

I am investigating the experience of health care for people who use illicit opioids living in small cities and rural communities. I will be interviewing people who use opioids as well as nurses in the Four Counties. I am interested in what nurses have to say about providing care to people who use illicit opioids.

If you have about 30 minutes to participate in a confidential, 1:1 interview, please contact me at XXX XXX XXXX or at khardill@yorku.ca

Appendix D: Consent Script for People Who Use Illicit Opioids

Consent to Participate in a Research Study

Title of Research Study

Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis

Principal Investigator

Kathy Hardill, RNEC, Master of Science in Nursing Candidate, York University

kathy.hardill@yorku.ca Tel: XXX XXX XXXX

Introduction

Before agreeing to participate in this research study, it is important that you read and understand this research consent form. It includes information you need to know in order to decide if you wish to take part in this study. If you have any questions, please ask. You should not agree to participate until you are sure you understand the information. Taking part in this research is completely voluntary. If you decide not to participate, it will not affect your ability to get the services you usually get at this agency.

Purpose of the Research

In this project I would like to find out more about the experience of health care for people using opioids in small towns and rural communities.

Description of the Research

If you agree to participate, you will be asked to do one open-ended, conversational interview and one follow up interview to make sure I have interpreted what you told me correctly. During the first interview you will be asked questions about your drug use and your experiences of health care. Your interview will be audio-recorded and later I will listen to the tape and write down what you said. If you are uncomfortable with any particular question or topic, you can skip that question or stop talking about the topic. Your answers will be kept completely confidential. The first interview will take from approximately 30 to 60 minutes, perhaps more, depending on how much information you share. The follow-up interview will probably be shorter, lasting about 20 to 30 minutes. You will be provided with $20 cash after the first interview and $10 cash after the second interview.

Potential Harms/Discomfort

It is possible that you may feel some discomfort because you will be asked about experiences of seeking health care or getting health care which may be difficult or painful to recall. If you have had bad experiences, it may have affected your health or wellbeing in a negative way, and this may be emotionally difficult to recall and may bring back bad memories. You do not have to answer any question you do not want to answer and you can ask to stop the interview at any time. If you decide to stop participating, it will not influence your relationship with researchers or staff of York University now or in the future.

If you feel upset during or after the interview, these agencies are available for support:

Forest County Addiction Services and Treatment –XXX XXX XXXX
140 Forest Street West, Unit 200, Forest, ON

Canadian Mental Health Association Four Counties Crisis Services
XXX XXX XXXX

Forest Regional Health Centre Crisis Unit
Located at Forest Regional Health Centre, Forest, ON.
XXX XXX XXXX

Telecare distress telephone line
XXX XXX XXXX
Because you will be talking about your drug use and possibly other illegal activities, I will ask only for your verbal consent so that your name is not recorded anywhere. Research data is not protected from being subpoenaed for court, and although this is unlikely to occur, if it does I want to make sure your name will not be recorded anywhere.

Potential Benefits

I am doing this research because I hope to use the information I learn to improve health services for small town and rural people who use drugs by increasing awareness and education for health care providers like nurses and doctors. Although you may not benefit right away from participating in this study, and you may not benefit personally at all, the information you share may help improve treatment of people who use opioids by health care workers in small cities and rural areas.

Protecting Your Information

The information you give me for this study will be kept private and confidential. I will not be collecting your name or other information that directly identifies you. The transcript of your interview will be identified by a unique number identifier only. Confidentiality will be respected and no information that reveals the identity of participants will be released or published without your consent unless required by law. Confidentiality will be provided to the fullest extent possible by law. The audiotapes and transcripts and any handwritten notes I make will be stored in a locked filing cabinet that only the principal investigator (myself - Kathy Hardill) and members of my school supervisory committee will have access to. This will be located in Kathy Hardill's home office. The demographic forms will be stored separately from the transcripts. The electronic data from the audiotapes will be stored on a password protected laptop computer and deleted once the data analysis has been done. The audiotapes will be erased after five years. All paper data will be stored for five years after which time it will be destroyed by shredding.

Study results

I hope to publish the results of this study in an article in a health or harm reduction journal and possibly present the findings at a conference. You will not be identified in any article or presentation. I will ask you to give me a false first name so that any quotations you make can be identified in some way. The research findings will be presented to small town and rural health care practitioners and social service workers. Any information that could identify you will be taken out, and confidentiality will be maintained at all times when presenting the findings. A report outlining the important findings will be written up and made available to you and also distributed to this agency and other agencies that provide services to people who use opioids who did not participate but who may find the report interesting.

Participation and Withdrawal

Participating in this study is completely voluntary. If you decide to participate, you can refuse to answer any questions, or stop the interview at any time, for any reason. You can also contact me, Kathy Hardill, to withdraw from the study after you have completed the survey. Your audiotape and transcript will be destroyed immediately. If you decide to stop participating, even part way through the interview, you will still be eligible to receive the promised pay for agreeing to be in the project.

Study Contact Information:

If you have any questions about this study or your role in it, you may contact

Kathy Hardill at: kathy.hardill@yorku.ca or my supervisor,

Dr. Cheryl Van Daalen-Smith, RN PhD, at XXX XXX XXXX x XXXXX or cvandaal@yorku.ca .

You may also contact the Faculty of Graduate Studies at York University at fgsro@yorku.ca .

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, telephone 416-736-5914 or e-mail ore@yorku.ca

Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis - Consent Script

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my choices about participating in this study, including the right not to participate and the right to withdraw at any time. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study.

I understand that I have not given up my legal rights and have not released the investigator or involved institutions from their legal and professional duties. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would reveal my personal identity without my permission unless required by law. I have been given enough time to read and understand the above information. I agree to have my interview audiotaped.

I understand that the project has been approved by the York University Research Ethics Board. I consent to participate in the above named study, and have been given a copy of this consent form.

Do you agree to be audio-recorded?

Do you give your verbal consent to participate in "Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis"?

Appendix E: Demographic Form – Participants who used opioids

1. What is your age? ___ years

2. What is your gender?
   Male ___ Female ___ Transgendered/transsexual ___Other (specify)_____

3. What racial group or groups do you identify with?

4. Which of the following best describes your present housing situation?
   Homeless living in a shelter
   Homeless staying with friends
   Homeless living outside
   Room I pay rent for
   Apartment I pay rent for
   House I pay rent for
   House I own
   Other _____

5. Which of the following best describes your income situation?
   Ontario Works
   Ontario Disability Support Program
   CPP or CPP – Disability benefits
   EI
   Temp labour
   Regular part time work
   Regular full time work
   Non-traditional work (such as sex work, selling drugs, selling stolen goods, etc.)
   Other _____

6. What is your average monthly income range?
   No income
   $1 to $500
   $501 - $1000
   $1001 - $1500
   $1501 - $2000
   $2001 - $2500
   $2501 - $3000

   >$3001/month

7. How long have you been using opioids?
   Six months to less than one year
   One year to less than two years
   Two to less than three years
   Three to less than five years
   Five years to less than ten years
   More than ten years

8. Thinking about the past 30 days, how often, on average, do you typically use opioids?
   Daily
   Several times weekly
   Several times monthly
   Less often than monthly

9. Which of the following routes have you used for opioids?
   Oral
   Inhaled (snorting)
   Inhaled (smoking, chasing the dragon)
   Injection intravenously
   Other _____

10. What is your preferred route of using opioids?
    Oral
    Inhaled (snorting)
    Inhaled (smoking, chasing the dragon)
    Injection intravenously
    Other _____

11. What is your opioid of choice, if you can get it?
    Oxycocet (Percocet – short acting)
    Oxycodone (Oxycontin, OxyNeo – long acting)
    Hydromorphone (Dilaudid) - short acting
    Hydromorphone Contin (long acting)
    Morphine
    Codeine (eg Tylenol # 1, 2, 3 or plain codeine)
    Fentanyl patch
    Heroin
    Other _____

12. Not including opioids, in the past 30 days, list all substances you have used, even once:
    Alcohol
    Nicotine
    Cannabis
    Cocaine – powder
    Cocaine – crack
    Benzodiazepines (such as valium, lorazepam, clonazepam, temazepam, etc)
    Methamphetamine
    Ketamine
    MDMA (ecstasy)
    LSD
    Mushrooms
    Other _____

Appendix F: First Interview Guide – Participants who used opioids

1) I would like to learn more about what it is like to look after your health when you use illicit opioids. What can you tell me about that?

2) What can you tell me about your experiences with health care providers (doctors, nurse practitioners, nurses, pharmacists, etc.)?

   Can you tell me a story about an experience of health care that you will never forget?

   What was that like for you? Did it affect your health? Did it affect your ability to get care or services that you needed?

3) Sometimes people who use opioids turn to non-traditional ways of making money, such as theft and sex work. Do you think that people who use opioids are judged or blamed for how they get money? Can you talk about that?

4) What is the hardest thing about staying healthy when you are using opioids?

5) What do you want to say to health care providers, especially nurses, about how to provide health care to you?

6) When the results of this research are written up, I will use a false name to identify your quotes. What name would you like me to use for you?

Appendix G: Second Interview Guide – Participants who used opioids

1. I'd like to review the write up of your first interview to make sure I interpreted what you told me accurately [RETURNED TO POINTS IN FIRST INTERVIEW TRANSCRIPT WHICH NEEDED CLARIFICATION OR ELABORATION]

2. Several of the points you brought up were raised by other people as well. I wonder if you had anything more to say about: [RETURNED TO POINTS IN FIRST INTERVIEW TRANSCRIPT WHICH WERE ALSO RAISED BY OTHERS – not necessarily all the points in this list]

    a. Stigma related to drug use, to injection drug use, to having Hepatitis C or HIV

    b. Discrimination related to – what?

    c. Being judged – for what?

    d. Unequal power relationships between people who use drugs and health care providers?

    e. Barriers to care/poor access to care/not getting care that you needed

    f. Effects of low income on your ability to get health care? Such as lack of transportation, making/missing appointments, etc

    g. Some people who use drugs have socially acceptable jobs, or high social positions, or high incomes – have you seen this group of people who use drugs treated differently in the health care system? In society?

    h. Positive characteristics of people who use drugs such as people sticking up for themselves, advocating for themselves, assuming the best of people

3. Can you think of any strategies for improving the care of people who use opioids? Any possibilities for changing things? How could health care providers improve our understanding of people who use opioids?

4. Sometimes when the world stigmatizes you and discriminates against you, and says "you're less than the rest" – it affects how you see yourself. How do you see yourself?

Appendix H: Consent Form for Nurse Participants

Consent to Participate in a Research Study

Title of Research Study

Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis

Principal Investigator

Investigator can be reached from Monday to Friday, 9:00 a.m. to 4:00 p.m.

Kathy Hardill, RNEC
Graduate Studies in Nursing Sciences, York University

kathy.hardill@yorku.ca

Tel: XXX XXX XXXX

Introduction

Before agreeing to participate in this research study, it is important that you read and understand this research consent form. It includes information that we think you need to know in order to decide if you wish to take part in this study. If you have any questions, please ask. You should not sign this form until you are sure you understand the information. Taking part in this research is completely voluntary. If you decide not to participate, please feel free to decline.

Purpose of the Research

In this project I would like to find out more about the experience of providing nursing care to people using opioids in small towns and rural communities. In particular, I am interested in whether people who use opioids in small towns and rural communities have specific challenges related to their health and to obtaining health care.

Description of the Research

If you agree to participate, you will be asked to do one open-ended, conversational interview. You will be asked questions about your experiences of providing nursing care to people who use illicit opioids. Your interview will be audio-recorded and later I will listen to the tape and write down what you said. If you are uncomfortable with any particular question or topic, you can skip that question or stop talking about the topic. Your answers will be kept completely confidential. The interview will take from approximately 30 to 60 minutes, perhaps more, depending on how much information you share.

Potential Harms/Discomfort

It is possible that you may feel some discomfort because you will be asked about experiences of providing care for people using opioids which may have been negative. This may be emotionally difficult to recall and may bring back memories of negative experiences. You do not have to answer any question you do not want to answer and you can ask to stop the interview at any time.

Potential Benefits

I am conducting this research because I hope to use the information collected to improve health care services for small town and rural substance users through increasing awareness and education. Although you may not benefit immediately from participating in this study, the information you share may help improve awareness and education of health care providers with respect to providing care to people who use opioids in small cities and rural areas. It may also improve the ability and confidence of health care providers to provide care to people who use opioids.

Protecting Your Information

The information you provide for this study will be kept confidential. I will not be collecting your name or other information that directly identifies you. Your interview transcript will be identified by a unique number identifier only. Confidentiality will be respected and no information that reveals the identity of participants will be released or published without your consent unless required by law. The audiotapes and transcripts will be stored in a locked filing cabinet that only the principal investigator (myself, Kathy Hardill) and members of my thesis supervisory committee will have access to. This will be located in Kathy Hardill's office. The demographic forms and consent forms will be stored separately from the transcripts. All data will be stored for five years after which time it will be destroyed by shredding.

Study results

I hope to publish the results of this study in an article in a health or harm reduction journal and possibly present the findings at a conference. You will not be identified in any article or presentation. I will ask you to give me a false first name so that any quotations you make can be identified in some way. The research findings will be presented to small town and rural health care practitioners and social service workers. Any information that could identify you will be taken out, and confidentiality will be maintained at all times when presenting the findings. A report outlining the important findings will be written up and made available to you and also distributed to this agency and other agencies that provide services to people who use opioids who did not participate but who may find the report interesting.

Reimbursement of Participants

If you agree to participate you will be provided with a $10 coffee card as a token of appreciation for your time.

Participation and Withdrawal

Participating in this study is completely voluntary. If you decide to participate, you can refuse to answer any questions, or stop the interview at any time. You can also contact me, Kathy Hardill, to withdraw from the study after you have completed the survey. Your audiotape and transcript will be destroyed.

Research Ethics Board Contact

The study protocol and consent form have been reviewed by a committee called the Research Ethics Board at York University in Toronto. The committee is set up by the university to review studies for their scientific and ethical value.

Study Contact Information:
If you have any questions about this study, contact Kathy Hardill at: Telephone: XXX XXX XXXX or email: kathy.hardill@yorku.ca

Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis

Consent Form – Face to Face Interview

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my choices about participating in this study, including the right not to participate and the right to withdraw at any time. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study.

I understand that I have not given up my legal rights and have not released the investigator or involved institutions from their legal and professional duties. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would reveal my personal identity without my permission unless required by law. I have been given enough time to read and understand the above information. I consent to having my interview audiotaped.

I understand that the project has been approved by the York University Research Ethics Board. I consent to participate in the above named study, and have been given a copy of this consent form.

Name of research participant: Print:_____

Signature: _____

Date: _____

Investigator obtaining consent: Print: _____

Title: _____

Signature: _____

Date: _____

Witness Statement (required where participant is unable to read consent form)

I hereby state that I have been a witness to the above consent discussion, that the information in the consent form has been accurately explained and apparently understood by the participant. Consent has been freely given by the participant.

Witness: Print: _____

Signature: _____

Date: _____

Relationship of witness to participant, if any

Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis

Verbal Consent Script – Telephone Interview

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my choices about participating in this study, including the right not to participate and the right to withdraw at any time. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study.

I understand that I have not given up my legal rights and have not released the investigator or involved institutions from their legal and professional duties. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would reveal my personal identity without my permission unless required by law. I have been given enough time to read and understand the above information. I agree to have my interview audiotaped.

I understand that the project has been approved by the York University Research Ethics Board. I consent to participate in the above named study, and have been given a copy of this consent form.

Do you agree to be audio-recorded?

Do you give your verbal consent to participate in "Health Care Experiences of People Who Use Illicit Opioids In Small Cities and Rural Communities: A Critical Social Theory Analysis"?

Appendix I: Demographic Form – Nurse Participants

1) How long have you been an RN/NP?
   < 2 years
   2 to 5 years
   5 to 10 years
   10 to 15 years
   15 to 20 years
   More than 20 years

2) How would you describe your current primary practice setting (the setting where you work most often)?
   Emergency department
   In patient unit
   Short stay unit
   Primary care clinic
   Specialty clinic
   Other (please name) _____

3) Do you have a secondary practice setting?
   Yes
   No (if no, skip to question 5)

4) If so, how would you describe your current secondary practice setting (the setting where you also work)?
   Emergency department
   In patient unit
   Short stay unit
   Primary care clinic
   Specialty clinic
   Other (please name) _____

5) How long have you practiced in your current primary practice setting?
   _____ years

6) What is the highest level of nursing education you have achieved?
   RN diploma
   Baccalaureate degree in nursing
   Master's degree in nursing
   Doctoral degree in nursing

Appendix J: Interview Guide – Nurse Participants

1) As you are probably aware, Canada has seen a huge increase in the use of illicit opioids over the last two decades. In Ontario in 2010, the College of Physicians and Surgeons of Ontario (CPSO) called it a "public health crisis." Among people aged 25 to 34 in Ontario, one of every eight deaths is opioid related (Gomes, Mamdani, Dhalla, Cornish, & Paterson, 2014).

   What is it like caring for people who use illicit opioids in your practice setting(s)?

2) Can you think of a story – one you will never forget – about caring for someone who uses illicit opioids?

3) The literature indicates that some health care providers feel conflicted when caring for people who use illicit and injection drugs, sometimes because they feel that people bring about their own health issues through their drug use, or because they see them as "drug seeking," or because they do not follow through on treatment advice.

   What can you tell me about your experience witnessing these types of reactions by nurses or other health care providers to people who use illicit opioids?

4) There are some specific issues related to caring for women who use illicit opioids. What is it like to care for women who use illicit opioids?

5) I have heard from people who use illicit opioids about their experiences of health care and they have told me that some health care providers, when they find out about their opioid use, and especially about injection opioid use, have a change in attitude "like a switch being flipped" which leads to stigma, judgment and discrimination – such as being treated rudely, being given less information, having to wait longer for care, being undertreated for pain, being inadequately assessed, and being blamed for their health issues or for having difficult veins, etc. What can you tell me about your experience of this?

6) Is there anything else you would like to tell me?

7) When the results of this research are written up, I will use a false name to identify your quotes. What name would you like me to use for you?

Glossary

Carries – terminology referring to the ability of people enrolled in methadone maintenance programs to take their daily methadone dose home with them for up to seven days' worth of doses; typically allowed for people who are relatively stable in their recovery

Cooker – colloquial term for a container used to heat drugs in order to prepare them for injection; sterile single use cookers are part of safer injection kits; often colour-coded so that individuals can identify their own cooker and avoid sharing with others in group settings

Dope sick – slang terminology for the symptoms of opioid withdrawal including nausea, vomiting, diarrhea, muscle pain and tremors

Drink – slang terminology sometimes used by people on methadone to refer to their daily dose of methadone, which is mixed in a large volume of juice to prevent it being injected

Harm reduction - Harm reduction is a range of practical strategies and ideas focused on reducing the harmful consequences associated with drug use and other risky health behaviours. The principle of harm reduction is grounded in social justice and emphasizes respecting the rights of an individual to choice and addressing the inequalities of health and wellbeing in the drug using community (Ontario Harm Reduction Distribution Program, 2016).

Hydromorph – slang short form for hydromorphone. a prescription opioid available in short-acting and long-acting formulations and which has been prescribed more frequently in Ontario since oxycodone was removed from the Ontario provincial drug formulary

Illicit substances – substances whose use is illegal or forbidden either because they are prohibited by law for anyone to use or through the use of legal substances which one does not have legal authorization to use (such authorization usually conferred by having a prescription for use).

Methadone – a synthetic long acting analgesic medication used as opioid replacement therapy in the treatment of opioid dependence

Naloxone (Narcan) – an opioid antagonist medication used to reverse the effects of opioids, especially in the situation of opioid overdose; sometimes referred to by the trade name Narcan

Natural helper – see peer helper below

Needle exchange program (NEP) – a harm reduction strategy aimed at reducing the risks of injecting with used or contaminated needles and syringes to lessen the risks of transmission of blood-borne infections such as HIV or Hepatitis C

Opiate – a substance derived from the opium poppy which acts on the brain's opioid receptor system; commonly used to relieve pain (including opium, morphine, codeine)

Opioid – substances which act on the brain's opioid receptor system; commonly used to relieve pain (including opiates and semi-synthetic substances such as heroin, oxycodone, hydromorphone)

Panhandling – the act of asking passersby on the street for assistance in the form of money or food

Peer helper – people who are currently using substances or who have experience doing so who are enlisted as employees or as volunteers to distribute harm reduction supplies and education to their substance-using peers

PWUD – abbreviation for "people who use drugs"

PWUO – abbreviation for "people who use opioids"

Safer inhalation kit – a supply of harm reduction materials designed to reduce some of the harms associated with smoking substances; usually contains safer pipes with protection from burns as well as screens to prevent heated solids from being inhaled accidentally

Safer injection kit - a supply of harm reduction materials designed to reduce some of the harms associated with injection substances; usually contains clean needles and syringes, single use tourniquets, sterile water to liquefy substances for injection, alcohol swabs for cleaning skin prior to injection, etc.

Secondary distribution – term used to describe clients of a harm reduction supply program who take supplies for themselves as well as for others who cannot or will not use the program themselves; particularly important in rural areas where some people have limited means of transportation or where stigma prevents people from feeling safe to use such programs

Spoon – a common kitchen utensil often used as a makeshift drug cooker for preparing drugs for injection

Suboxone – a medication comprised of two drugs, buprenorphine (a partial opioid agonist) and naloxone (an opioid antagonist); used as a treatment for opioid addiction and as an alternative to methadone