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# Injection Drug Users' Perceptions of Received Nursing Care: A Case Study

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Injection Drug Users' Perceptions of Received Nursing Care:  
A Case Study

A Dissertation Presented

by

KIMBERLY DION

Submitted to the Graduate School of the  
University of Massachusetts Amherst in partial fulfillment  
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2015

Nursing

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Injection Drug Users' Perceptions of Received Nursing Care:  
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KIMBERLY DION

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## DEDICATION

To my family, and especially Maddie, for truly being the wind beneath my wings.

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I would like to thank my chair, Donna Zucker for her guidance, support, encouragement, patience, and for sharing my passion. I am appreciative of your mentorship, and willingness to let me do what I needed to do. I would also like to thank my committee members, Cynthia Jacelon, Daniel Gerber, and Karen Kalmakis for their encouragement and support.

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I wish to express my appreciation to the participants for sharing their stories so willingly. Your sentiments will forever resonate in my thoughts as I continue to push forward to address the social injustice you so articulately shared.

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I wish to thank my family for their support, and willingness to work around the pile of research materials on the kitchen table. Your love and support has meant the world to me.

ABSTRACT

INJECTION DRUG USERS' PERCEPTIONS OF RECEIVED NURSING CARE:  
A CASE STUDY

MAY 2015

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The primary aim of the exploratory case study was to explore the injection drug users' experience with received nursing care while hospitalized on a medical unit. Data were gathered using semistructured interviews with nine injection drug users at two needle exchange services. Five men and four women were interviewed for 27–90 minutes. Travelbee's (1971) interpersonal nursing model served as the theoretic framework for this study.

Data were analyzed through the process of coding, pattern matching, and the convergence of emerging themes. For the rival case, the theme of *Understanding Addiction* emerged. For the comparison cases, the overarching themes of *Marginalization*, *Defensiveness*, and *Repeated Victimization* were discovered. Subthemes of *Feelings of worthlessness*, *Mistrust*, *Unpredictability of care*, *Self-care management and delay in seeking care* were also examined.

The study findings reveal the cyclical process of marginalization, defensiveness, and repeated victimization that these nine injection drug users experienced when

receiving care from a nurse on a medical unit. This study led to the findings that suggest that addiction-focused nursing education and role support, implementation of addiction-trained health care teams, and application of Travelbee's (1971) theory were missing from the injection drug users' hospital experience. Addiction-trained nurses are essential in providing culturally specific care for substance-dependent individuals across their addiction trajectory.



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# CHAPTER 1

## INTRODUCTION

In 2012, an estimated 22.2 million persons (8.5% of the population) were classified as having substance use dependence (Substance Abuse and Mental Health Services Administration [SAMHSA], 2013). During 2009–2010, Massachusetts was among the top 10 states with increased rates of illicit drug use, especially among the 21–25-year age group, and exceeded the national average for drug-induced deaths (SAMHSA, 2012a). Moreover, in 2010, the numbers of drug-related visits to the emergency department were estimated at 2.3 million (SAMHSA, 2012b).

This increased use and availability of illicit substances has resulted in a greater number of injection drug users (IDUs). The continuing use of injection drugs increases the risk for chronic blood-borne diseases such as HIV, hepatitis C (HCV), and complications of the injection site (Stein, 1990; World Health Organization [WHO], n.d) resulting in greater contact with nurses. It has been well documented that stigma and discrimination of the IDU exists among health care providers (HCPs), including nurses (Myers, Fakier, & Louw, 2009; Paterson & Backmund, 2007; Varas-Diaz, Negron, Neilands, Bou, & Rivera, 2010) and this has been shown to have a negative impact on both mental and physical health of the IDUs (Aherna, Stubere, & Galeaa, 2007; Brener, Von Hippel, Kippax, & Preacher, 2010; Carroll, 1993, 1996). By understanding the IDU's perceptions and meaning of nurse interaction, improved health care outcomes may result, as nurses may better understand how their care is perceived and received by the IDU.

## Problem Statement

According to the most recent results from the National Institute on Drug Abuse (2011), drug-related emergency department (ED) visits increased from 2.5 million in 2004 to 4.6 million in 2009. The complications from injection drug use regularly lead to contact with nursing staff and disclosure or discovery of drug use during the IDU's hospitalization. Often it is the nurse whom the IDU will first encounter and interact with when accessing health care, both in the emergency department and on the acute care unit. This interaction may influence the IDU's decision to honestly disclose information, be receptive to education, remain hospitalized for the fully recommended treatment, and to implement harm reduction concepts. Moreover, this interaction might be the catalyst that an IDU needs to begin a relationship that may result in their rehabilitation.

Nurses receive specific training based on their area of specialty. Care received from a nurse on the medical unit is different from that received in the ED, or on an inpatient psychiatric or detoxification unit, as the medical nurses do not typically receive the specialized training in addiction as a nurse on a detoxification unit would. In addition, the patient's stay is typically longer on a medical unit than in the ED, which results in longer nurse interactions. Identifying the positive and negative components of received nursing care experiences will increase the knowledge base available to inform nurses' clinical practice of caring for the IDU. What *is not* known is the IDU's perception and attitude toward received nursing care on the medical unit, and if this affects their decision of when to seek health care the next time it is needed. It is crucial to understand the IDU's experiences and aspirations in order to develop helping strategies to be employed by the nurse to provide effective care to this vulnerable population.



### **Purpose Statement**

The purpose of this study was to describe the IDU's most recent experience with nursing care received in the acute care setting. The aims of the descriptive case study research were to (a) describe the IDU's most recent experience receiving care from a nurse, (b) describe the IDU's interpretation of the meaning of this experience, and (c) describe if the IDU feels this experience has, or will have, an effect on when the IDU will seek care the next time it is needed. This study analyzed the factors and themes that emerged from interviews with IDUs about the care received from a nurse during a hospitalization on a medical unit. These rich interviews increased the understanding of the meaning and effect of these nurse encounters from the IDU perspective. Conducting this qualitative study allowed for the development of strategies for nurses to gain insight and, therefore, improve care for this vulnerable population.

### **Significance to Nursing**

Evidence is strong that IDUs and their HCPs have difficulty with communication and perceived care. The literature also shows that nurses and other HCPs feel they are poorly trained and lack the skills for working with this vulnerable population. Results of this research may assist nurses to understand the pivotal role they have in caring for stigmatized populations, decreasing complications from drug use, reducing health inequities, recognizing an opportunity to provide education about harm reduction, and the impact of the effect of marginalization on increased drug usage. Results of this study may change the current substance dependence treatment approach by providing nurses with the information needed to provide better care to IDUs and improve access to resources

across the addiction trajectory. The framework for this study was Travelbee's (1971) human-to-human relationship model.

### **Case Study as a Research Strategy**

The case study research strategy was chosen as this approach has the purpose of “investigating activities or complex processes that are not easily separated from the social context within which they occur” (Munhall, 2007, p. 350). The case study has been a common research strategy in the fields of sociology, psychology, social work, economics, and business (Yin, 1994, 2014). As cited in Baxter and Jack (2008), a case study design should be considered when you want to answer a “how” or “why” question, when behaviors of the participant cannot be manipulated, when the context of the situation is important, or when the boundaries between phenomenon and context are not clear. By employing this method, the researcher can better explore contextual conditions experienced by the participants in a way that another research method may not.

IDUs from two settings were solicited to participate in this study. One setting was a needle exchange service (NES) that primarily services individuals from the northwest section of the Commonwealth of Massachusetts. This setting was located in a predominantly Caucasian area with a median household income of \$54,413 (U.S. Census Bureau: Northampton, 2013), where approximately 14% of the population lives below the poverty line (U.S. Census Bureau: Northampton, 2013). Three different hospitals are located within this region.

The second NES site was located approximately 12 miles from the first study site, and is primarily Latino populated, economically depressed with a median household income of \$33,915, and more than 31% of the population is below the poverty limit (U.S.

Census Bureau: Holyoke, 2013). Individuals from this area typically use the same three hospitals located in this region. Hearing the stories told by IDUs from these different settings enabled the researcher to obtain a broad perspective of nursing care obtained in economically, ethnically, and socially different inpatient hospital experiences.

### **Research Question**

The following question served as the foundation for this study: What is the experience and meaning attributed to care by nurses, received by adult substance abusers during a health care encounter in the acute care medical setting?

### **Operational Definitions**

The following operational definitions informed the study:

- Unspecified Drug Dependence: “A state, psychic and sometimes also physical, resulting from the interaction between a living organism and a drug, characterized by behavioral and other responses that always include a compulsion to take the drug on a continuous or periodic basis in order to experience its psychic effects, and sometimes to avoid the discomfort of its absence. Tolerance may or may not be present. A person may be dependent on more than one drug.” (Unspecified Drug Dependence, 2015, para 1). The 2013 ICD-9-CM code for drug dependence is 304.9. (Center for Medicare & Medicaid Services [CMS], n.d.).
- Discrimination: “The unjust or prejudicial treatment of different categories of people or things” (Discrimination, 2013).

- Harm reduction: “A set of practical strategies and ideas aimed at reducing negative consequences associated with drug use” (Harm Reduction Coalition, n.d.).
- Health care provider: A nurse, nurse practitioner, physician, physician’s assistant, medical assistant, aide, or phlebotomist.
- Injection drug user: Any individual who has injected illicit drugs into their skin.
- Stigma: “The situation of the individual who is disqualified from full social acceptance” (Goffman, 1963, p. 9).
- Substance Use Disorder: “The essential feature of a substance use disorder is a cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues using the substance despite significant substance-related problems” (American Psychiatric Association [APA], 2013, p. 483).

### Summary

Illicit drug use remains a significant public health threat and contributes to rising health care costs associated with acute and chronic conditions (Drumm et al., 2003). Receiving assistance in the early stages of drug use may help to decrease the risk of contracting sexually transmitted infections, hepatitis, HIV, endocarditis, skin abscesses, and/or being incarcerated. In response to perceived marginalization from HCPs, the IDU will often delay treatment until their situation becomes life threatening or requires extensive treatment. Rather than openly disclosing their drug use and withdrawal symptoms, the IDU may instead make the decision to leave against medical advice

(LAMA) or continue their drug use while hospitalized, thereby further compromising their health care. Unfortunately, once an individual has a negative experience with a HCP, this interaction becomes the expected response that may cause the individual to be defensive during an initial interaction with future providers (Drumm et al., 2003; McCoy, Metsch, Chitwood, & Miles, 2001). A case study strategy was used as this approach allows for a variety of participant perspectives to be examined in order to understand a phenomenon. Understanding the experience and meaning that the adult IDU ascribes to the nurse/patient encounter in the acute care setting can inform and improve the quality of nursing care delivered to this vulnerable population.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### Introduction

Substance use and abuse is rampant not only in the United States, but also worldwide. Illicit drugs are classified as marijuana, hashish, cocaine (including crack), heroin, hallucinogens, inhalants, and a nontherapeutic use of controlled substances (SAMHSA, 2013). The most commonly used illicit drug is marijuana (SAMHSA, 2013). However, the use of marijuana is strongly associated with the use of other illicit drugs (SAMHSA, 2013). The number of individuals with pain reliever dependence increased from 1.4 million in 2004 to 1.9 million in 2012 (SAMHSA, 2013). With the rise in the use of illicit narcotic prescription use, the number of IDUs is expected to increase due to the easy access and lower cost of heroin, which serves as a replacement for prescription opioids.

Substance dependence is a chronic and relapsing disorder (Goldman, Oroszi, & Ducci, 2005). Unfortunately, withdrawal symptoms may not always be managed well in the acute care setting, which results in demanding behaviors and the individual leaving prior to completion of care. The stigma and discrimination received from the HCP has been shown to have negative physical and emotional effects (Aherna et al., 2007). What had not been well researched were the IDUs' experiences with received nursing care in the hospital. A review of the literature was performed to integrate and analyze the HCPs' perspective of caring for an IDU and the IDUs' perspective of care received from the HCP. Facilitators and barriers of the IDUs' received care were also reviewed and this will be reported below.

The essence of nursing is caring. While the IDU is in the acute care hospital recovering from a medical event related to their substance use, the nurse has the opportunity to implement the phases of an interpersonal relationship theory while caring for the vulnerable patient. An additional review of the literature for the nurse-patient relationship was also performed with a focus on the effects from an interpersonal process between the nurse and patient. An applicable interpersonal process theory to promote the development of rapport is Joyce Travelbee's (1971) human-to-human relationship model. A brief overview is included, as this theory served as the framework for this research study.

### **The Process of Review of the Literature**

Databases used for this review of the literature included Pub Med, CINAHL, Cochrane Library, Google Scholar, Academic Search Premier, PsychInfo, and Sociological Abstracts. Search terms included a variety of combinations of the following: injection drug user, injecting drug user, intravenous drug user, substance user, substance abuser, substance dependence, perceptions of care, attitudes or perceptions toward nurses, experiences with nursing and good nurse characteristics, social exclusion, health care personnel, and health care delivery and treatment barriers. Inclusion criteria included these terms: qualitative, quantitative or mixed review, pertaining to an injection drug user, reference of care from a health care provider that included a counselor, therapist, physician or nurse, stigma or discrimination voiced by the IDU and written in the English language. The goal of this review was to integrate and generalize findings. All abstracts were reviewed and exclusion criteria included articles not written in English, non-injection drug use, and care received by non-HCPs. A keyword search was initiated in

September 2010 and was updated again in December 2013 and December 2014. In addition, I had two PubMed searches on the National Center for Biotechnology Information (NCBI) collecting articles related to IDUs since 2013. I also performed a systematic review of the reference list of all selected articles.

### **Review of the Literature**

The review of the literature was initially separated into two major categories: (a) HCP's perspective on working with IDUs, and (b) IDU's perspective on received care from HCPs. There were an overwhelming number of studies about the HCP's perspective of caring for a substance-dependent person. There were significantly fewer articles about the IDU's perspective about received care from the HCP. A noted gap in the literature was the IDU's perspective on nursing care on a medical unit.

In order to understand the IDU's perceptions of received nursing care, it was important to begin to appreciate what the life of an IDU looks like. This review of the literature will provide a brief snapshot of the IDU, the HCP's views of caring for the IDU, the IDU's perceptions of received care from HCPs, facilitators of received care, and barriers to received care. Also included in this review were articles on the importance of the nurse-patient relationship.

### **A Snapshot of the IDU**

A number of studies have provided insight as to why an IDU began using drugs. Some of the most common factors seen among IDUs include the following: (a) history of childhood trauma (Hadland et al., 2012; Moneyham & Connor, 1995; Ompad et al., 2005; Roy, Haley, Leclerc, & Boudreau, 2007; Roy, Nonn, & Haley, 2008; Stajduhar, Funk, Shaw, Botoroff, & Johnson, 2009), (b) early deviant behavior (Dinwiddie, Reich, &



Cloninger, 1992), (c) substance-abusing parents (Abelson et al., 2006; Roy, Nonn, & Haley, 2008), (d) homelessness (Roy et al., 2008), (e) curiosity and peer pressure (Crofts, Louie, Rosenthal, & Jolley, 1996; Draus & Carlson, 2006; Roy et al., 2008), and (f) to have a sense of belonging (Fitzgerald, McDonald, & Klugman, 2004).

The science/field of genetics is only beginning to scratch the surface of the predisposition for an addictive disorder by analyzing monozygotic and dizygotic twin studies. Many researchers agree that addiction has both genetic and environmental factors (Goldman et al., 2005). Environmental factors contribute to exposure and initiation of drug use, but genetic factors have been shown to contribute to substance dependence (Ducci & Goldman, 2012; Tsuang, Bar, Harley, & Lyons, 2001). “Addictions are in a sense “end-stage” diagnoses because at the time a diagnosis is made, potentially irreversible neuroadaptive changes have occurred—changes that were preventable at an early point of the trajectory of the illness” (Ducci & Goldman, 2012, p. 519). Ongoing research in genetics may allow for earlier identification of those at risk for addiction so that targeted treatment may occur prior to the onset of irreversible neuroadaptive changes.

The most common substances used for injection are amphetamines and opioids. In 2007, the number of unintentional drug overdoses increased approximately 5 times the number of those in 1990 (Centers for Disease Control [CDC], 2010). Correspondingly, the number of drug-related visits to the emergency department in the U.S. increased over 70% since 2004 (SAMHSA, 2012b). Additionally, in FY 2011, heroin was the primary drug that adults sought treatment for in Massachusetts (SAMHSA, 2012a). A growing trend of purchasing illicit drugs online through underground trafficking centers is

emerging as another source of access (Hout & Bingham, 2013). The risky behaviors associated with substance use and misuse result in a number of encounters with HCPs for chronic diseases such as HIV, HCV, as well as sexually transmitted infections, endocarditis, and skin infections related to injection of illicit substances.

Individuals who are substance dependent will deliberately be manipulative in order to obtain what they need. In McLaughlin, McKenna, and Leslie's (2000) study, 15 out of 20 of the illicit users stated that they used the knowledge deficits of the staff and providers in order to obtain a prescription, and six of the 15 substance users admitted to lying and withholding information from their HCPs. The chronic drug user's life revolves around getting and using drugs.

Injection drug users typically underuse health care services and often only seek assistance for episodic care such as that associated with abscesses, endocarditis, overdose, and other substance-related disorders (Haber, Demirkol, & Murnion, 2009) in order to avoid unpleasant encounters with healthcare providers (Drumm et al., 2003). Evidence exists that female IDUs experience stigma more profoundly than male IDUs (Kirtadze et al., 2013; Swift & Copeland, 1998) and could lead to further complications and inadequate prenatal care for the pregnant IDU (Terplan, Smith, & Glavin, 2010).

The literature has also shown that even when the substance user is no longer using, the individual still experiences stigma. In one study, 84 men who had a dual diagnosis of mental illness and substance abuse were interviewed at the beginning of treatment and while they were highly symptomatic of their mental illness and substance abuse (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). The men were interviewed one year after being in treatment, and the researchers found that they still experienced

stigma despite being nearly symptom free of their mental illness and had ceased their drug use (Link et al., 1997). The differences between baseline stigma perception and post-treatment scores were minimal. This effect on depressive symptoms from perceived stigma can be presumed to last significantly longer than one year post-treatment (Link et al., 1997).

Similar results were found in Aherna et al.'s (2007) study, in which 1,008 illicit substance users were interviewed about stigma and discrimination related to their drug use. The participants revealed that avoidance of others who would look down on their drug use (73.8%), feeling ashamed of their drug use (68.4%), rejection from family (75.2%), and rejection from friends (65.8%), all contributed to their feelings of devaluation, alienation, and discrimination (Aherna et al., 2007). These coping mechanisms differed slightly from Link et al.'s (1997) study in that 45.2% of the individuals would talk to family or friends about the situation, 44.1% would become angry, and 40.6% would try to avoid being in that situation again. A significant limitation of this study was that the majority of the respondents were poor, ethnic minorities (Aherna et al., 2007). Although both the Link et al. (1997) and Aherna et al. (2007) studies looked at effects on mental health, only the latter study examined the physical health of the illicit user.

### **Mental Health as Comorbidity**

In addition to the risk of HIV, HCV, endocarditis, abscesses, skin infections, tuberculosis, and overdose, the substance user often is afflicted with a mental illness that is not always diagnosed or treated (Lo, Monge, Howell, & Cheng, 2013). In one secondary analysis, the researchers used the dataset from the 2010 National Survey on

Drug Use and Health to find that of the 5,241 full-time college students who completed the survey, 31.1% reported having a mental illness in the past year, 14% had just a prescription drug dependence, 6% had a prescription drug and alcohol dependence, and 7% reported a need for mental health treatment, but did not seek treatment for their mental illness (Lo et al., 2013). The researchers also concluded that those students who had a higher degree of mental health impairment also had a higher rate of alcohol and prescription drug use. A significant finding revealed that the group who felt they needed mental health services had nonmedical prescription drug dependence, but did not seek care (Lo et al., 2013). Findings from a SAMHSA survey found similar results with the use of nonmedical prescription drugs. According to SAMHSA's (2012a, "Young Adults Aged 18 to 25", para 1) report, "In 2011, the rate of current illicit drug use was higher among young adults aged 18 to 25 (21.4 percent) than among youths aged 12 to 17 (10.1 percent) and adults aged 26 or older (6.3 percent)."

In a prospective cohort study in Canada, 1,931 active IDUs from three different studies were examined for a history of depression, social support, and number of near fatal overdoses that occurred bi-annually over a 3-year period of time (Pabayo, Alcantara, Kawachi, Wood, & Kerr, 2013). Of the 1,278 males enrolled, 1,040 were found to have severe depressive symptoms (Pabayo et al., 2013). Findings from this study showed that the estimated proportion of men with depressive symptoms who had a near fatal overdose was 7.7%, and for women it was 10.4%. An interesting finding was that women with severe depressive symptoms who had three or more social supports were significantly less likely to experience a near fatal drug overdose (Pabayo et al., 2013). It is difficult to

determine if mental illness results in substance misuse or if substance misuse is the catalyst for the mental illness (Charles & Weaver, 2010).

### **Stigma and Discrimination Among the Users**

Stigma and discrimination from society is a common occurrence for the IDU. Interestingly, stigma and discrimination exist among the substance users themselves, with a general sense of a hierarchy among themselves. In Moore's (2009) ethnographic study, IDU individuals who do not share needles and dispose of the used syringes appropriately define themselves as being responsible users, as distinguished from "junkies," who are those users who do not behave in this manner. In addition, stigma can be found among those with HCV and those who are not infected, as those infected are deemed to be irresponsible (Fitzgerald et al., 2004). For some users, having visible track marks is a sign that the individual doesn't have enough self-respect to be presentable (Fitzgerald et al., 2004). The pregnant or homeless individual is viewed as being the lowest among IDUs (Simmonds & Coomber, 2009).

Interestingly, those who inject steroids and obtain syringes from a syringe injecting service are frequently concerned about being labeled a "junkie" (Simmonds & Coomber, 2009). The steroid users felt they were different because they rarely shared needles and did not have a dependence on or withdrawal from the drug (Simmonds & Coomber, 2009). Heroin users had a higher rate of reported discrimination than cocaine users, even when route of use (IDU or non-IDU) was controlled for (Crawford, Rudolph, Jones, & Fuller, 2012). The perception that cocaine is a middle-class drug has been widely reported. A poignant statement by a substance user summarizes what is generally seen in the literature for substance-dependent persons abusing any type of drug: "There

isn't a day that I've woken up and said, oh, I'm happy that I'm an addict. The fact is that I'm an addict. So I have to deal with that" (Stajduhar et al., 2009, p. 313).

### **Effect on the Family**

Addiction is considered a family disease (Henderson, 2000). A great deal of research has been done in the literature about the effects of having a family member who abuses illicit substances. Parents are usually the support for their addicted child. However, the parent has all of the social responsibility for the adult child, without any of the legal power to enforce rehabilitation. Much existing studies refer to parental grief in the context of the death of a child, or having a child with a devastating disability. According to Doka (1989, p. 4), disenfranchised grief is defined as "the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned, or socially supported." Because the IDU is still alive, the loss of a healthy parent/child relationship is not validated as a loss.

The burden of managing the problems associated with substance use inevitably falls on the family (Usher, Jackson, & O'Brien, 2007). The physical and psychological effects on the family of having an addicted family member are profound, and comparable to that of individuals with chronic illness such as schizophrenia or cerebral palsy (Hussaarts, Roozen, Meyers, van de Wetering, & McCrady, 2011; Usher et al., 2007). The stigma of injection drug use frequently extends to the parents of the substance user, and they often avoid seeking support from HCPs due to fear of being blamed or scrutinized (Corrigan, Miller, & Watson, 2006; Henderson, 2000; Jackson, 2003; Jackson & Mannix, 2003). The shame associated with having an addicted family member has been shown to be a barrier for the family seeking treatment for the substance abuser

(Corrigan, et al., 2006; Dion, 2014; Myers et al., 2009). Remarkably, in one study, the public held stigmatizing views of those with a family member who had a substance dependence disorder and not family members with a relative who had a mental illness (Corrigan et al., 2006).

### **HCPs' Views of the IDU**

Unfortunately, stigmas, discrimination, denial of services, or services withheld were found to occur in interactions between IDU and HCPs. The literature reviewed depicts how the IDU fails to differentiate between the care provided by a nurse, physician, pharmacist, or counselor. It has been well documented that HCPs, specifically physicians and nurses, have been reported to give less favorable care to the IDU, and have a preference to not work with this population (Brener et al., 2010; McLaughlin, McKenna, Leslie, Moore, & Robinson, 2006). Numerous studies demonstrate the difficulty of caring for the IDU (Crockett & Gifford, 2004; Habib & Adorjany, 2003; Myers et al., 2009; Treloar & Rhodes, 2009; Winstock, Nettis, Whitton, & Lea, 2009). In the acute care setting, IDU patients are often described as being difficult, manipulative, drug seeking, angry, demanding, and challenging (Brener et al., 2010; McCaffrey, Grimm, Pasero, Ferrell, & Uman, 2005; Natan et al., 2009). Physicians and nurses have admitted to having less pity, concern, empathy, and a general feeling of disgust, which led to less helpful behaviors toward the IDU (Aherna, Stuber, & Galea, 2007; Brener et al., 2010; Crockett & Gifford, 2004; Haber et al., 2009; Habib & Adorjany, 2003; Myers et al., 2009; Natan, Beyil, & Neta, 2009; Treloar & Rhodes, 2009; Winstock et al., 2009).

The IDUs' needs are complex as they are often faced with many

comorbidities, such as HCV and HIV/AIDS, requiring frequent interactions with the nurse as a care provider. Drug use is particularly stigmatizing because it is perceived to be under the control of the individual, and therefore the individual is blamed for the outcomes of the drug use (Brener et al., 2010). In Ding et al.'s (2005) study, physicians were surveyed to determine if they had a positive or negative attitude toward working with the IDU. The authors found that HIV-infected IDUs who were treated by physicians with a negative attitude toward them, had a lower rate of prescribed antiretroviral therapy than those treated by a provider with a positive attitude. Nurses who encounter a substance user feel uncomfortable treating the person and are concerned about becoming infected with HIV or HCV (Natan et al., 2009).

In one study, 369 nurses were surveyed using a pre-test to determine their perspective on the meaning of drug seeking (McCaffrey et al., 2005). Of the 369 nurses in the sample, 295 were nurses from general nursing, which included areas such as medical surgical, 35 nurses were from the ED, and 39 nurses were from a pain clinic. All three groups agreed that the following behaviors represented a drug seeker: (a) frequently comes to the same emergency department for opioids, (b) tells inconsistent stories about pain or medical history, and (c) asks for a refill because the prescription was lost or stolen (McCaffrey et al., 2005). The authors provided possible circumstances that may occur to explain these three behaviors identified as drug seeking that are other than addiction or abuse. For the individual utilizing the ED to obtain opioids, this may be the result of inadequate pain management for a chronic condition, a prior visit to a different ED that failed to manage pain sufficiently, or insurance that does not cover office visits. For inconsistent medical histories, this may be the result of a cognitive impairment,



psychiatric illness, and memory or communication impairments. For the final behavior of asking for a new script, items may be misplaced due to cognitive impairment, theft, or the individual simply ran out of their opioid due to inadequate pain control. The authors cited examples from the literature to support these rationales.

Some of the findings of that study included the recognition that when nurses were given this survey, 59.5% of the medical surgical, and 61.1% of the pain clinic nurses were less apt to use the stigmatizing term “drug seeking” after completing the survey. A noteworthy finding was that the ED nurses were fairly divided on continuing to use the stigmatizing term after completing the survey (McCaffrey et al., 2005). An important point is that by having a predisposed opinion of an individual, before the nurse was able to develop an understanding of the patient’s problem, was damaging to the individual.

### **IDUs’ Perceptions of Received Care From HCPs**

Many IDUs report discrimination and stigma not only in a societal context, but also in the privacy of a treatment room in a clinic or hospital. A limited number of articles described the IDU’s perspectives of received care. The majority of the studies included participants from outside the United States including Australia (31%), United Kingdom (20%), Ireland (7%), Canada (7%), and Bangladesh (3%). A review of the literature does not readily differentiate between the care given by a physician, nurse practitioner, physician’s assistant, or a nurse. In many of the articles reviewed, the substance user would make overarching general statements that made it difficult to discern who the individual was referring to as the term “they” would often precede a statement.

In addition, details of what defined “good” or “bad” HCP behavior were not always discernible. Instead, individuals would just categorize the provider as being “good” or “bad” (McCreddie et al., 2010). In Crockett & Gifford’s (2004) study, some participants reported positive interactions with physicians, nurses, secretaries, and consultants, but no specific examples were given as to what made these interactions positive. Neale, Sheard, & Tompkins (2007) found that IDUs who reported having experienced a helpful treatment encounter had better psychological and emotional health.

### **IDUs’ Perceptions of Received Care From Physicians**

Discrimination was an overarching theme to describe the IDU’s perceptions of received care from physicians. Discrimination was described as poor access to care, denial of services (Aherna et al., 2007; Day, Ross, & Dolan, 2003; Habib & Adorjany, 2003; Swan et al., 2010), and failure of the provider to inform them of potential services because of injection drug use and/or infection of hepatitis or HIV/AIDS (Habib & Adorjany, 2003; Link et al., 1997; Neale, Tompkins, & Sheard, 2008; Winstock et al., 2009). Respondents cited examples of denial of services such as surgery, sleep medications, antidepressants and medical treatment (Habib & Adorjany, 2003; Neale et al., 2008; Winstock et al., 2009). Some of the richest evidence of less favorable treatment comes from Neale et al.’s (2008) qualitative study in which current injectors described situations in which they were looked down upon by health care personnel and made to feel less worthy than others of obtaining assistance. Many IDUs reported that they are viewed as being weak, immoral, and were threatened with having their medications discontinued or the provider discontinuing their care (Habib & Adorjany, 2003; Neale et al., 2008). The usual occurrence of being discriminated against may cause the IDU to

internalize this stigma and, therefore, they expect to be discriminated against while interacting with the HCP (Link et al., 1997; Tindal, Cook, & Foster, 2010).

Attitudes of health care personnel toward the IDU ranged from judgmental to hostile (Hindler et al., 1996), with some personnel verbally stating that the individual “deserves” what they have. One 29-year-old woman stated, “The doctor actually said to me, ‘You have inflicted it on yourself and you shouldn’t really be here, because you are wasting not only our time, but [the time of] whatever family you have got’” (Neale et al., 2008, p. 150). Another participant who was trying to show an infected injection site stated, “He [doctor] said, ‘Oh, I can’t do nothing about that.’ He said, ‘If it gets any worse, go to casualty,’ and that was the end of that. Well, they are supposed to refer you and have a look at the injection site and make sure there is no infection” (Neale et al., 2008, p. 149). In another study, an alarming 68% of 178 IDUs reported discrimination because of their drug use, with one female stating, “He would not give me anything to help...because I was a user” (Habib & Adorjany, 2003, p. 261). In Winstock et al.’s (2009) study, injection users would wear long-sleeve clothing to hide their injection marks due to fear of being the target of discrimination.

The literature provided instances of IDUs’ positive interactions with HCPs. Examples included help with accessing services and treatment such as housing assistance, furthering their education, information and support for domestic violence, and mental health issues (Neale et al., 2008). Two female IDUs cited examples of positive interactions with their providers; one provider was the woman’s doctor for a long time and the other provider was familiar with the issues surrounding injection use (Crockett & Gifford, 2004; Neale et al., 2008). Familiarity and long-term relationships with the

provider proved to be beneficial for the IDU, as cited in Swan et al.'s (2010) study, "Even though I have slips...I can talk to me doctor (GP) about it" (p. 758). Honesty, caring about the person, taking the time, and listening were all cited as examples of positive provider behaviors that were experienced in a group of 21 individuals receiving treatment at a HCV center (Bruning, Klar, Butt, & Nijkamp, 2012). The most positive statements made by IDUs were toward addiction specialists (McLaughlin et al., 2000).

### **IDUs' Perceptions of Received Care from Nurses**

The literature often combines nurses and physicians together when describing the HCP. Although the physician does see the IDU at least once a day in the acute care hospital, the majority of time is spent with the nurse. Information is scarce on the IDUs' perceptions of received nursing care. Much of what has been reported in the literature is not favorable to nurses. HIV-infected IDUs reported that the nurses stigmatized them due to the mode in which they became infected and by violating confidentiality (Surlis & Hyde, 2001). Other examples of negative interactions included nurses who were judgmental and dismissive (Fitzgerald et al., 2004). When one IDU expressed to the nurse that he was in pain, the nurse stated, "Well that's what you get for using drugs" (Surlis & Hyde, 2001, p. 72). In the same study, not all participants were critical of nurses' attitudes, as participants cited nurses who were supportive, nonjudgmental, and treated the HIV-infected IDU as a "normal patient" (Surlis & Hyde, 2001). In like manner, participants who received care from their HCV providers cited the nurses as being compassionate and caring (Brunings et al., 2013; Shattell, Starr, & Thomas, 2007). In another study (Shattell, Hogan, & Thomas, 2005), 20 participants between the ages of 24 and 90 were interviewed about their acute care hospital experience. Human

connectedness was a considerable aspect of what made the experience positive or negative. “It’s the people that make the environment good or bad” and “I think it’s the staff that make or break a patient’s stay” (Shattell et al., 2005, p. 161).

An initial barrier noted between the IDU and nurse was the difference between the hospital environments being highly structured, which is synonymous with authority and control, and the lack of structure and chaos that is typical in the life of an IDU. The nurse works within the confines of the hospital structure for workload, documentation, tasks, and limited resources. An example of the hierarchical structure of the health care environment and the effects on the care of IDUs is when medications such as methadone are given according to hospital convenience, not the substance user’s normal routine (McCreddie et al., 2010). This rigid approach led to discomfort due to early withdrawal symptoms and the substance user’s belief that the nurse was solely responsible for the timing of the medication to be administered.

Lack of empathy, uncaring behaviors, stigmatizing behaviors, and violation of the substance user’s confidentiality were the primary themes noted as negative behaviors displayed by nursing personnel toward the substance user. Statements from substance users such as “nurses shouldn’t be in the job” (McCreddie et al., 2010, p. 2735) in regard to behaviors of “looking down on,” stigmatizing, and potential ethical erosion, were evident in the literature. One theory of the reason that nurses have compromised caring with the substance user is the expectation that nurses working in the acute care center are accustomed to admitting patients, treating them successfully, and discharging them (Healy & McKay, 2000). If the patient is not discharged as a “successful treatment,” the nurse internalizes this as a personal failure. Admitted stress of caring for

the IDU often causes avoidance, which is a compromised coping mechanism (Healy & McKay, 2000). Unfortunately, drug cessation is not the usual discharge outcome as relapse is part of a potential recovery in the trajectory of substance users (Genberg et al., 2011; Henderson, 2000).

Examples of uncaring behaviors that were deliberate included a nurse at a needle replacement center withholding a syringe from an IDU for an extended period of time. When confronted by another person pleading to the nurse to just provide the needle to the person, the nurse provided the needle but stated, “I should be giving you a bloody horse needle” (Fitzgerald et al., 2004, p. 11). Other examples of the ethical erosion of the nurses included a participant in Surlis & Hyde’s (2001) study stating that a nurse told him “We haven’t got time for you, there’s more sicker people than you” (p. 71). Blaming the IDU for being infected with HIV or HCV was another area in which uncaring behaviors were displayed by nurses as evidenced by one nurse’s statement about an IDU, “Well you knew the virus was out, so long ago, and why are you still using” (Surlis & Hyde, 2001, p. 72).

The stigma of being substance dependent carries on even while receiving treatment. One participant reported a nurse stating, “right, blue eyes, here’s your green monster” (McCreaddie et al., 2010, p. 2737) while dispensing the person’s methadone. Respondents cited other examples of stigma and discrimination such as not being able to have visitors while in the hospital, not being given education about inpatient and outpatient care, failure to medicate heroin users with a substitute medication while an inpatient, and physicians being unwilling to continue to care for the person due to cancelled appointments or fear that they will be drug seeking (Neale et al., 2008).

It has been suggested that nurse behaviors mirror societal behaviors, which places the IDU at a disadvantage before the person is given an opportunity to disprove the stigma (Corley & Goren, 1998). Examples of these nursing behaviors may include: expecting the IDU to be demanding, difficult, drug seeking, non-adherent to their medication regime, and that the individual will leave against medical advice. The IDU may see the stigmatization and react by behaving in the manner that the nurse expected the IDU to display (Corley & Goren, 1998). Meeting an individual who either admits to injection drug use or displays evidence of use of substances often results in an immediate negative judgment by the nurse. The nurse and physician often perceive the IDU's responses to questions to be suspicious or exaggerated in an attempt to drug seek (Windish & Ratanawongsa, 2008). This initial reaction is a barrier to not only hearing the patient but also to truly understanding the situation.

### **IDUs' Perceptions of Received Care From Other Community Providers**

Other community health care personnel who are typically involved in an IDU's life include pharmacists, counselors, outreach workers, and individuals located in a NES. In 2006, Massachusetts allowed pharmacies to sell sterile syringes without a prescription, to persons over the age of 18. This led to an increase in the interaction between the IDU and pharmacist. Received care from these individuals outside the hospital personnel ranged from being very positive to being stigmatizing and discriminatory.

Interactions with pharmacists and pharmacy staff were generally negative (Neale, 1998; Simmonds & Coomber, 2009). Pharmacies would sell syringes only during certain hours (Neale et al., 2007), refuse to sell syringes to individuals, overcharge for them, or demand that a homeless individual get "cleaned up" before coming back to the pharmacy

(Pollini et al., 2010). A common theme noted was the image that the pharmacist wanted, and didn't want, for their establishment (Simmonds & Coomber, 2009). Some IDUs felt that once they developed a rapport with the pharmacist and staff, they were treated like any other customer (McLaughlin et al., 2000; Neale, 1998; Pollini et al., 2010).

Specialist addiction staff was rated in the highest regard by the IDU (McLaughlin et al., 2000; Neale et al., 2007). One participant stated an example of feeling cared for: "That's the main thing that gets me, they listen to you, they comprehend what you are talking about and they can give you some sort of resolve for it" (McLaughlin et al., 2000, p. 438). Workers at NESs generally received positive comments from the IDU (Treloar & Cao, 2005). One barrier noted was being seen using the NES as this made it apparent to others that the individual was an IDU (Fitzgerald et al., 2004; Treloar & Cao, 2005).

### **Facilitators of Perceived Care**

Positive examples of interactions with nursing personnel were also evident within the literature. The majority of the statements had to do with the interpersonal relationship formed between the patient and nurse. Individuals cited examples of nurses advocating for them to receive HCV treatment by suggesting to the patient that they downplay their substance use as the provider would not provide treatment to anyone actively using substances (Hopwood & Treloar, 2007). Providing information, support, an empathetic ear, and a general sense of caring about the IDU was also noted to make receiving care easier for the person (Swan et al., 2010). Continuity of care with the empathetic, knowledgeable, and caring nurse allowed the IDU to feel comfortable seeking care and asking questions (Swan et al., 2010). Recognizing that mistakes happen and that the individual should not be shamed for their illness was an example of how a HIV-infected



individual described the response from a supportive nurse (Surlis & Hyde, 2001). A simple act of making a cup of tea and being treated as “normal” was recalled as being part of a supportive environment (Surlis & Hyde, 2001). Effective and therapeutic communication was noted between the IDU and nurse in a center that specialized in HCV care (Brunings et al., 2013).

### **Effect From a Non-Marginalized and Harm Reduction Approach**

Substance-using individuals have cited a variety of turning points in their lives that led to less substance use or recovery. Caring relationships (Drumm et al., 2003; Lee & Petersen, 2009; Moneyham & Connor, 1995; Neale et al., 2007; Swan et al., 2010), significant loss (Moneyham & Connor, 1995; Neale et al., 2007), or a change in health status (Moneyham & Connor, 1995; Neale et al., 2007) have been shown to be influential turning points in the lives of persons with a substance use disorder. The nurse has the ability to provide prevention, intervention, and harm reduction actions throughout the IDU’s hospital stay. Although limited in the interaction time, the ED nurse has the ability to begin the destigmatization toward the IDU by being a patient advocate and initiating a therapeutic nurse-patient relationship. The nurse on an inpatient medical unit has the opportunity to provide care for the IDU during a shift that is normally 8–12 hours.

Prior research done on a harm reduction treatment program for marginalized homeless substance users proved to be beneficial in understanding and planning for treatment of this vulnerable population (Lee & Petersen, 2009). The program was based on the philosophy that the individual “experiences the treatment setting in a destigmatizing, normalizing, and humanizing manner, which is non-judgmental and where open conversation about drug use and other matters is encouraged” (Lee &

Petersen, 2009, p. 625). The authors report that the findings from the original, unpublished work had positive outcomes for “demarginalization, engagement in the program, quality of life, social functioning, changes in substance use, and articulation of future goals and plans” (Lee & Petersen, 2009, p. 625).

Similar findings were found when 74 Canadian substance users were asked to identify descriptions of what a helpful “service provider” looked like (Allmana et al., 2007). The individuals described service providers that were non-judgmental, professional, demonstrated the ability to accept free will, caring, communicative, and maintained confidentiality as favorable qualities (Allman et al., 2007). All of these positive provider characteristics can be instrumental in promoting humanized, patient-centered care. In addition, demonstration of caring behaviors can decrease the impact of stigma and discrimination that often results in increased substance use, LAMA, and avoidance of HCPs. Logic suggests that if at all possible, IDUs will avoid care providers who are hostile, judgmental, biased, disrespectful, or negative.

### **Barriers to Received Care**

#### **Lack of Knowledge and Training**

IDUs cited the nurse’s lack of knowledge, training, and experience of working with the substance-dependent person as being both a barrier to treatment (Drumm et al., 2003), and a way for the IDU to manipulate the staff into accessing medications (McLaughlin et al., 2000). Individuals would demonstrate dramatic behaviors in order to obtain prescriptions. The substance users would also share which providers were considered easy to deal with, to manipulate, and to access medications easily from (McLaughlin et al., 2000).

Medical-surgical nurses identify that they often lack the time, knowledge, and training to work with substance users. These limitations negatively affect the nurses' opportunity to intervene, plan, and evaluate for proper care of the substance user and, therefore, results in patients being inadequately managed (Kelleher & Cotter, 2009; Munro, Watson, & McFadyen, 2007; Natan et al., 2009; Tran, Stone, Fernandez, Griffiths, & Johnson, 2009).

Often, HCPs receive little education about managing the care of the IDU; thus they become easily frustrated by behaviors seen in the person with an addiction disease. In one study done at three emergency departments in Ireland, of the 58 nurses and 8 physicians surveyed, over 73% of the respondents stated they had not received specific training regarding alcohol and other drugs, despite 75% of the respondents stating they had daily interactions with patients with alcohol and/or other drug problems (Kelleher & Cotter, 2009). Surprisingly, only 10% of the respondents felt that patients with substance use disorders were inadequately managed because the provider lacked training; 66% of the respondents stated it was because there was a shortage of services or that the patients themselves were difficult to manage (Kelleher & Cotter, 2009).

The findings of Munro et al.'s (2007) randomized controlled study are in stark contrast to the self-reported view on training in Kelleher and Cotter's (2009) study as there were statistically significant differences between the 49 nurses' therapeutic attitudes after receiving a 4-day training than there were before the training. The results of Munro et al.'s (2007) study demonstrate that training has an impact on nurses' attitudes. In Happell, Carta, and Pinikahana's (2002) study, 134 nurses completed a survey on their knowledge, attitude, beliefs, and practices. Results of this study were encouraging in that

overall, the nurses were found to have adequate knowledge and problem-solving abilities regarding alcohol and drug use. However, the findings also revealed a need for training in identification of substance withdrawal, management of dual diagnosis, and detoxification (Happell et al., 2002). The nurses' perceptions of the need for training appear to be in conflict with the findings of the two aforementioned studies.

### **Failure to Identify Upon Admission to the Hospital**

Substance users do not often self-identify or are not identified by physicians or nurses upon hospital admission, which may lead to unexpected drug withdrawal, complications, and the patient leaving against medical advice, all of which further increase the cost associated with re-admittance to the hospital (Chan, Stooove, & Reidpath, 2008; Haber et al., 2009; Lind, 2003; Tran et al., 2009). These limitations affect the opportunity to intervene, plan, and evaluate for proper care of the substance user and therefore, results in patients being inadequately managed for their specific needs (Kelleher & Cotter, 2009; Munro et al., 2007; Natan et al., 2009; Tran et al., 2009). The ever-changing substance use terminology used by the patient may be unfamiliar to the health care professional, which may lead to a communication gap between the nurse and substance user. Even when the patient discloses the drug and amount used, the nurse may not recognize the severity of the addiction if the patient uses slang terminology.

“Furthermore, the assessment interview has historically been characterised as the ‘starting point in any nurse/patient relationship’ ... where a nurse’s time and skill are required to reveal the patient” (Jones, 2007, p. 213). Failure to assess and treat due to an individual’s drug use is a missed opportunity to provide harm reduction education,

prevention, and intervention techniques, which promote self-care, and decrease health care complications.

### **Lack of Confidentiality**

Breaching confidentiality occurred with individuals who were infected with HIV (Surlis & Hyde, 2001), HCV (Fitzgerald et al., 2004; Swan et al., 2010) and receiving methadone (McCreaddie et al., 2010; Neale, 1998). Participants noted that they overheard nurses telling other patients that there were addicts on the floor, as well as informing one patient to hide his belongings (Surlis & Hyde, 2001). A woman infected with HCV recounted when she had given birth, “All the doctors, nurses etc. were yelling loudly, get your gloves on, be careful, she’s got hep C” (Habib & Adorjany, 2003, p. 260). A disregard for the privacy of the substance-dependent person is common for the substance user (Surlis & Hyde, 2001). Although many factors must be considered when determining if an individual avoids health care due to feeling discriminated against and how this affects their health care needs, it is essential to recognize that informed and nonjudgmental HCPs must be part of the IDU’s health care team. Although one would expect nonjudgmental HCPs, the literature clearly proves that this is often not the case for the IDU.

### **Leaving Against Medical Advice**

Unfortunately, substance users often do not self-identify or are not identified by the HCPs upon admission to the hospital. This lack of identification may lead to unexpected drug withdrawal, complications, and/or the patient leaving before their treatment is complete, all of which further increase costs associated with re-admittance to the hospital (Chan et al., 2008; Conway & Fairbrother 1999; Haber et al., 2009; Lind,

2003; Tran et al., 2009). Nationally, substance abusers have odds for LAMA that are 5 times higher than non-substance abusers (Tawk, Freels, & Mullner, 2013). Two of the top five reasons for LAMA are mental illness and substance abuse (Stranges, Wier, Merrill, & Steiner, 2009). Poor communication (Onukwugha et al., 2010; Windish & Ratanawongsa, 2008), mistrust, and conflict have been cited as some of the multifactorial reasons that patients leave the hospital against medical advice (Windish & Ratanawongsa, 2008).

Leaving before medical treatment has been completed often results in readmission for the same problem within a short period of time, increased health care costs, and a higher risk of morbidity and mortality (Corley & Link, 1981). In Chan et al.'s (2008) study, of the 1,056 IDUs admitted, 263 (24.9%) left AMA. Individuals who were prescribed in-hospital methadone use had a lower rate of LAMA than those who did not receive methadone (Chan et al., 2008). In Endicott and Watson's (1994) study, the nurses noted that 26.5%–50% of their LAMA discharge rates were opiate-addicted individuals. By implementing the following four strategies on the unit, the nurses noted a drop to 20% of opiate-addicted individuals LAMA: (a) a treatment pledge, which provided information about the opiate-withdrawal process, (b) medication changes to deal with withdrawal symptoms, (c) an opiate-withdrawal scale that included the patient's input as to where they were on a withdrawal scale, and (d) a community resource link for community resources to provide support during the withdrawal process (Endicott & Watson, 1994). Development of a therapeutic nurse-patient relationship, performing accurate assessments, treatments, and addressing substance use issues early in the

admission process may decrease the chance that an IDU will leave the hospital prior to receiving the recommended medical treatment.

In another study (Onukwugha et al., 2010), focus group interviews were held with three separate groups of HCPs and substance users: 18 patients (6 in each group), physicians (5), and another group that had both nurses (6) and social workers (4) in one group to hear what each group felt were reasons that patients LAMA. Findings from these focus groups included seven common themes as reasons for LAMA among the three groups. These themes included “1) drug seeking patients, 2) pain management, 3) other obligations, 4) wait time, 5) doctor’s bedside manner, 6) teaching-hospital setting, and 7) communication” (Onukwugha et al., 2010, p. 421). The most common theme for a solution to decrease the rate of LAMA was increased communication. With the ever-rising health care costs, the institution may be placed at financial risk with this increasing rate of LAMA discharges and re-admittances requiring costly care.

Recognizing the high-risk patient prior to the beginning of withdrawal symptoms may interrupt the behaviors that health care personnel recognize as making the substance user difficult to work with, and the substance user LAMA. Anticipating and intervening prior to the withdrawal period for an abused drug can alleviate the fear of withdrawal, decrease the physical symptoms experienced, decrease the negative behaviors, and increase the communication an IDU has with the HCPs (Gerace, Hughes, & Spunt, 1995; Haber et al., 2009; Kelleher & Cotter, 2009). Patients who are not satisfied with the care they receive seldom follow up with their HCPs and are less likely to adhere to medications, directions, and advice (Johansson, Oleni, & Fridlund, 2002).

### **Fear of Withdrawal Symptoms**

Recognizing the high-risk patient prior to the beginning of withdrawal symptoms may interrupt the demanding and disruptive behaviors that health care personnel identify as making the substance user difficult to work with. These behaviors include the patient being viewed as drug seeking, increased anxiety, and general demanding behaviors (Chan et al., 2008; Chang et al., 2008; Haber et al., 2009). In Natan et al.'s (2009) study, nurses who had stereotypical views of drug addicts perceived the quality of care that they provided to patients who were drug addicts to be lower than that provided to other patients. Anticipating and intervening prior to the withdrawal period for an abused drug can alleviate the fear of withdrawal, decrease the physical symptoms experienced, decrease the negative behaviors, and increase the communication a substance user has with the HCP (Haber et al., 2009; Kelleher & Cotter, 2009). IDUs cited examples of not being medicated for their withdrawals, delay in receiving their methadone, and inadequate pain control (Habib & Adorjany, 2003). By identifying the substance user upon admission to the acute care medical unit, the nurse can advocate for the individual to receive buprenorphine/naloxone or methadone according to evidence-based practice (Handford et al., 2011).

### **Missed Appointments, Lengthy Waiting Times, and Numerous Providers**

Many IDUs cited lengthy waiting times (Drumm et al., 2003; Neale et al., 2007; Swan et al., 2010), missed appointments (Swan et al., 2010), and being dropped from services because of missed appointments (Neale et al., 2008) as being barriers to receiving treatment from HCPs. Barriers to treatment such as transportation, finances, not having a telephone to make or cancel appointments, and the vast number of health care



appointments with various providers in different locations, all contributed to the IDUs' inability to effectively utilize services. These barriers often resulted in a vicious cycle of providers dropping the person from their caseload due to missed appointments (Neale et al., 2008).

### **The Nurse-Patient Relationship**

According to the U.S. Department of Labor Bureau of Labor Statistics (2014), more than 2.7 million registered nurses are employed nationally. The nurse is in the unique position of caring for an individual's biopsychosocial needs, adjusting a plan of care based on outcome measurement, recognizing the behavioral and medical needs of a client, as well as being able to provide the emotional connection that promotes a healing environment. The nurse-patient relationship is a significant aspect of the hospitalized patient's experience.

The term "nurse-patient relationship" is frequently used, but the definition is nebulous and varies among nursing specialty areas. The nurse-patient relationship can be seen as dynamic, complex, interactive, and evolving. Oxford Dictionaries Online (Relationship, 2010) defined relationship as "the way in which two or more concepts, objects, or people are connected, or the state of being connected" and "the way in which two or more people or organizations regard and behave toward each other." Similarly, Merriam-Webster (Relationship, 2010) has the same definitions with an additional aspect of "a specific instance or type of kinship."

The concept of the nurse-patient relationship can be traced back to Florence Nightingale (Wagner & Whaite, 2010). This concept has evolved in that the intended outcome is no longer caring only for the physical being, but now focuses on the

psychosocial being of the patient as the primary focus (Halldorsdottir, 2008; Wagner & Whaite, 2010; Whiting, 1959). The nurse-patient relationship is considered to be the essence of nursing, and an expectation in every interaction between the nurse and patient (Halldorsdottir, 2008; Moyle, 2003; Williams, 2007).

The nurse-patient relationship is a central component to the overall health and wellness of a patient. Currently in hospitals, patient satisfaction is measured as a quality indicator. A number of theoretically informed studies about the nurse-patient interaction were evident in the review of the literature (Courey, Martself, Draucker, & Strickland, 2008; Merritt & Procter, 2010; Shattell, 2004, 2005). Numerous researchers have revealed that when the nurse demonstrates interpersonal care such as courteousness, kindness (Berg, Spaeth, Sook, Burdsal, & Lippoldt, 2012), responsiveness, attentiveness, calmness, being encouraging (Johansson et al., 2002; Shattell et al., 2005), being respectful, displaying empathy, listening (Shattell, 2004), using soft-hand care, being compassionate, appropriate use of touch (Irurita, 1999) and other caring behaviors, these behaviors directly correlate with higher patient satisfaction scores.

The nurse and patient as a dyad have been extensively researched in the nursing literature. The consequences of the nurses' behaviors in regard to internal factors such as labeling the patient are preconceptions that may be detrimental to an effective and therapeutic nurse-patient relationship. When an emotional wall is formed between the nurse and patient, detachment and distrust occur (Halldorsdottir, 2008).

The individual's connection or disconnection to nurses is an important element in the hospitalized patient's view on received care. "A positive approach can communicate hope and help to strengthen the patient" (Hansson, Fridlund, Brunt, Hansson, & Rask,

2011, p. 444). Patients in the acute care setting experience vulnerability (Irurita, 1999; Shattell et al., 2005; Shattell, McAllister, Hogan, & Thomas, 2006) and feel the hospital is dangerous, confining, and an insecure place (Shattell, 2005). The technological world in which we live may also threaten the nurse-patient relationship by diverting attention from the patient and directing it toward the electronic device that is now used for documentation and medication administration in the hospital setting (Foster & Hawkins, 2005). The nurse may easily miss the nonverbal behaviors that the patient may display, which is a missed opportunity for further communication between the dyad. A nurse-patient relationship that includes competence, willingness to listen to the patient (Shattell et al., 2007), confidence and commitment, is the best environment to meet the health care needs of the patient in providing a healing and comfortable environment (Bernstein, Brophy, McCarthy, & Roepe, 1954; Moyle, 2003; Wagner & Whaite, 2010; Williams, 2007).

The significance of the nurse-patient relationship is detailed in the literature. In a study done by Polcin, Mulia, & Jones (2012), 38 recovering substance users and alcohol abusers were interviewed about unhelpful and helpful confrontations that propelled them toward their recovery. Unhelpful confrontations included (a) hypocrisy, (b) being overtly hostile, and (c) occurring within embattled relationships (Polcin et al., 2012, p. 147). Six themes of helpful confrontations were identified: (a) perceived as legitimate, (b) offer hope and practical support, (c) delivered by persons who are trusted or respected, (d) delivered by persons who are very important relationships, (e) received after experiencing a severe event or an accumulation of negative events related to substance use, and (f) received during early recovery (Polcin et al., 2012, p. 147). Brief motivational

interviewing and intervention is common (Saunders, Wilkinson, & Phillips, 1995), and is the recommendation from the Department of Veteran Affairs for management of substance use disorders (Department of Veteran Affairs, 2009). The nurse is easily able to fulfill this helpful role while working with the patient in the hospital.

For this study, the theoretical perspective of Joyce Travelbee's (1971) human-to-human relationship model was used. This framework is based on the assumption that the nurse and patient should travel through phases that go from orientation to development of rapport, in order to develop the human-to-human relationship. A description of the model and phases will be explained below.

### **Joyce Travelbee's Human-to-Human Relationship Model**

Joyce Travelbee was born in 1926, and died unexpectedly at the age of 47. She was a psychiatric nurse, educator, and writer, who passed away while engaged in her Ph.D. studies. Travelbee was the Director of the Graduate Education program at Louisiana State University up until her death. Her theory was based on both a deductive and presumed inductive approach, as she remained active in psychiatric clinical nursing up until the time of her death. Although studies based on Travelbee's (1971) theory are limited, her theory has informed the clinical work of nurses to decrease burnout (Cook, 1989) and to determine nursing behaviors in bereavement (Freihofer & Felton, 1976).

The claim of Travelbee's (1971) theory is based on Viktor Frankl's existentialist work of logotherapy, which is a psychotherapy aimed at the importance of meaning in a person's life (Viktor Frankl Institute of Logotherapy, n.d.). Evidence of this influence can be found through several references within the book (Travelbee, 1971, p. 158), as well as a strong emphasis on the concept of "meaning." Meaning of an experience, including

illness and suffering, is emphasized throughout Travelbee's (1971) book. "Meaning is the reason given to particular life experiences by the individual undergoing the experience" (Travelbee, 1971, p. 162). Those who surround the ill person (i.e., nurse, family, friends') cannot "give meaning" to the person; they can only help the person to arrive at his/her own meaning of the experience.

Travelbee's (1971) theory speaks to an interpersonal process between two human beings, one who needs assistance, and the other who is able to provide the assistance. This interpersonal theory was appropriate for the proposed study as the IDUs perspective/meaning of the interaction between the patient and nurse was being sought. The theory is based on Travelbee's (1971) belief that the "nurse" and "patient" cannot establish a relationship until each individual perceives the other as a human being (p.119). A major assumption of the theory is that a human-to-human relationship can occur only after the nurse and recipient of care have progressed through four interlocking phases. These phases are (a) the original encounter, (b) emerging identities, (c) empathy, and (d) sympathy. The completion of these four phases results in the final phase of rapport, which results in the establishment of the human-to-human relationship.

The first phase of Travelbee's (1971) theory is the original encounter. During this phase, the nurse encounters the person for the first time and makes inferences about this encounter, which have an impact on decisions made by the nurse. Travelbee (1971) states, "These inferences are important because what one 'sees' or perceives about another—the thoughts and feelings engendered—tends to determine how one will behave or react towards the other individual" (p. 130). This first encounter is when the nurse and other person use first impressions, verbal and nonverbal cues, feelings, and prior

experience to base one's initial value judgment. Travelbee stresses that at this point, the nurse and other person must break the bond of categorization and recognize the other as being a unique individual. If either person fails to do this, then the relationship cannot move to the next phase and rapport cannot be achieved. By recognizing each other as human beings, the hierarchical relationship of nurse and "patient" is nonexistent.

The second phase of Travelbee's (1971) theory is emerging identities. It is during this phase that each individual recognizes the other as unique and establishment of a bond begins. This phase lays the foundation for empathy, which is an important phase of this theory. The emerging identities phase may be troublesome if the nurse over-identifies with the other person, as this is the result of the nurse's inability to separate himself/herself/zerself from the other person. It is at this point that if the nurse and other person are markedly different, the nurse may discount the other person as being someone who "doesn't know better" (Travelbee, 1971).

The next phase of empathy is thought to be one of the most important phases of the theory. Empathy is described as a conscious process in which one person is able to predict the behavior of another. In order for empathy to occur, there must be some similarities between the persons, "the thoughts and feelings of the other person are accurately perceived" (Travelbee, 1971, p. 137). The initial inferences made about the other person resurface during this phase and either change, or remain the same. It is at this point that the nurse is sharing in the experience of the other person. An interesting facet that Travelbee (1971) emphasizes is that nurses should not strive to be nonjudgmental. Instead, the nurse should strive to be aware of the judgments made about

the other person. Being empathetic is not enough to move the interpersonal process forward; it is the next phase of sympathy that provides the prelude to action.

Sympathy is the fourth phase of the theory, and it is at this point that the nurse wants to relieve the other person's distress, or lessen the suffering being experienced, but either does not help, or does not know how to help. The nurse is not incapacitated at this point; rather, involved with the other person's experience. Sympathy is not being courteous or kind. Instead, sympathy is a caring quality that cannot be feigned and is experienced on a feeling level (Travelbee, 1971). This requires the nurse to care, and to provide emotional support to sustain another person during their time of need. The person in need perceives the nurse as a caring and helping human.

Rapport is the final dynamic phase of Travelbee's (1971) theory. This phase is the goal of the human-to-human relationship. The nurse and "patient" must move through the previous four interlocking phases before attaining this goal. It is at this point that the nurse demonstrates interventions that lessen the other person's suffering. Although the nurse may not be able to alleviate the other person's distress, the nurse must not add to the distress. Travelbee (1971) states that rapport does not just "happen"; instead, it is established and built upon with each interaction.

Patients from a vulnerable population who experience stigma and discrimination may benefit from the application of Travelbee's (1971) theory as the focus is on each person's uniqueness, and demonstration of caring behaviors. Travelbee's (1971) theory meets the persons "where they are at" at that time and does not attempt to progress the individual's personality development. The interpersonal relationship between the nurse and patient is not only the core of nursing but is essential to the well being of both the

nurse and patient. To cultivate a nurse-patient relationship, the nurse must be able to holistically demonstrate commitment, competence, foster goodwill toward the patients, as well as being willing to listen, advise, and to meet the patients where they are at for that time.

### **Summary**

This chapter reviewed the literature that is relevant to the IDU's experience with health care providers. The five major areas reviewed included the following: a brief snapshot of the IDU, the HCP's views of caring for the IDU, the IDU's perceptions of received care from HCPs, facilitators of received care, and barriers to received care. A snapshot of the IDU in the literature revealed that the IDU often has mental health issues as a comorbidity, experienced stigma and discrimination among other IDUs, and that the IDU's substance dependence had a negative effect on the family. There were a significant number of articles pertaining to the HCP's view of working with the IDU. The findings of these studies were generally negative. The IDU is perceived to be difficult to work with, manipulative, and drug seeking. The IDU's views of the HCP were also generally negative in the literature. The IDUs experienced stigma, discrimination, judgmental behaviors, and an overall lack of caring from their HCP. Facilitators of perceived care for the IDU were less populated in the literature, but behaviors such as being treated as "normal," the provider being nonjudgmental, and the HCP's implementation of harm reduction techniques were all perceived as caring. Barriers to perceived care were more plentiful in the literature and included the HCP's lack of knowledge and training, failure to identify the IDU upon admission to the hospital, lack of confidentiality, LAMA, fear



of withdrawal symptoms, missed appointments, lengthy waiting times, and interactions with numerous providers.

The overarching themes noted in the review of the literature include stigma and discrimination, denial of services, and staff connection issues. Stigma and discrimination is an ever-present part of the IDU's life. The interactions that the IDU has with family members, the public, and health care personnel contribute to the physical and emotional well being of the person. The increase in substance use has become a public health issue that must be addressed globally as addiction has no geographic boundaries. The inconsistent and general negative manner in which IDUs are interacted with by the HCPs who are there to help them makes it difficult for the IDU to know what to expect when seeking care. The nurse is in the position to ease the distress that an IDU experiences as a patient on an acute medical care unit. The review of the literature highlighted the importance of connectedness between the nurse and patient. Furthermore, this connectedness informed and influenced the care given by the nurse and received by the IDU. Engaging in Travelbee's (1971) phases, the nurse-patient relationship must be developed, thereby promoting optimal wellness for both the IDU and the nurse.

## CHAPTER 3

### METHODOLOGY

#### The Qualitative Approach

The qualitative approach of in-depth interviewing as a research method was used for this exploratory case study because the IDU's perceptions of received nursing care could not be adequately quantified. The rich description of phenomena is important to understand the relationships and realities of the participant. The qualitative approach allowed the researcher to understand not only the event, but also the context of the event. Qualitative methods allow the researcher to recognize patterns and to develop themes. These patterns and themes assisted the researcher to interpret the individual's experience in a holistic manner. The emphasis for this study was on both objective and subjective data of the participant, and the use of the researcher as a tool.

Qualitative researchers understand that there are many realities to consider when attempting an understanding of a particular phenomenon. The lives and experiences of the IDU cannot be fully appreciated by placing their perspectives within the confines of a Likert-type scale. Allowing the individual to tell his or her story allowed the researcher to participate in the discovery process and provided data that is seated within a context. The human-to-human relationship model (Travelbee, 1971) was the philosophic and theoretic framework for this study.

#### Unit of Analysis

The unit of analysis, or case, (Yin, 1994, 2014; Zucker, 2009) for this study was any individual over the age of 18, who spoke and understood English, has had an

encounter with a nurse while receiving care in a hospital, and was an active IDU during that time.

### **Study Aims**

The aims of the study were to (a) describe the IDU's most recent experience receiving care from a nurse, (b) describe the IDU's interpretation of the meaning of the experience, and (c) explore if the IDU feels this experience has, or will have, an effect on when the IDU will seek care the next time it is needed.

### **Research Question**

The research question for this exploratory descriptive case study was this: What is the experience and meaning attributed to care by nurses, received by adult substance abusers during a health care encounter in the acute care medical setting?

### **The Design**

The case study design has been used in a variety of disciplines such as business (Chetty, 1996), nursing (Cook, Siden, Jack, Thabane, & Brown, 2013; Zucker, 2006), education (Forsgren, Christensen, & Hedemalam, 2013), and the classic example in sociology of *Street Corner Society* (Whyte, 1993). Understanding the contextual aspects of an experience is an important aspect of this holistic, real-world research approach (Munhall, 2007).

Case study is based on a constructivist paradigm (Baxter & Jack, 2008). "Constructivists claim that truth is relative and that it is dependent on one's perspective" (Baxter & Jack, 2008, p. 545). Through this method, the participant was able to tell their story, and the researcher was able to understand the participant's actions within the context of the situation being described (Baxter & Jack, 2008). This methodology can be

used to “develop theory, evaluate programs, and develop interventions because of its flexibility and rigor (Baxter & Jack, 2008, p. 544).

Case study research relies on multiple sources of evidence such as “documentation, archival records, interviews, direct observations, participant-observation, and physical artifacts” (Yin, 2014, p. 105). For this research study, nine individual interviews were conducted. In addition, overt observation of the interactions between the employees and the IDUs at the NES occurred. A case study protocol (see Appendix A; Yin, 2014), contact summary sheets (see Appendix B), memos, journaling, field notes, and interview data were used. A case study database (Yin, 2014) for each participant was developed. This database consisted of de-identified transcripts (both a clean copy and a copy that had been coded for themes), the interview questions and related notes, field notes, and the contact summary sheet. A numbered code was placed at the top of each document to keep all related materials together for that participant. The number code was also placed at the top of the consent form (see Appendix C). The signed consent form and tapes with identifiable information were kept in a locked cabinet separate from the database materials.

### **The Participants**

Individuals utilizing the two NESs vary in age, gender, race, ethnicity, and socioeconomic status. Two NESs are located in western Massachusetts and, therefore, the two sites serve individuals from a vast geographic area. Purposeful sampling did not occur as a diverse sample of participants was recruited naturally. Participants reflected the demographic data of city A and city B and the clientele of the NES (see Table 1 for population demographics for both cities). Of the nine participants, two identified as

Black/African American, three identified as Hispanic/Puerto Rican, and four identified as White/Caucasian. Five of the participants were males and four were female. Five minority participants and one White participant were interviewed at city A NES and three White participants were interviewed at city B NES. The youngest participant was 22 and the oldest was 61 years of age. The average age of the participants was 40.2 years. The demographic profile of the sample was consistent with the cities in which the NES was located.

Table 1: Demographic data for cities where the two needle exchange services are located (U.S. Census Bureau: Holyoke, 2013; U.S. Census Bureau: Northampton, 2013).

City	Population	White (Not Hispanic or Latino)	Black/African American	Hispanic/Latino
City A	40,000	46.8%	4.7%	48.4%
City B	29,000	84.2%	2.7%	6.8%

Table 2 displays how the participant sample reflected the statistics for admission to a substance abuse treatment center during 2012 for city A and city B, MA.

Table 2: Admissions to a substance abuse treatment center during 2012 (Massachusetts Department of Public Health, Bureau of Substance Abuse Services, Office of Data Analytics and Decision Support, 2013).

	City A	City B
Number of Admissions	1,038	294
Gender	Male (74%) Female (26%)	Male (71%) Female (29%)
IDU	43%	33%
Race	Black/African American (5%)	Black/African American (3%)
	White (non-Hispanic) (11%)	White (non-Hispanic) (71%)
	Hispanic (51%)	Hispanic (13%)
	Other (34%)	Other (13%)

Tapestry Health (2012) is a western Massachusetts community-based nonprofit agency aimed at providing health care to marginalized persons. Tapestry Health offers at two sites free or reduced-cost services such as the following: health care, HIV testing, family planning, testing for sexually transmitted infections (STI), nutritional counseling, and NES. The two NESs collected data about each client who had an encounter at a NES. Paper forms are completed for each encounter; these data are then entered into an electronic database. The data are aggregated and reported to the Department of Public Health (DPH) on both a monthly and yearly basis, as the DPH is the funding source for Tapestry Health. For the year 2013–2014, the data in Table 3 were collected from city A’s NES for the 696 unduplicated participants of the NES (L. Whynott, personal communication, July 14, 2014). An individual becomes a client of the NES after completing a questionnaire to assess the individual’s risk for HIV and HCV. Information

such as drug use, substances being used, sexual practices, and use of harm reduction methods is queried from each new client to the NES.

Table 3: Summary report of City A needle exchange service, 2013–2014.

Race (n)	Gender (n)	Age at last service (n)
Latino: 320	Male: 518	18–24: 104
African American: 18	Female: 175	25–34: 264
White: 350	Transgender: 2	35–44: 162
American Indian/Native American: 2	Unidentified: 1	45–54: 117
Unidentified: 2		55–64: 31
Not collected: 4		65–74: 5
		Unidentified or not collected: 13

Table 4 illustrates the data collected for city B’s NES during 2013-2014 for the 867 unduplicated participants (L. Whynott, personal communication, July 14, 2014).

Table 4: Summary report of City B needle exchange service, 2013–2014.

Race (n)	Gender (n)	Age at last service (n)
Latino: 95	Male: 564	18–24: 142
African American: 13	Female: 287	25–34: 279
White: 742	Transgender: 11	35–44: 188
Asian: 5	Unidentified: 5	45–54: 151
American Indian/Native American: 7		55–64: 91
Native Hawaiian/Pacific Islander: 1		65–74: 14
Unidentified: 4		75+: 2

## **Demographic Data**

A brief demographic instrument was used to collect data at the beginning of each encounter (see Appendix D). The participants were informed of the rationale for the questions and were informed that they could skip any question they wished. All participants completed all of the demographic questions. I positioned the demographic question form on the desk between the participant and myself. As I asked each question, I wrote down the response to ensure transparency and to promote trust due to this being a vulnerable population that has a known distrust of disclosure due to fear of legal ramifications (Anderson & Hatton, 2000; Moore & Miller, 1999). Participants were not given categories to choose from for each of the open-ended questions so that the response was how the participant self identified.

## **Procedure**

The researcher was the instrument used in the case study. The researcher is a nurse who has 19 years of nursing experience that include 16 years interacting with individuals who have a substance use disorder. An approval to perform the study was obtained by Tapestry and the University of Massachusetts Amherst IRB. Due to the vulnerability of the IDU, permission to obtain written or verbal consent on the digital audio recorder was granted by the IRB. Once IRB approval had been obtained, the appropriate personnel at both study sites were contacted. A case study protocol was developed and followed (Yin, 2014). The researcher met with the director, and appropriate staff at each NES in order to provide information about the study, the study protocol, and to answer any questions that staff had. Staff was asked to only inform clients at the NES that a study was taking place and to refer the client to the recruitment



flier (see Appendix E). A copy of the flier was placed on the door of each NES, as well as on a corkboard where informational pamphlets were located. A phone number and e-mail address of the researcher and supervising faculty were listed on the flier.

### **Inclusion/Exclusion Criteria**

Individuals were eligible to participate in this study if they had ever had an experience receiving care from a nurse on a medical unit during a time they were actively injecting illicit drugs. In addition, participants had to be at least 18 years old, not impaired by alcohol or drugs at the time of the interview, and able to speak and understand English. IDUs under the age of 18 were excluded from this study, as the NES requires all persons to provide proof of age 18 or older in order to obtain services from the NES. All participants not previously scheduled for an interview were recruited after their encounter with the counselors of the NES had been completed.

### **Recruitment**

Two of the participants interviewed contacted the researcher after being referred to the flier by a counselor or the director; the remaining seven participants were recruited by the researcher while at the NES. I positioned myself in the waiting area located at each of the NESs during the morning and afternoon periods over a period of 6 weeks. For the first week at each NES, I remained there for various periods of time without attempting to recruit participants. Familiarity with the settings and exposure to the individuals who utilize the NES is important to increase rigor of the study, and to increase a sense of trust among the individuals (Morse, 1994). The time period ranged from 3 to 5 hours, two to three times a week. After the client had participated in the services they had gone to the NES for, I would approach the individual to ask if they had ever been hospitalized on a

medical unit (clarifying that it was not a detoxification or psychiatric unit). After receiving an affirmative answer, I would introduce my study. If the client agreed to participate in the research study, informed consent was obtained at the time of the interview.

A total of 16 IDUs were interested in and qualified for the study. Three of the six IDUs not interviewed contacted the researcher via telephone but did not follow up with scheduled meeting times. The remaining three IDUs made an appointment with the researcher in person but did not return to the meeting site at the scheduled time. Nine IDUs from two NESs were interviewed over a period of 6 weeks between March 2014 and May 2014. Six of the interviews were held at the NES in city A, and the remaining three were held at the city B NES.

### **The City A NES**

The city A NES setting is located in an area known for its high rate of drug and gang activity. The needle exchange offers a one-for-one, plus one, syringe exchange service. Individuals count their syringes in the presence of the counselor and then dispose of them in a large needle box container located at the entrance of the NES. The counselors reported that most individuals visit the NES at least once per day.

The NES staff consists of three bilingual outreach counselors, one Hispanic female and two males. One of the males was Hispanic and the other was of Jamaican descent. The director of both the city A and city B NESs identified as a Caucasian, bilingual female. The primary language spoken in this setting is Spanish. Most times two counselors were available on site. Interviews were held in one of the counselor's office.

The room consisted of a phone, desk, and two chairs. To view the clock, one must turn their head around and look up. There are no windows located in any of the offices.

### **The City B NES**

The city B NES is located in the heart of the city and is housed in a multilevel building that contains services from psychotherapy to a health clinic. The city B NES does not have a limit on the number of syringes dispensed as the site services individuals from remote areas of the state. The average dispensed amount is a box of 100 syringes. The counselors reported that the average time between visits for the clients is 1 to 2 weeks.

The NES staff consists of two Caucasian female outreach counselors. Neither of the counselors is bilingual but the bilingual director of the NES splits her time between the two NES sites. Interviews were held in the director's office. The room was small and contained a phone, desk, two chairs, and windows overlooking the city. A clock was visible by turning one's head to the right and looking up. The primary language spoken in this area is English.

### **The Interviews**

All interviews were held in a private office in the NES. Participants were informed that the researcher was a nurse but did not work in a hospital. Prior to requesting consent, participants were informed of their right to not answer any question or to stop the interview at any time. They were assured of confidentiality and also assured that they would not be asked about any active illegal activity. None of the participants asked to end the interview due to the questions being asked or declined to respond to any question asked of them throughout the interview.

At the beginning of the interview, non-alcoholic beverages were offered to the participant to promote comfort. Participants were offered the choice of a written consent or verbal consent on the audiotape. All participants signed the consent form. One individual (Christopher) was very concerned that his name would be reported to the police if he signed the consent. He was reassured that this would not happen and again was offered to perform verbal consent, but he declined this offer. After several minutes of describing protection of human subjects and how I would protect his information, he stated he was comfortable proceeding with the interview. Christopher shared that there was a warrant out for him and he was trying to “lay low.” Another participant, a male with an associate’s degree and a background in research, asked several questions about the consent. His questions were related to inquiry in the process of obtaining the consent from the IRB. Responses to his questions were satisfactory, and he agreed to participate in the study.

A copy of the interview questions was kept near the researcher. The participant was notified in advance that I may be writing short notes during the interview and that these notes would be reminders for me to ask further questions or clarifications. An attempt at full disclosure and transparency was used prior to and during the interview to promote trustworthiness and respect for the participant.

The semistructured interview schedule (see Appendix F) followed the aims of the study: (a) describe the IDU’s most recent experience receiving care from a nurse, (b) describe the IDU’s interpretation of the meaning of this experience, and (c) describe if the IDU feels this experience has, or will have, an effect on when the IDU will seek care the next time it is needed. Participants were advised from the beginning that the

interviews would be audio-recorded and last between 60 and 90 minutes. The interviews ranged from 27 minutes to 90 minutes with an average of 60 minutes. The interviews were terminated by the participant and normally followed a decline in further information. During the interviews, questions were used to clarify or to elicit a further response from the participant. A restatement of what I heard, or understood to be the message, was used at various times as a form of member checking. Follow-up interviews were not conducted with the participants as this population often has lives that are chaotic (Moore, 2009).

All interviews began with the request for the participant to tell me about their most recent experience receiving care from a nurse while they were in the hospital. I did not provide the participant with an operational definition of nursing care since each participant may have perceived this differently. Participants were steered toward elaboration of the care received from the nurse while on the medical unit. Participants often began their story in a chronological order beginning from the time they sought care, or their experience in the emergency department. At times, the participants would begin to tell their story immediately upon being asked if they would like to participate in the research study. The participant was asked to reiterate their story during the interview. The researcher's iPhone was used as the primary recording device and was placed on the desk between the researcher and participant. A second tape recorder was used as a backup and was also placed on the desk. The participant was informed prior to the start of the interview the rationale for using two recording devices during the interview. None of the participants had questions or concerns about the devices.

Throughout the interview, probing questions were used to determine if the person the participant was speaking about was in fact a nurse. Answers such as “because she told me,” “that’s how she introduced herself,” and “I read her name tag” clarified the role of the person being spoken about. It was difficult at times to determine the various persons the participant was referring to while sharing their experience. Participants were asked to describe their most recent hospitalization. However, this did not always occur, as the participants would jump from one experience to another.

For several of the participants, frequent redirection was needed to return to the question that was asked. At times, I would allow the participant to continue with a story that did not have to do with the question asked if I noted through observation that the telling of the information was important to the participant. I used my skills as a nurse to demonstrate genuineness, empathy, and to promote trust. Allowing for this diversion resulted in a visual display of the participant appearing more at ease in their chair, facial responses, and vocal mannerisms.

As an introduction to the natural conclusion of the interview, all participants were asked if they had anything else that they wanted to share with me. This form of member checking proved useful as several of the participants continued on for an additional 20 minutes or more after being asked this question. Two of them appeared to be looking at the clock or their cell phone periodically during the interview. One participant terminated by saying he was hungry and another terminated by saying she had an appointment that she needed to keep. One participant set a time limit from the beginning of the interview due to being parked at a meter. The remaining participants did not look at the clock or

their cell phone during the interview. All participants were given a \$20 gift card to a retail pharmacy and general merchandise store as compensation for their time.

### **Ethical Considerations**

This study had multiple ethical considerations. Participants were given adequate information as to the purpose of the study, the process of the interview, the storing of the data, pseudonyms, and the assurance of confidentiality. Participants were asked to read the consent (see Appendix C) and all questions were answered to the satisfaction of the participant. Participants were never asked their name and the researcher did not ask for discussion of any present illegal activity. Participants were advised that all audio recordings would be transcribed but that identifying information would be removed. As the researcher proofread each transcript, any names or identifying location information used by the participant were immediately de-identified. The participants were also assured that the data would be kept in a password-protected computer and their signed consent and audiotape with identifying information would be kept in a separate locked drawer. Throughout the recruitment, interview, and post-interview process, I remained as transparent as possible in regard to all of my actions in order to promote trustworthiness and respect for the participant.

### **Data Analysis**

According to Yin (1994, p. 102), data analysis consists of “examining, categorizing, tabulating, or otherwise recombining the evidence to address the initial propositions of a study.” A contact summary form (see Appendix B; Miles & Huberman, 1994) was completed after each interview. A review of the interview questions was performed and additional amendments were made based upon the ongoing analysis of the

data. Additional inquiry during the interview occurred as a result of this journaling and contact summary form. For example, it was noted that the first two participants used the phrase “the look” when describing their nurse. I made a conscious effort to elicit more information about this theme during future interviews if the participant alluded to this descriptor. The data was reviewed and compared to existing data and the literature throughout the data collection period. Themes began to emerge by the third interview and continued throughout the remaining six interviews. The meaning of the participant’s experiences were described and interpreted to capture their essence in the context of their experience.

Field notes were recorded immediately after each interview but were not coded. Instead, the field notes were reviewed to bring me back to thoughts and observations made during the interview with the participant. The field notes contained my observations of the participant’s dress, appearance, speech, mannerisms, language pattern, and any other general impressions the researcher felt were important to the research study. A journal was kept to promote reflexivity of the researcher as well as to keep track of my thoughts in regard to emerging themes, questions, or thoughts about the phenomenon described by the participants. Ongoing discussions with a peer not familiar with substance abuse assisted me in remaining aware of my personal bias.

Interviews were conducted until a rival case (Yin, 2014) had been determined. A rival case is one that differs from the comparison cases (Yin, 2014). Replication logic is similar to performing multiple experiments (Yin, 2014). In case study, “each case must be carefully selected so that it either (a) predicts similar results (a literal replication) or (b) predicts contrasting results but for anticipatable reasons (a theoretical replication)”



(Yin, 2014, p. 57). This was an important part of this case study, as interviews were performed in areas that are ethnically, socially, and economically diverse.

A professional transcriptionist transcribed all interviews. All transcripts were read word for word by the researcher to ensure accuracy. All audiotaped recordings were listened to several times throughout the analysis period. For each interview transcript, data were first level coded and operationalized, as described in Miles and Huberman (1994) using an initial list of a priori codes, as seen in Appendix G, based on the research questions and the theoretical framework of Travelbee (1971). Additional codes were added as data were transcribed and reviewed. In addition, in vivo codes were used whenever possible in order to remain close to the meaning of the data as expressed by the participants.

NVivo (2014) 10, an electronic software used to collect and categorize data, perform a query, and analyze content, was utilized to assist with management of the data and when categorizing themes to look for patterns among participants. The query function of the software was used to aid in recognition of patterns. In addition, word count in a visual format was used for each of the interviews and compared across participants, and again using all nine transcripts. A separate transcript of each interview was printed and coded for themes by hand to further immerse myself into the participant's experience using a different sensory experience. Themes were written on colored index cards and manually separated into categories of overarching themes. In addition, a handwritten model of the various connections between patterns, categories, and overarching themes was performed. The overarching themes were compared to the

literature and ultimately reflected a cyclical process of marginalization, defensiveness, and repeated victimization.

The literature had been examined several times throughout the analysis. A content expert reviewed the themes of each transcript. In addition, an e-mail and phone exchange of the researcher's interpretation of the data was performed with the content expert. Discussion of the themes was shared with a peer in order to receive feedback from an individual inexperienced with addiction or an addiction trajectory.

### **Trustworthiness**

Qualitative research uses a variety of methods to support trustworthiness and to demonstrate rigor of the study (Lincoln & Guba, 1985). Trustworthiness strategies used included methodological triangulation, use of a protocol (Yin, 2014) seen in Appendix A, use of participant quotes, peer discussion, a case study database, and a reflective journal. Yin recommends the use of four tests to judge the quality of the research design. These four tests are (a) construct validity, (b) internal validity, (c) external validity, and (d) reliability. Construct validity is “the accuracy with which a case study measures reflect the concepts being studied” (Yin, 2014, p. 238). Internal validity is the strength of a cause-effect link and rejection of rival hypotheses (Yin, 2014). External validity is the extent in which the findings can be generalized to other areas beyond the immediate study (Yin, 2014). Reliability is the “consistency and repeatability of the research procedures used in the case study” (Yin, 2014, p. 240). These tests are similar to those described by Lincoln & Guba (1985) of transferability, credibility, dependability, and confirmability.

Construct validity strategies utilized included two NESs located in different cities to ensure active injection drug use. The use of two NES sites increased the probability of gathering a sample of individuals utilizing six different area hospitals, thereby increasing the representativeness of the sample. The NES sites are easily accessible via public transportation and provided contact with a diverse group of individuals who accessed a variety of hospitals in the local area, in the state, as well as on the west coast. Additional strategies to increase construct validity included audit reflexivity, member checking, use of a content expert, and a contact summary form (Appendix B; Miles & Huberman, 1994) was used for each case.

Internal validity strategies included pattern matching and addressing rival explanations. Pattern matching was performed during analysis and is the matching of patterns within the collected data with a pattern defined prior to the data collection (Yin, 2014). Rival explanation is a plausible alternative to the original concepts of the study (Yin, 2014). External validity strategies included coding using Travelbee's (1971) phases of the development of rapport. Reliability strategies included the use of a case study protocol and case study database (Yin, 2014). A case study protocol is the procedural guide for collecting the data. A case study database is a systematic archive of all of the data from a case study so that if needed, the information may be easily reviewed by an outside reader (Yin, 2014).

Another aspect of external validity included the use of triangulation. According to Yin (2014), triangulation is defined as "the convergence of data collected from different sources, to determine the consistency of a finding" (p. 241). Yin (2014) cites Patton's (2002) explanation of triangulation of the data, which can occur through four methods.

Data can be triangulated through (a) data sources, (b) different evaluators, (c) theory, or (d) methods (Yin, 2014). Data sources for this study included interviews, observations, and a demographic survey. A content expert was used for validation of themes that emerged from the interview data. Triangulation-using theory is achieved by using multiple theories or perspectives (Patton, 2002). Triangulation-using methods include the comparison of findings and often include both quantitative and qualitative approaches (Patton, 2002). For this research study, data triangulation was implemented methodologically by performance of individual interviews in two diverse settings with the aim of convergence of evidence (Yin, 2014) and the use of a content expert for themes.

### **Summary**

This design was a descriptive case study that examined the IDU's perceptions of received nursing care during a hospitalization on a medical unit. The case study was chosen as the best method to explore the IDU's experience with received nursing care as this is a complex issue and the context of the experience can be examined through the perspective of the IDU and result in a greater understanding of the phenomenon. Little is known about the IDU's experience with received nursing care, and a case study approach can help one to understand how and why everything has happened in a particular way (Yin, 2014). The goal of this case study was to understand a real-life complex problem and the meaning of this experience for the IDUs interviewed for this study. Through in-depth interviews, a diverse sample, and a carefully constructed analysis of the data, a greater understanding of the IDU's experience of received care on a medical hospital unit

was accomplished. Understanding the IDU's experience can inform nurses and researchers and improve care to this vulnerable population.

## CHAPTER 4

### FINDINGS

The annual cost of alcohol and illicit substance use to society nationally is over 6 billion dollars, which comes from health care costs, crime and loss of work productivity (The National Institute on Drug Abuse, 2012). The lack of resources for substance abuse treatment has a significant impact on the addiction trajectory of an individual. In 2013, 6.1 million people who felt they needed substance abuse treatment did not receive treatment (SAMHSA, 2013). In order to address the culturally specific needs of the IDU, an understanding of their perceptions, facilitators, barriers, and limitations must be achieved.

The purpose of this study was to describe the IDU's most recent experience with nursing care received in the acute care setting. The aims of the study were to (a) describe the IDU's most recent experience receiving care from a nurse, (b) describe the IDU's interpretation of the meaning of this experience, and (c) describe if the IDU feels this experience has, or would have, an effect on when the IDU will seek care the next time it is needed. Five male and four female IDUs from two NESs were interviewed using a case study strategy and semistructured interview question format. The demographics of the participants, their profiles, a rich description of the rival and comparison cases will be described. For the rival case, the theme of *Understanding Addiction* will be described. For the comparison cases, three themes and associated subthemes will be described in depth. The first theme of *Marginalization* and the subthemes of *Feelings of worthlessness*, *Mistrust*, and *Unpredictability of care* will be described. The second theme of *Defensiveness* will be portrayed. The third theme of *Repeated Victimization* and

the subtheme of *Self-care management and delay in seeking care* will be explained. Lastly, an outlier theme of *Young Enough To Be Saved* will be revealed.

### **Demographic Findings**

Five men and four women were interviewed for this study. The sample consisted of five minority persons and four White persons. The youngest participant was 22 years of age, the oldest was 61 years of age, and the average age was 40.2 years. Five of the participants reported initiation of drug use prior to the age of 18, with one beginning at age 12 and another at age 14. Six of the nine participants have abused illicit substances for at least 10 years with the longest being 43 years. Eight of the participants reported mental illness such as depression, anxiety, post-traumatic stress syndrome (PTSD), or trauma. The one participant who did not report mental illness on the demographic sheet reported during the interview a history of abuse, depression, and trauma. The nine cases did not differ in regard to the participant's economic status. Income ranged from "some" to 25 thousand dollars per year, with an average of 10–20 thousand per year. All participants had housing, although one reported staying with a friend or sleeping in a tent, and all received some type of government subsidizing. Four local hospitals, two hospitals in eastern Massachusetts, one hospital in Connecticut, and hospitals in Oregon and California were utilized by the IDUs over the last 4 years. Four of the participants stated they did not have a mentor. One cited their Narcotics Anonymous (NA) sponsor; two cited friends; the remaining two cited family members as being their mentor. None of the participants identified their substance dependence as a mental illness. A summary of the participant demographic data is described in Table 5.

Table 5: Demographics of research participants (n = 9).

<b>Gender</b>	
Male	5
Female	4
<b>Race/Ethnicity</b>	
White	4
Black	2
Hispanic/Puerto Rican	3
<b>Age</b>	
18–25	1
26–35	3
36–45	2
46–55	2
56–65	1
<b>Years of Schooling</b>	
<12 <sup>th</sup> grade	2
12 <sup>th</sup> grade/GED	1
Some college/trade school	5
College degree	1
<b>Income Level</b>	
<10K	3
10–20K	4
Over 20K	2
<b>Work Status</b>	
Full time	1
Part time	1
Unemployed	7
<b>Who do you live with?</b>	
Alone	3
Partner	2
Sibling	2
Kids	1
Homeless	1
<b>Type of Housing</b>	
House	1
Apartment	6
Dormitory	1
Tent/friend's couch	1
<b>Years of Substance Abuse</b>	
<1	1
1–5	2
6–10	2
11–20	1
21–30	1
31–40	1
41–55	1



<b>Age of First Drug Use</b>	
<18	5
18–25	0
26–35	3
36–45	1
<b>Hospital Where Care Was Received</b> (more than one response included in total)	
Local	9
Massachusetts	1
Out of state	1
<b>Other Medical Conditions</b>	
HCV	6
Depression/anxiety	7
PTSD	2
Other mental illness	3
Medical: Back injury	3
Seizures, meningitis, chronic constipation, asthma, Hypertension (HTN), lupus, attention deficit Hyperactivity disorder (ADHD)	
<b>Mentor</b>	
Yes: Higher power	1
Friend	1
Brother	1
Boyfriend	1
Narcotics Anonymous sponsor	1
No:	4

As part of my recruitment technique, I would sit near the entrance of the NES at both settings in order to observe the interaction between the participant and counselor. For many interactions, the client would greet the counselor by name. In city A, the verbal exchange was often in Spanish. The client would frequently look at me briefly before turning their attention to the counselor. In city B, I rarely received a second look from the clients visiting the NES. At both settings, the counselors greeted clients warmly and with a smile. In city A, the clients were often greeted by their first name, and a short exchange of small talk would occur prior to the syringe exchange. These interfaces allowed me to observe the interactions between the IDU and individuals in a health care provider role,

as counselors are trained to provide harm reduction education, counseling, and testing for STIs, HIV, HCV, and pregnancy tests.

To reiterate, the participants were comprised of five men and four women. Of the nine participants, two identified as Black/African American, three identified as Hispanic/Puerto Rican, and four as White/Caucasian. Five minority participants and one White participant were interviewed at the city A NES, and three White participants were interviewed at the city B NES. The youngest participant was 22, and the oldest was 61 years of age. The average age was 40.2 years. In keeping with presenting a rich description of these individuals' experiences, the following is a brief narrative for each participant that culls relevant demographic descriptive data. Pseudonyms were chosen for the participants to protect their identity.

### **Participant Profiles**

Alex was a 61-year-old Black male. He had a high school diploma and “some technical” schooling. He had been using substances for 42 years, beginning at the age of 18 while in the service, as he stated, “That’s what you do when you are trying to hide from ghosts.” Alex has not had any significant periods of sobriety that he can recall. He had a history of HCV, bipolar disorder, chronic depression, and HTN. He was a polite, engaging man who maintained eye contact throughout the interview but was obviously troubled by his past as an active combat Vietnam veteran. Alex maintained a balance of accepting responsibility for his actions but often spoke about the injustices of being an IDU.

Bob was a 54-year-old Black male. He only partially completed the 11<sup>th</sup> grade in high school. He was articulate and had an extensive vocabulary. He had been using

substances since the age of 15 and “maybe younger” and had not had any significant periods of being sober. He had a history of HCV, seizures from a head trauma, anxiety, and back injuries. Bob was also a veteran but had not been active in combat. He maintained a pleasant demeanor and often jumped from one story to the next making it difficult to follow what he was stating. Bob’s voice was monotone throughout the interview and he maintained eye contact. He spoke often of being a victim and being “wronged” by others.

Christopher was a 33-year-old Puerto Rican male. He completed 9 years of formal education and had been using substances since the age of 17. He had two periods, 4 years and 2 years, respectively, of being sober during his 16 years of substance use. He had a history of schizophrenia, depression, anxiety disorder, and viral meningitis. Christopher had a flat affect, a significant stutter, and often struggled to find words. He wouldn’t regularly engage in eye contact but remained respectful throughout the interview. Christopher was very interested in medicine and spoke frequently about looking up his various diseases and illnesses. He asked questions about several medical conditions after the interview was complete.

David was a 30-year-old Hispanic male. He graduated from a trade school and was recently unemployed. David was also a veteran who had been overseas in combat. He had only recently begun using substances within the past 6–8 months. He was married and had a very young child; David’s wife was unaware of his substance use. His only medical history was chronic constipation for which he has had multiple hospitalizations. However, he spoke a great deal about his history of childhood abuse. David was very

soft-spoken, respectful, and his eyes would well up with tears at times throughout the interview.

Ella was a 37-year-old White female. She was a high school graduate and did 9 months of training as a medical assistant. She started taking prescribed Percocet (oxycodone with acetaminophen) for an automobile injury 7 years prior, progressed to purchasing the prescription pills 2 years later, and had been injecting for the last 2 years. She had a history of anxiety disorder, depression, HCV, and asthma that had resulted in a number of hospitalizations. Ella was engaging and maintained eye contact throughout the interview. Her responses appeared to be rapid, rote, and rushed. At one point during the interview, she broke down crying when discussing her mother's death from an overdose and how she vowed she would never use drugs like her mother did.

Grace was a 36-year-old Puerto Rican female. She had a GED and "some college." She first used illicit substances at the age of 33 and had one period of 6 months when she was sober. Grace had a history of HCV, anxiety disorder, and PTSD. Grace appeared much younger than her stated age and assumed an aura of kindness and compassion. She wept frequently throughout the interview, was engaging, compassionate, and reflective. Grace maintained eye contact throughout the interview and often initiated conversations.

Hillary was a 22-year-old White female in her third year of college. She first began using substances at the age of 14 and has had 1 year since then of being sober. Hillary had a history of lupus, depression, anxiety, and OCD. She was articulate, appeared her age, and maintained a flat affect throughout the interview. Her voice rarely wavered and her eye contact with the researcher was only occasional. Hillary was very

concerned about maintaining her anonymity, as she did not want to get in trouble with her school. She yearned to go to a detoxification center and rehabilitation unit, but stated that she couldn't while school was in session. She had lost her significant other to a heroin overdose 3 weeks prior to the interview.

Isaac was a 35-year-old White male with an associate's degree. He has been using substances since the age of 12 and had one period when he was sober for 2 years. Isaac had ADHD, HCV, anxiety disorder, and depression. Isaac was very demonstrative during his interview and would often get loud and passionate about what he was saying. He fidgeted in his chair and was constantly in motion. He would fluctuate between being articulate to speaking "from the hood" and he brought along a 24-ounce can of an energy drink that he consumed during our interview. Isaac spoke often about being a victim and had difficulty seeing a situation from a perspective other than his own. He had difficulty maintaining eye contact due to his rapid and frequent movements.

Jane was a 54-year-old White female who had one year of college. She stated she began using substances at the age of 36 after a motor vehicle accident and became addicted to opioids a year later. She had only had 90 days of sobriety in the last 18 years, and this was due to an incarceration. Jane had a history of back surgeries, HCV, and PTSD. She was engaging, maintained eye contact, laughed frequently, and appeared nervous at times. Once the tape had been shut off at the end of the interview, Jane shared other aspects of her story that she didn't trust to be on tape. Jane was a victim of domestic violence and only recently moved to the area after escaping her abusive relationship.

To make it easier for the reader, a summary of the participants' facts and drug use information can be found in Table 6.

Table 6: Participant (identified by pseudonym) facts and drug use information.

Pseudonym	Age	Race/Ethnicity	Education	Years using	Age at first use
Alex	61	Black	12 <sup>th</sup> grade	41	18
Bob	54	Black	11 <sup>th</sup> grade	39	15
Christopher	33	Puerto Rican	9 <sup>th</sup> grade	10	17
David	30	Hispanic	12 <sup>th</sup> grade	6–8 months	29 or 30
Ella	37	White	12 <sup>th</sup> grade and 9 months training	2	35
Grace	36	Puerto Rican	GED	3	33
Hillary	22	White	3 years college	7	14
Isaac	35	White	Associates degree	21	12
Jane	54	White	1 year college	18	36

### **Researcher Observations**

Upon walking into the NES at both sites, the clients of the NES appeared to be comfortable. I was able to witness three new client interactions with the counselors. The individuals who were new to the NES had a more cautious approach than the regular clients. All of the NES clients at both sites were greeted warmly and with a smile. There was more small talk engagement at the city A NES, which would be expected as culturally the Latino/Hispanic populations often engage in this social courtesy (Centers for Disease Control [CDC] Healthy Communication, n.d., p. 13). Individuals at the city B NES often only provided a greeting such as “How’s it going?” or “Hey, what’s up?” when approaching the counselor. At both settings, the client’s dignity was maintained by bringing the individual into a counseling room for the exchange and counseling that occurred with each client interaction. During lunch breaks or a staff shortage, syringe exchanges would occur openly and, if the client wished to receive testing or counseling for a STI, HCV, HIV, or a pregnancy test, they would be offered a return visit when another staff person would be present. I noted that the counselor would attempt to make

the interaction as confidential as possible. The respectful interchange appeared to be in contrast to what is reported in the literature between the IDU and their HCP.

During the interviews, I was able to observe the mannerisms displayed by the participant. This included their eye contact, speech, body posture, gait, emotions displayed, and language pattern. Subtle signs of discomfort with a topic, anger with a recollection of a HCP encounter, and reflective periods were noted by the researcher and were used to guide the interview. For all of the interviews, the participant left the room in what I perceived to be a more positive mood than when they entered the interview. I noted an increase in smiling, a less stooped appearance, a higher volume to their speech, and their initiation of thanking me for this experience prior to my expression of gratitude.

### **The Interviews**

Prior to the interviews, I set the room up to be the least distracting as possible. I offered each participant a beverage, and I found it interesting that only one requested a particular type of beverage; the others either declined the beverage or just picked one of the available choices presented. After being offered a beverage and encouraged to place their chair where they were comfortable, I again explained the study before obtaining consent. I tried to be as transparent as possible by placing the forms on the desk between the participant and myself. I noted that several of the participants watched me write the responses. I made sure to explain the rationale for collecting the information and to ensure the participant again that they could skip any question they wanted. None of the participants declined to answer any question.

Throughout the interview, several of the participants would go off on tangents that did not pertain to the research study or question that had been asked. I would use my

experience as a nurse to determine the importance of the topic for the participant. At an appropriate time, I would redirect the conversation back to the question that had been asked. For several of the participants, they would either apologize for diverting the conversation or they would just respond to my restated question. At a time that appeared to be a natural end to the interview, I would ask the participant if they had anything else they would like to say or that they would want me to know. More often than not, the participant would continue on for another 20 minutes. I found this interesting for two reasons: (a) This question gave the participant permission to share whatever they wanted and felt was important at that time; and (b) The information given after this statement often obtained a rich description of the participant's feelings. I would again ask the participant the same question when there was a natural end to the conversation. This experience of being heard and respected was apparent and likely contributed to the change in the participant's demeanor as they left the room. One participant returned the next day to share a pamphlet about an upcoming show that his mother was participating in and that he had spoken about during his interview. This sharing of self and appreciation for the time spent with the researcher exemplified how important the gift of presence can be for an individual.

Two of the participants initiated the end of the interview. Bob initiated by stating that he was hungry and wanted to go get lunch. Ella was very quick in her responses and appeared rushed. She ended the interview by stating that she had another appointment that she needed to keep. Upon escorting her to the waiting room (as I did with all participants), I noted that a male was sitting in the chair and stood up as she entered the room. Ella was one of the participants that would periodically look at her phone during



our interview. Ella appeared slightly uncomfortable approaching the waiting room, and the male person appeared agitated. I was able to quietly ask Ella if she was okay and she responded, “Yes.” The third person to set a limit for her interview was Jane. There is limited parking at city B’s NES, and Jane stated that she only had 50 minutes on the meter. I offered to provide her with money to allow for more time so that she did not need to worry about receiving a parking ticket. Jane refused this offer and stated, “By the time I go to the car and put the money in, it won’t make much difference.” To be respectful of Jane’s request, I did remind her at a few points during the interview as to what time it was as I did not want to breach our agreement. Jane did stay a few minutes after the interview to ask questions about the effect of cocaine for a person on methadone.

### Summary

Highlights of the survey data revealed that the participants represented a diverse sample of IDUs located within the geographic area of each NES, as evidenced by Tables 3 and 4. The average age of the participants was 40.2 years with the youngest IDU being 22 and the oldest being 61. The participants’ average length of time abusing substances was 17 years, with sobriety periods from 90 days to 4 years. Five of the participants reported initiation of illicit substance use prior to the age of 18. The participants all had a history of trauma or PTSD but did not share details about these events.

Observations made during my visits to the NES included the participant’s interaction with the counselor. This counselor encounter was respectful, engaging, and was clearly different from the experiences with the HCPs in the hospital described by the participants. Observations made during the interviews allowed the researcher to use her skills as a nurse to recognize both verbal and nonverbal behaviors that added further

depth and meaning to the participant's spoken words. A markedly positive difference in appearance and demeanor was noted between the beginning of the interview and the time when the participant left the room. An open display of emotions ranging from tears, disgust, anger, and excitement occurred throughout most of the interviews. Observations were also made as to how the participant responded nonverbally to questions throughout the interview. This allowed the researcher to view the participant from a different lens than just focusing on the participant's verbal response.

The individuals were engaging, and all shared an appreciation for being able to tell their story. Three of the nine interviews were set up at least one day in advance. The remaining six interviews occurred within 10 minutes of the participant being informed about the study. All of the participants had experienced care from a nurse that was described as marginalization. All of the participants described the meaning of these negative encounters with the nurse, and several further offered how this experience had an effect on their emotional or physical wellbeing. The section that follows describes interview findings outlining the rival and comparison cases. Unless otherwise noted, the following excerpts are derived from the IDU's experience with the nurse.

### **Rival Case**

For this study, Jane's experience illustrated Yin's (2014) definition of a societal rival, which is "Social trends, not any particular force or intervention, account for the results ('the times they are a-changin')," (p.141). The general theme for Jane's story was *Understanding Addiction*. Jane's experience will be told through her voice via indented block quotes. The comparison cases will follow and will also be told through the voice of

the participants. The participant whose quote it is will not always be identified unless the researcher felt this knowledge was relevant to understanding the context of the quote.

### **Jane's Story: Understanding Addiction**

#### **Experience**

Jane, appearing older than her 54 years of age, visited the NES approximately once a month. She was engaging, friendly, and maintained eye contact throughout the interview. Jane spoke a great deal before and after the interview to share her history of severe domestic violence that resulted in a number of fractures and scarring defects. Jane made it clear that she had never used drugs ("I never even smoked a joint until I was 40") until she was prescribed narcotics for injuries sustained in a motor vehicle accident. After she was "cut off" by her doctor, Jane turned to buying the narcotics "on the street." This cessation of prescription opioids ultimately led to her use of heroin as a cheaper and more easily accessible alternative to the costly pills.

Jane began oral methadone treatment "about 4 years ago" and was on a "take home" program. She stated that she injects the methadone "about 4-5 times a day." She reported this information after the tape had been stopped, as she feared that the methadone clinic would find out and discharge her from the program. Track marks were visual on her wrists and neck. Jane stated, "I think that I am addicted to the needle. This way of taking my methadone works for me." Jane appeared to be living several different lives as she often stated, "But they don't know about that" throughout our encounter. Jane was living with her boyfriend (who is not a drug user) and a roommate who was unaware of her addiction.

Jane began to eagerly share her story of her last hospitalization with me immediately after she had been screened and agreed to participate in the study. Jane tells the story that approximately two years ago, she had helped a friend who was dope sick (in withdrawals from heroin) by providing her friend with methadone. In turn, this left Jane “short” on her methadone; therefore, she was experiencing her own withdrawal symptoms. She “shot a Suboxone (injected a mu-opioid partial agonist) and went into instant withdrawals.” This resulted in her son calling an ambulance for her to receive care at a local hospital. Jane did not want to go to the hospital, as she stated that she had had “bad experiences” in the past and “didn’t want to have to deal with it on top of everything else.” However, once the ambulance and attendants arrived, Jane reported that she immediately recognized that this time would be different because the emergency room doctor ordered the paramedics to “start an IV (intravenous catheter) and to administer Ativan (Lorazepam) as soon as possible. So I kind of knew then—well, I’ve got a doctor who is at least going to be sympathetic to my situation.”

This provider was a doctor certified to administer Suboxone (buprenorphine and naloxone). Jane stated that she was honest with her provider and that he was genuine in his care, “He was just a saint—honest to God.” The provider informed Jane of each medication she would be receiving and the rationale for the drug. Jane worried that her action with the Suboxone would cause her to lose her privilege of her take-home methadone. The Suboxone was obtained illegally and would be a violation of the rules of the methadone clinic. Jane shared her concern with the provider that she would have to account for why she was not at the methadone clinic to pick up her medications. She felt he understood that she had been doing well in her program, and Jane reports that he

stated “I don’t want to take that from you.” Jane reports that the provider stated, “Why don’t we just tell them you were dehydrated.” This interaction was in stark contrast to the relationship she describes with her primary provider, who is unaware of her current substance use, “She would rat me out.”

Jane received medication to assist her through the withdrawal period until it was deemed safe for her to resume her ordered methadone. During one of her nursing assessments on the medical floor at the hospital, an abnormality was noted on her electrocardiogram, resulting in a transfer to the cardiac unit in the same hospital. During the 3 days that Jane was in the hospital, she received care on three different units. She stated that the nurses were caring, attentive, and supportive. Jane stated that all of the nurses provided “excellent care” and that she “did not have one negative experience during her stay.” She provided examples of these caring behaviors by declaring the nurses were always looking in on her and asking,

Are you okay? How is your heart? Are you feeling okay? Is there anything you need?...was it the heart unit? I don’t know. Nothing bad I can say and that’s saying something to me being in the hospital three days.

Jane provided other examples of what she described as “compassionate nursing care,” which included “not treating me like a piece of shit,” “giving me useful advice,” and “talking to me about recovery options.” When asked what it meant to her to be cared for by the nurses in this way, Jane immediately smiled and excitedly stated,

Good! Knowing that I was an addict and they were concerned. They were more concerned about my care. They didn’t judge. I didn’t feel judged. I didn’t feel like the next patient was better than me because they may not have been an addict.

During her stay at the hospital, Jane spoke of the education she received: information about detox centers, referral to a counselor, referral to NA, and being asked

if she felt she needed any other services. Although Jane declined the nurses' offer, she appreciated the information provided. "You know they were there for the medical part—if I needed counselors, if I wanted to speak to anybody about it. They were more than willing to hook me up with it." Jane stated she currently had a private counselor and that she knew how to obtain resources. Jane felt that the nurses were aware of addiction and addiction treatment but that they just couldn't relate because they hadn't experienced what she had been through. She declined to speak to a counselor at the hospital for the same reason.

I don't think they really know. How can you help me with something you've never experienced? It's not like a medical issue. It's just not. They just don't know. I feel more comfortable talking with someone who's been there. Talking to a counselor in recovery. Someone who's walked a mile in my shoes and really understand what it's like to be in recovery. What it's like to be truly dope sick or what it's like to truly almost die from recovering from alcohol. Then you know and you can help me and let me know how you did it. There's one time you're going to hear that thing that clicks. So as far as the medical care—it was excellent, but I just wasn't interested, but that's me.

Initially, when Jane went into withdrawal at home, she did not want to seek treatment and voiced her fear of unpredictability of care, "Because I didn't know how they were going to treat me. What they were going to do? What would happen? I didn't know." Her son insisted that she be seen and called an ambulance for Jane. She had had previous negative experiences with receiving care in a hospital for a "missed injection" (the drug was not injected into the vein) as she stated that she is "not a good injection drug user." Jane reported that the HCPs at the "other" facilities were "all the same" in how they treated her. "They were judgmental. They didn't want to give me any pain medication. An abscess is excruciating, excruciating pain, and they just weren't

sympathetic at all.” Jane reports that during a previous encounter receiving care for a missed injection, the nurse had stated, “Well, it’s self inflicted and I really don’t care.”

### **Meaning**

When asked about the meaning of her most recent experience at the hospital where she received what she described as “excellent care,” Jane stated it meant,

A lot. I thought maybe, just maybe because of the big rise in the use of narcotics or opiates or heroin—the increase of so many more people using now, and now they see it as a disease. That they’re more apt to try to work with patients and not just judge them and treat them like a piece of shit. Like I did when I didn’t know.

Jane stated that she felt that with the advanced research on the brain and addiction process, the medical field would be more understanding than they were 30–40 years ago, “Because now it’s considered a medical thing. It’s a disease as opposed to just being a junky.” The theme of *Understanding Addiction* emerged from Jane’s experience.

### **Impact**

Jane was asked if her positive experience at the hospital had an impact on when she would seek care the next time it was needed.

I think so...I’m sure not every single nurse at (hospital A) would be as wonderful an experience as I had just as I’m sure not every nurse in (hospital B) would have been a piece of shit that that nurse was. But I’m more apt to go somewhere where my odds are going to give me better treatment and be more sympathetic for my situation regardless of what it is, whether it’s substance abuse related or not.

Although Jane recognized that her experience was unique, she stated that the meaning of this experience gave her a “whole new perspective” on going to the hospital. After having had this experience, Jane went out of her way to go to this hospital when her son required care despite it being a longer drive.

### **Comparison Cases**

Unfortunately, Jane's recent experience was unique and did not reflect the themes of *Marginalization*, *Defensiveness*, and *Repeated Victimization* or the subthemes of *Feelings of worthlessness*, *Mistrust*, *Unpredictability of care*, or *Self-care management and delay in seeking care* that emerged from the stories shared by the other eight participants. The pattern of themes became evident by the third interview. The following section will describe the comparison cases and description of the themes that emerged from the participants' stories.

### **Overarching Themes**

All of the comparison cases portrayed a cyclic process that described the IDU's experiences of marginalization by HCPs. Marginalize is defined as "to put or keep (someone) in a powerless or unimportant position within a society or group" (Marginalize, 2015). The subthemes found under this category include *Feelings of worthlessness*, *Mistrust*, and *Unpredictability of care*. These interactions led to the participant describing defensive feelings or actions in response to this HCP interaction. All of the participants expressed their feelings of what this interaction meant to them, and this can be best described as repeated victimization. To victimize means to "single (someone) out for cruel or unjust treatment" (Victimize, 2014). The participants described nurse encounters that moved through a cyclic phase of marginalization, defensiveness, and repeated victimization.

A subtheme found within the category of *Repeated Victimization* includes *Self-care management and delay in seeking care*. An outlier theme of *Young Enough To Be Saved* also emerged from one participant's interview. The following sections will



describe the overarching themes and the subthemes that fell under this cyclic process. Included will be text from the participants to describe their experience.

### **Marginalization**

All of the participants described marginalization in their experiences receiving care in the hospital setting. The IDU described marginalization behaviors from many HCPs but, unless otherwise noted, only those interactions with the nurse will be described in the following text. The interactions with the nurse were associated with descriptions of feelings of worthlessness, mistrust, and unpredictability of care.

### **Feelings of Worthlessness**

All of the participants provided examples of both internal and external perceptions of negative self worth. Participants described themselves using statements such as “I ain’t worth anything,” “a junky,” “a low-life,” “worthless,” “a low-life, an undesirable—I fit that category,” and “a second class citizen.” The use of “*just an addict*” was stated in a self-deprecating manner and verbalized by almost all of the participants.

In addition, all of the participants portrayed situations in which they described being disregarded by their HCPs. According to the participants, the negative behaviors were not germane to one type of HCP; instead the actions were seen across all disciplines within the hospital experience. Participants provided examples of comments ranging from “Oh my God, not another one” (when discovering the person was an IDU), to comments being made about the IDU’s track marks when looking to insert an intravenous catheter, “You know you’re messing up your veins. Do you have a better one?” David shared his belief of how a substance user is viewed and treated by HCPs.

When you use, people look at you as if you’re a lowlife. You don’t have nothing. All you do is drugs. They’re going to look at you as a thief.

They're going to look at you as all type of negative things instead of helping you trying to get better. I don't know, some people just don't care I guess. A lot of people... because if I would have seen somebody suffering like that, I wouldn't leave him like that.

The timing of the IDU's disclosure of injection use varied among the participants.

Several of the participants stated they would always tell the nurse immediately upon arrival to the emergency department. Others stated they were honest but would only disclose to the nurse who would be providing direct care to them. Several of the participants felt strongly that the hospital personnel needed to know right away so that any medications that were given would not interact with the drug, or that a medical problem would not be missed. "They have to know" was the mantra of several of the participants.

I don't want to find out I have something else or not say—I'm an IV user and them not run some sort of test and I leave the hospital thinking I'm OK and then I have something. You understand? I should be able to tell someone in the medical field that and not get treated badly by them. I don't feel I have to keep this a secret. I don't run around, go pay the light bill and tell the lady over there—hey, I'm an IV user. It's none of her damn business, but when I go to the hospital, I feel I should be able to tell these people that.

Alex spoke of how he tells the nurse right up front that he is an addict:

You go into the hospital you tell them you're an addict. They tend to look at you like you're a bad person. You ain't worth anything. It just sucks. I'm straightforward so I'll let them know if I have a problem. I have a problem. Because I want to get help. At least I'm coming forward, but some people don't see it like that.

Alex, David, Grace, and Hillary made statements that they were not ashamed to admit they were injection users. Hillary made the following statement:

Yeah, usually I like to get it out of the way because they're going to be looking at my track marks and it's so obvious it's weird to not say it. I have these infected things sticking out and probably feel like it's best to get it out of the way and also because I feel like it gives me the chance to

assert, to respect—I'm an IV drug user, just to say it—not be ashamed of it and just say it like I'm not scared to say it. I feel like it's a way to ask to be treated respectfully. I don't know why I think that but I just feel like it is.

Similarly, David stated:

A lot of people are ashamed to tell, "I'm an addict." I'm not ashamed. I'm not. It's just a problem that I have. Nobody's perfect. At least I'm out there trying to seek help. Talking about it. Some people don't see it like that. They don't. You're an addict and that's it. And you're always going to be an addict to them. No matter how much you do, how much you try to do to become better, a better person...change...still going to look at you like an addict. That's it, that's the stamp.

Others did not disclose their injection use and would attempt to hide it fearing that they would receive "lesser medications" because the doctors and nurses would think that they were drug seeking.

I'm still kind of hesitant because also the addiction plays a role on there too because I want to see how far I get without being asked that or any bump in the road. Sometimes I'll be in real pain and I may need Dilaudid because not the nurses, but the doctors will put you in a gray side of what kind of medication they going to give you—Motrin, Morphine, or Dilaudid—sometimes they're going to give you Motrin or something because they know that you're an addict so they're not going to give you and I think that's kind of wrong on the part of the doctors.

Christopher described how he does not inform his HCPs that he is an IDU for two reasons. "I'm still kind of hesitant because also the addiction plays a role on there too because I want to see how far I get without being asked that." He spoke of how he will only inform the nurse if this person will be providing care to him. Christopher reports being a "regular" at the hospital and reported "They all know me there."

Participants referred to many verbal and nonverbal behaviors displayed by the nurse during their hospital stay, once the IDU disclosed their addiction, such as looks, sounds, and behaviors. Several of the participants reported the nurse making a

“disgusted” look and noises such as “Phft” or “huffing and puffing” once the IDU disclosed. Hillary spoke the most about how she believed others perceived her.

I had a nurse who went to take my blood and she was making all these comments and one of them, she put a bandage on after she took my blood. She was like—“don’t want that to bruise any more than it already is.” I was like—wow, that’s really rude. When she was putting the tourniquet on me she was like—“wow, your veins are ready to go.” Like making all these comments like that and making me feel really weird about myself and self-conscious and just bad about myself.

Behaviors such as physically pushing oneself away from the IDU after learning of their addiction was reported by three of the participants. One participant described and demonstrated how the nurse had a look of disgust as she physically pushed her chair away from the participant. He became louder and was visually upset as he demonstrated the action he had witnessed. Two other participants repeated the similar actions of demonstrating the disgusted look on the nurse’s face as she physically distanced herself from the IDU during their disclosure of injection drug use.

Not being informed of care to be received or present health status for the admitting condition was shared by six participants.

Yep, or about how I’m feeling or explain to me what jaundice means because I didn’t know either. Explain to me the symptoms. Explain to me what medications. Explain to me aftercare. No one explained anything to me. I was just there.

Being “kicked to the curb” as one participant stated, was evident in several of the participants’ experience, “They are rushing talking to me when I wanted to ask questions about what they were doing. They didn’t want to tell to me. They acted like I didn’t deserve to know.” Another participant stated, “They basically don’t spend time. They’re just in the room doing what they need to do and when you try to get their attention—you’re nobody.” Hillary felt like she was being treated and rushed out the door

because she was wasting the HCP's time. "Yeah, they wanted to treat the symptoms and get me done with—the cycle of antibiotics and to get out so I would stop wasting their time. That's how I felt. Just really rushed."

Three participants described examples in which the nurse had physically abused them. Examples included being poked in the chest, having their arms pulled while being moved, and being excessively rough while inserting intravenous angio catheters. Bob spoke of being shoved to the ground and his glasses being broken by an aide. He stated that the nurse was present and observed this activity. Christopher also spoke of being physically restrained and handled rougher than necessary by staff. However, he stated he understood they needed to do this to keep safe, as he was "really high."

Several participants spoke of how they felt punished by their nurse because they were substance dependent. "I was wasting the time for valuable people in the waiting room who deserved care more than I did because some thing they did...they didn't bring it upon themselves." David recognized the difference in the nurse before and after he was caught with drug paraphernalia in the hospital.

Grabbing my arm and telling me to do this and stop this. Just because I seen the difference in the voices and the body language told me everything from when she didn't see me with the drugs and when she seen me with the drugs.

Hillary spoke about an incident when she was having extreme pain during a "rough" insertion of an intravenous catheter. When she informed the nurse "That hurts really bad, I feel like you hit a nerve", the nurse did not acknowledge that Hillary had even spoken. Hillary stated this:

They just did all their care for me based on just looking at me and assessing from what they saw. I feel is a good symbol for the fact that I felt like they were just judging me for what they thought that I was, which

was a junky who had given themselves sepsis because I used filthy needles and that I didn't clean right and I was doing something that I wasn't supposed to be doing in the first place.

Two of the participants indicated that they would have appreciated advice on how to prevent abscesses, sepsis, and hepatitis. Instead, what the participants received were statements such as “If you don't do drugs, you won't get this.”

But when I went in to get treated for sepsis no one—I felt like people weren't trying to educate me or help me or tell me next time maybe this is a safer way for you to shoot up. They were just—you shouldn't be doing this.

Several participants verbalized that their HCPs simply did not understand, or care to understand the IDU, or what the IDU had been through in life. Hillary stated she knew she reacted strongly to others' opinion of her and that this caused her to have a negative self-image.

It's a combination of being grossed out, like disgusted and angry because I feel being a drug addict goes against so many different social rules or values it's hard for people to feel empathy for drug addicts. I guess—yeah, it's hard for some people because it's just—maybe the look is also kind of threatening or scared even a little bit. I feel like sometimes my presence is threatening. The doctor when I did say I was a drug addict acted – they moved back a little bit. I could tell they were a little bit nervous.

David shared his view on this lack of understanding that contributes to the way the IDU is treated.

Somebody that doesn't use doesn't know what I'm going through and I've been through everything. I'm a veteran. I've been through it all. I've been through it all. My childhood, I've been through it. Abuse, everything, I've been through it all. So I guess my way of coping with things is using drugs because it cures me for the meantime, but in the long range it's just hurting myself. It just coming right back, it just resets. So I'm stuck in this—I don't know what to do world.

Ella illustrated her frustration with the nurses' lack of awareness and understanding that addiction is a disease. She stated that it had a negative effect on her self-image.

Made me feel like crap. Really worthless because I don't expect someone to—oh, poor you. I don't expect that, but I didn't expect to be treated the way I was treated either because if I came in with cancer I'd be treated differently. Because it's considered an illness, a disease, and a lot of people don't consider addiction a disease. They think it's more by choice. You would expect someone in the medical field to be a little bit more compassionate—know..... or if they don't know get some damn training on it.

David spoke the most about not being understood for what he had experienced in his life. He detailed that his childhood abuse, being in war overseas, and the resulting PTSD contributed to his drug use. "I try to help. I'll be happy. I'll feel better, but some people don't see it like that. Some people say fuck them, I don't care. That's not my life. He could kill himself for all I care." David stated that the lack of understanding and compassion from his HCPs contributed to his depression and continued drug use. He reported that he left the hospital and was "using more" than prior to the hospitalization.

Six of the participants spoke about being disregarded in the hospital. This was described in ways such as the nurse avoiding interactions with the IDU, refusal of care, and delay in responding to the IDU's requests. Alex described the nurse's response after he had disclosed that he had been using cocaine prior to his arrival at the hospital for chest pain. He indicated that he had a significant family history of cardiovascular disease and that he had been concerned. After it had been determined that he was not having a heart attack, Alex stated that he was left in a room where no one bothered to turn on the light.

When they found out I was OK. I wasn't having a heart attack. Bimp...that's it...they said your blood pressure's up because you do cocaine. I'm like duh. That's how they looked at it from there. This guy is self-medicating I don't care about him. That's how it goes.

Hillary explained how she was treated in comparison to her roommates.

I felt they were coming in asking how they were doing in a nice voice. Like a general air of respect that I wasn't being treated with. It was really noticeable because it was the same couple nurses, the same staff treating them and they would go from one person to the other. I could notice a change in their voice and the way they were asking if they were doing OK, if they needed anything? No one ever asked me the whole time I was in the hospital if I was feeling OK. Or if anything was wrong with my IV or anything was uncomfortable or if I felt like I was going to die. No one ever asked me.

David shared that at times he would ring the call bell to ask for help and no one would show up, "Making me suffer and when I asked for help she wouldn't even show up."

David portrayed the difference between the care he had received and the care his roommate had received in response to use of the call bell.

Just being nasty to me and when I used to call for help for the pain they would take their time to come to me. And I know this because I had a roommate and every time he pressed the button, and I was under more care than he was. I was in more pain – my stomach was already extended and him, they would come quick. I pressed the button four or five times – they keep telling me—we on our way, we on our way.

David left against medical advice due to the way that he was treated by his HCPs.

Because they didn't want to deal with me. That's just the way that I felt because the vibe, the negativity was out there. It was just insane. So I had to leave, I had to leave. I wasn't comfortable with the fact that she could spread—tell everybody, her coworkers—I go out for a walk or something and everybody would look at me different. I just didn't feel comfortable. I had to go.

The comparison cases provided numerous examples of the care received in the acute care setting. Due to the consequences of drug use and the ongoing care needed for chronic conditions, the participants required episodic health care. Although the stories shared in this study represented the interactions during an inpatient stay on a medical unit, the participants offered similar examples of received treatment for visits at a clinic, the ED, psychiatric unit, and detoxification unit.



## **Mistrust**

Mistrust of the nurse and other HCPs was evident while listening to the participants as they shared their stories of the various HCP encounters. Unless otherwise noted, the following examples of mistrust refer to the nurse:

I don't know, I can't tell you because I haven't been to the hospital after that, but if I did go I wouldn't go with the mindset—she's out to get me. It would be in my head, but then I'd be more careful what I say, what I do in front of people. Just a little bit more closed.

David clearly stated his mistrust of the nurse:

They giving you medication. I don't know what they're going to do to me. I don't know. I'm not saying they're bad people but if you're giving me that vibe? How do I know you're not going to give me the wrong meds? You don't make me feel comfortable enough to trust you giving me meds.

Isaac shared his mistrust of the nurses after receiving care for a gunshot wound. He reported that he had been clean for 6 weeks at the time and that he was “in the wrong place at the wrong time.” He believed that the nurses and doctors were working together to “frame him.”

They were stalling me for the police to come. They weren't interested in my benefit. They were keeping me there so the cops could come. That's what I meant by the clandestine cop/nurse deal. I felt like they weren't at all interested in treating me. They were interested in interrogating me, drug testing me. Getting reactions out of me, seeing if I would detox while I was in there. I felt like there was everything going on, but my interests.

Isaac also mistrusted the nurses caring for him because he felt that they were pushing opioids on him during a time that he was 6 weeks clean from heroin use.

They were pushing drugs on me and they wouldn't fucking take “NO” for an answer and it felt like—you're already treating me less than a second class citizen and you're just going to give me more of what destroyed my life? And I'm trying to not do this stuff. Like awaken the beast!

Isaac reported he felt that the nurses were trying to set him up for failure by their continual offer for him to take Percocet (acetaminophen and oxycodone) after they had given him morphine for his gunshot wound. “Yeah, you’re going to want to take these. I’m like—I’m trying to recover. And they’re—this is not a lot. A couple of Percocet.”

Right, I told them that I wasn’t interested. OK, so at this point they’re like—all right we’re going to give you these two pills, two Percocets. I was like—ah, I’m good. You’re going to want these. I’m like—no, thank you. I wasn’t trying to be difficult, but it was getting to that point. Where I’m like—I don’t want your fucking medication. I don’t want you here now. I don’t care. Leave me alone. After the 19<sup>th</sup> time the 20<sup>th</sup> I gave in. I’m like—all right, fine. Give me them. Shut up. Get out of here. Eat them. Drink the water. Done.

Hillary talked a great deal about mistrust and being fearful of her college finding out that she was a substance abuser. She had not sought care from health services on the campus, as she was afraid that she would get “kicked out for being an addict.” Instead, Hillary would seek care for her substance use issues by visiting different emergency rooms to avoid being seen by anyone she may have known.

I have a lot of medical things happening because when you’re shooting up there’s all sorts of problems that can happen, but I don’t go to the hospital very much because I’m always scared that I’m going to be mistreated or that I’m going to get in trouble or have the cops called.

David’s first and only experience of being an IDU at a time he was hospitalized for his chronic condition changed how he felt about his caregivers. He stated he was surprised by the care that he had received and that the doctor “was the one who started it all.” He had disclosed that he was an IDU and had expected that they would be able to help him with this problem in addition to his admitting diagnosis of constipation.

“We can’t help you if you’re going to use.” Simple. I thought a doctor should be able to help you with all your situation. I understand you go in there for one problem, you know you go into two problems. You feel like they should be able to help you out that way you don’t suffer, you don’t

have to use drugs, but that's not the case because that's not their field. So they can't help you, they're only there for what you came in for. Because I got to the hospital and say hey I'm an addict and I got this problem. They admit me for being an addict, not for my problem. They'll admit me for being an addict and not take care of the problem I have because they think that's what's causing my problem.

Alex chose to go to a hospital that was much further away during an emergency situation due to his mistrust of the HCPs at the hospital located only a few minutes from his home. He had had a negative experience a few years prior and refused to seek care at this facility again unless it was "life or death."

I don't know something was wrong and when I walked in there the nurse thought that I had a stroke. One side, damn I was shaking, and my blood pressure was up so they said—you're going to the hospital. So they took me to that hospital they said—we'll take you to (hospital A). I said—no, no, no, no, no you're going to take me to (hospital B).

The participants provided examples of why they did not trust the nurse, their HCPs, or the hospital in general. David verbalized his belief that the hospital should be a place that you should feel safe in, but that he didn't. The crux of the disillusion of expected care had to do with the nurse. The interactions with the nurse were described in ways that illuminated the IDU's view of what the nurse's role is and the expected behaviors of a nurse. "It's just you take things for granted—you say—oh, she's a nurse she's going to take care of me." Alex shared how he perceived the nurse's role.

She could do anything. She got the power. The doctor just works there. The nurse has the power, right? Yeah, it's like that. They might make a few more dollars than the nurse, but the nurse knows. But she is the one interacting; she's the one holding the hand.

There was a clear mismatch between what the participants expected for nursing care and what they received. Isaac didn't trust the nurses at the hospital as he felt that they were trying to set him up to be arrested.

Second class human being..... I felt like they may have stalled for the police to go rummage through my house. I felt like there was this clandestine situation going on there because for what they did—they kept me there forever and I wasn't getting any support really—sponge to fucking wipe the blood off me with. Terrible care.

Isaac declared that the nurses had a responsibility to care for him as a “human being, it's the least they could do.” He stated that working with the police to get someone in trouble isn't what a nurse is supposed to do to their patients. He shared after the interview ended that he now knows not to tell them anything unless he has to because, “They aren't there for me, they're just taking care of themselves.”

Most of the participants used descriptive words to define what they believed a nurse should be like. Terms such as “compassionate,” “care about people,” “want to help,” “keep people from suffering,” and “not judge people, just take care of people” were descriptors used to identify what they believed the nurse's role is in health care. Unfortunately, very few nurses lived up to the expectations of the participants.

### **Unpredictability of Care**

Several participants articulated that they never knew how they would be treated when seeking medical care. This feeling of unpredictability was a precursor for not seeking care for a medical condition. “But then again, you get so nervous because of what I experienced at the hospital doesn't make me want to go to the hospital because I don't know how they're going to treat me there.”

Three of the participants had chronic conditions that required multiple hospitalizations during times when the participant had not been addicted, as well as during active addiction. All three cited a stark difference in the care received before and after initiation of their drug use, with a significantly poorer outcome noted during times

of active use. Hillary had lupus and had not seen her primary provider in several years because “I don’t want to deal with how he will treat me.” David suffered from chronic constipation and had been hospitalized four times for this condition, the latest being his first time while in active addiction.

You got to give everybody a chance. Not saying everybody’s bad out there, but I’ll think about going to the hospital. Before I would just go. Now you got that block, that wall in front of you like if you go you’re going to get mistreated.

Five participants referred to what is coined “the look.” This is the first few minutes of an encounter or reaction that the IDU experiences with the nurse. The participants spoke of reading the facial expressions, body language, tone, and general behaviors of the nurse to determine how they expected the nurse would treat them.

I kind of read their mood. Listen to what they say, it’s kind of like in my mind and kind of picking out what kind of person that person is. How they talk. Certain things like that. You can kind of know what that person is going to be with their language.

Alex spoke the most about “the look” and how the first two to three minutes of an exchange was the most important.

The right nurse would look at you. You got some nurses that will come in a room and they are looking at their watch or they’re looking over here and you’re talking to them and they glance once but most of the time, they are over here looking at the wall talking to you or they are doing something. I don’t know. It is a look that nurses have. You can tell.

Hillary also spoke about “the look”;

I have interacted with a lot of people who have harsh feelings towards drug addicts and I have seen a specific look people get on their face when they find out. And it’s really hateful and I felt like she had a really hateful mean look when she was doing my IV and when I told her that. And she didn’t say anything. I felt like I was getting punished or something for getting help. It just didn’t feel good.

Alex also described how he attempted to set the tone of the encounter when he first meets his nurse.

It's how you present yourself when you first walk in a room. My dad used to say, the first 2-3 sentences that come out of your mouth, that's what people will remember you by. So I knew I can't spell that good, so I had to speak well. You have to look people in the eye. You can't look like you are a paranoid or schizophrenic or something.

All of the participants described numerous encounters where they were marginalized by the HCP. For some, this response became “normal” and expected during any interaction with a HCP. Jane stated that “after a while, you don't even notice it anymore” and Alex stated, “You just get used to it.”

### **Nurse Encounters Without Experiencing Marginalization**

Three of the participants provided examples of received care that was based on a harm reduction model. Harm reduction education from the nurse or HCP has been shown to be part of ethical care and reduces health care disparities (Allman et al., 2007; Pauly, 2008). Hillary shared an experience with a nurse she had seen on several occasions for an abscess.

Sometimes I had a nurse, who was actually pretty nice usually to me but I came back a couple times when I'm on and she was like—you're here again. You used dirty needles again. What's going on? Why did you do that? And talked to me about it and been honest, but I didn't feel like she was making me feel bad. She was just trying to make me realize I'm doing something over and over and that's not working. It's not that I don't want to be questioned by doctors it's just that there's a human interaction that's hard to describe the way that respect is expressed. I don't know....trying to get it across is kind of hard.

Hillary shared with the nurse that she was using the same syringes because she couldn't afford to buy a new one for each injection. This nurse had given Hillary advice on places she could go to obtain free, clean syringes, as well as instructing her on how to properly

cleanse the skin prior to injecting. Hillary reported implementing these strategies as often as she could. This resulted in a reduction in the harm caused by Hillary's injection drug use as Hillary reported fewer visits to the ED for an abscess.

Another poignant, powerful example of a positive nurse encounter came from Grace's passionate description of her experience with the "only good nurse" during her 5-day hospitalization.

By just that nurse upstairs (in the hospital) genuinely caring about me and talking to me. Got me to go to the detox when those other nurses downstairs (in the hospital) were such bitches and so ignorant. They were getting me to leave. To say fuck it, I don't even care if I'm jaundice. I don't even care if my liver falls apart right now. I just want to get the hell away from you people. So that's what I mean. Just that little bit of compassion that other nurse showed me. She practically saved my life because I stayed. So you're in the field of saving lives and they were pretty much just killing me.

Grace credited the one nurse who explained her condition, her options, and demonstrated nonjudgmental behaviors as being the nurse who "saved my life." Having spent 5 days in the hospital, Grace encountered this nurse during Grace's last 8 hours at the hospital. This one nurse provided Grace with information and advocacy throughout her shift.

She talked to the doctor because they were giving me 5 mg of Methadone, which does nothing. She explained to me that they cannot give me any more Methadone because they're not a detox, she explained that to me....but she said she would talk to the doctor to see if the doctor could give me some Morphine, just enough to keep me not sick. Not enough to get me high she explained, but she said—just enough so that you're not sick so we can get you into the detox.

Grace had never been to a detoxification unit before. As a result of this nurse encounter, Grace decided not to go home and instead entered a detoxification unit and subsequent rehabilitation house and remained drug free for six months. The nurse was instrumental in assisting Grace's transfer to the detoxification unit. This was Grace's first

and only time of sobriety since the initiation of her drug use. Grace summarized her interactions with this nurse by eloquently stating, “I have plenty of excuses to get high, plenty of them. I can come up with a million reasons to get high. I’m trying to find a reason not to.” Grace shared how this one nurse was her reason to not get high and to enter a detoxification unit.

The way that she treated me saved my life because had I continued to get the care that I was getting those four days before I would have left and I could have OD’d. Or whatever the hell’s going on with my liver it could have collapsed. I don’t know. So I believe that she did save my life.

Grace was at a turning point in her life due to her changing health status. The literature has shown that this is an important time to reach out to the substance user (Moneyham & Connor, 1995; Neale et al., 2007). Grace’s nurse took the time to talk with her about her medical status and treatment. For Grace, this was a memorable encounter in her life. Grace shared that this experience had meaning because someone she didn’t know actually cared enough about her to help her. “It meant that there still are actually good people, caring people. Just cause..... she had nothing to gain. Just because they care. That felt really good. For whatever reasons, I don’t want you to die.”

### **Defensiveness**

All of the participants provided examples of defensive behaviors they demonstrated while receiving care in the hospital. This response usually was the outcome of receiving less than adequate care in the eyes of the participant. Defensiveness was usually the result of being accused of drug seeking or lack of response to the IDU’s physical and/or emotional needs, especially when the IDU disclosed their addiction or when they would begin to experience withdrawal symptoms.



Three participants talked about being dope sick and the responses of the HCPs to this physically uncomfortable experience. Two participants stated that they did not experience dope sickness because they were receiving opioids in the hospital for their admitting diagnosis. The remaining four individuals either did not stay long enough to go through withdrawals, did not talk about withdrawals, or left against medical advice because of their withdrawals.

Christopher and David talked about injecting while in the hospital. However, their reasons for use were different. Christopher had been admitted with viral meningitis and stated he used because he wanted to be “overmedicated for the headache and pain and stuff and not deal” and “to see what I could get away with.” He stated that he had been receiving opiates for the severe headache from the meningitis. When asked about this experience, Christopher reported that the nurses should have known he was using drugs because he “was in a nod all the time,” and that he “could have died.” Christopher left the hospital after 3 days because he was caught soliciting drugs over the phone at the nurses’ station.

They asked me if I was making phone calls to do those phone calls for deliveries and I denied it, but they know that’s what it was because the Spanish nurse was doing the interpreting for the whole unit. I was speaking in Spanish and I thought there was nobody who knew Spanish and there was somebody who knew Spanish.

Christopher reported being defensive (physically and verbally) only when he was under the influence of poly-substances. He said he recognized that the nurses were doing “what they had to do to keep themselves and me safe,” but that he was angry and physically out of control at the hospital. Christopher felt that his addiction also made him think a certain way and that this may not be based in reality, “When they say something

to you—we take it the wrong way. We may think it's mean or something but it's really our addiction that's playing that role.” Christopher explained how he would wait to see how the nurse would approach him before initiating an interaction.

If they talk to me it depends on how they talk to me and it depends on what kind of question it is. That's how I answer. It all depends on how they ask me and tone, the tone. How they ask the question and whether they're being polite and doing their job right. Things like that.

David reported that upon admission to the hospital, he confessed to being an IDU. He stated that he kept his drugs hidden because “I had to get cured because I was going to be sick for days.” David was setting up his drugs and was caught by the nurse as he was starting to inject. He stated that the nurse told him that she had to report him for going against policy and he was upset by this news. David described that the nurse's behavior changed after this encounter.

She was treating me good. If I called her she would come quick. She would come talk to me. Ask me questions about my family. Anything I need to call her, not to hesitate. Then after that it was like a totally different person. And I explained to her you can't judge me by this I'm still respecting you. I'm sorry that you had to see what I'm doing, but you're not going through what I'm going through you got to understand where I'm coming from. But she didn't like that.

David stated that the nurses looked in on him less often than before he was caught using, “because they didn't want to deal with me.” David described his feelings about the care he received after he was caught using drugs.

At that point I didn't care whether they kicked me out or not. They already treating me like shit so what are they going to do now? Can't do nothing else to hurt me. They didn't care. Let me rephrase that—she didn't care.

David did eventually leave the hospital against medical advice and has not sought medical care since this incident despite experiencing several abscesses.

Isaac and Grace talked the most about being defensive due to the treatment they received during their hospitalization. Isaac shared that he informed the nurses that he had been clean for 6 weeks but became upset when the nurse rolled her eyes upon hearing his statement.

I was on the defensive because of this whole situation. Like having police assuming I'm a criminal. I was on the defensive already and then.... and so any little attitude that they gave me I matched them with it. I'm just like—what the hell?

Isaac also got defensive when he believed that the nurses and police officers were in collaboration against him: “And the cops were saying I was uncooperative even though I gave a description of the guy. I was as cooperative as I could be, but I was also defending my rights because they already were attacking me”

Similarly, Grace reported becoming defensive when the nurse was making comments while trying to insert an angio catheter.

Do you have a better? How's your other arm? I was just like—whatever. Don't even put—I'm getting pissed now. Like do I fucking need that? Because if I don't need it, don't put it in. If it's so much of a problem.

Hillary and Jane talked about being told that they would not be receiving any narcotics when seen for an abscess. Hillary shared how the experience made her feel.

It makes me feel bad because I'm like—yeah, I do drugs, but I'm also living my life, also I'm just trying to go through my day to day things. I have something on my arm that hurts really bad—it shouldn't matter how I got it and I'm not drug seeking. That's not how I get my drugs. I don't go to the doctor and just for my infection. I just feel like it's unreasonable—maybe if they had some doubt that I had anything wrong with me, but then it would be reasonable maybe to remind me—we don't prescribe pain killers for this or that, but when it's something so visible. That would hurt anyone—on anyone's arm that would be hurting and I didn't even ask for painkillers. So it makes me feel bad and it makes me feel mad too.

Jane shared a similar story about a past experience she had while having a “really large, really bad” abscess examined. Jane reported asking for something to help with the pain while they lanced and drained the abscess. She stated that the nurse told her “too bad, it’s self inflicted and I don’t care.” Jane was more assertive and vocal in her response to the nurse than Hillary had been.

Well, I let her know how it made me feel. Yeah, I let her know—really, you’re a bitch and you shouldn’t even be a nurse. How do you look at yourself in the mirror? How dare you even talk to me? Even if you feel that—how dare you say that to a patient? You there to treat people, not judge people. That’s my outlook on it.

All of the participants described verbal and physical displays of defensiveness when they were being marginalized. Some of the participants described how they would internally respond to the behaviors, while others described how they would confront the person responsible for the inappropriate behavior. However, none of the participants reported that this was their first time experiencing marginalization. Instead, their responses to being marginalized appeared to be “expected” and the examples shared with the researcher were those that were outside what they perceived to be as normal given their history of substance dependence.

### **Repeated Victimization**

All of the participants described their response to the repeated negative care received in the hospital and how this made them feel about HCPs in general. This repeated victimization resulted in the participants increasing their drug usage, leaving against medical advice, which led to a delay in seeking care and increasing their feelings of shame. The following section will describe the participants’ experiences of self-care and delay in seeking care to avoid being further subjected to marginalization.

## Self-Care Management and Delay in Seeking Care

Seven participants made comments about expecting poor care when seeking medical care. These negative expectations often led to a delay in treatment. Hillary delayed seeking health care and would use the Internet to self-diagnose and treat. She reported that she has not seen a primary care provider for her lupus “for a couple of years” because she didn’t want to be judged by her provider.

Also just because half of it is being scared of being reported, but the other half is I don't want to be treated like shit. I already feel—I'm a heroin addict. I already feel like there's so much social stigma towards me and I don't want to go out of my way to be treated poorly. So that's one of the main reasons I don't go to the hospital.

David had only one experience being hospitalized while in active addiction and believed that this negative experience had a significant impact on his mental health. He felt that the negativity that the HCPs exhibited was “toxic” to him and made him want to “use more.” “I wouldn’t want nobody else to go through that pain. It’s not cool. That’s stressful. You go into depression. You start thinking crazy stuff. That’s why I just avoid all that shit. I’ll just stay home.”

David talked about the role of positive people in his addiction and the effect of a negative person.

But that’s what’s going to cure you and not make you feel that way. Instead of having someone be supportive and being positive. You don’t want to leave because you have somebody filling your mind with positive stuff. So it keeps you thinking instead of thinking about drugs. I don’t know that’s the way I process things. Everybody’s different, but for me it’s just different. I’d rather have positive people around me because it makes me use less than having negative people. It makes me want to use more. If I use more it goes up then I dig myself into a deeper hole. It’s going to be harder to climb back out. So I don’t go to the hospital.

David reflected on his most recent experience and stated, “That stays in my mind that’s it. Stays there. So everything I see at the hospital is negative.” David struggled between wanting to give people a chance and expecting that he would receive poor care.

You got to give everybody a chance. Not saying everybody’s bad out there, but I’ll think about going to the hospital. Before I would just go. Now you got that block, that wall in front of you like if you go you’re going to get mistreated.

Ella shared how she also prolonged seeking treatment due to an expected negative experience of being treated poorly.

Yeah, if I have marks on my arms I don’t want people to see that at the hospital. I don’t want to be treated differently so if I have track marks and I have marks I’m not going to go. I would wait until they’re healed if I had to.

Isaac managed his health by using herbals and implementing knowledge he had gained from his previous work experience in a health food store. He stated that his HCP would prescribe medications for him that he believed were deadly to his body.

I haven’t seen my primary care physician in a year because I don’t bother going because I was honest with him with my drug history so instead of giving me one opiate that has very little side effects on me they want to give me gabapentin and the Neurontin which has a ton of side effects. It’s also a mood stabilizer so it has a brain thing. All that plus meloxicam, a ton of heart attack issues—they want to give me all these other drugs that are deadly instead of something mild—like I can go get an Aspirin or something. I don’t want your quackiness. I don’t. I’m over it. I’m definitely over it with the health care system.

Another participant had this to say about seeking care:

Yeah, I would go if I had like nooooooo choice. I have to be bleeding out my eyeballs because I went to the ER in (name of hospital) and there I got treated like crap once I told them that I was an IV user. I got treated like crap.

The expectations of the nurse’s response led one participant to make this statement: “So now I don’t even want to go to the hospital. I don’t even want to have to

see the disgust in their face.” Alex shared how he preferred to travel rather than go to the hospital located just a few minutes walk from his home due to the expectation of poor treatment.

Yeah. I could walk up the street to get everything taken care of instead I come all the way over here. It’s obvious that there’s something I don’t like over there so that’s why I do this. I come here. . . . . It’s terrible there.

Three participants spoke about using the Internet and online substance user forums to diagnose and self-treat in order to avoid receiving care at a hospital. Hillary shared how she had been admitted with sepsis due to her delay in seeking care for fear of poor treatment:

Yeah, definitely because I’m so freaked out about being treated poorly because I already feel like it’s sad to be a drug addict. I’m not having a great time in my life and I don’t want to go out of my way to be treated poorly. So I only go—I’ll use the Internet and try to treat things myself if I have to. I’ll let things go for a pretty long time – it has to be pretty serious for me to go to the hospital because I want to avoid—just the whole experience of having to out yourself even if people are respectful it’s just not fun to have to go to the hospital and letting everyone know that you’re a drug user because it’s embarrassing.

David was the most passionate and articulate in his words and described his feelings about the expectation of negative care. He often spoke about how the hospital is supposed to be a “safe place.” Like all of the other participants, David had expectations of nursing care that were not met and contributed to his negative feelings about the hospital in general.

I mean that’s their job is to make people feel good and comfortable and make sure they’re safe. Not because you woke up mad. You’re supposed to leave your problems at home. Your job is to take care of people. Not make them feel like shit. You don’t get paid for that.

All of the participants described how they attempted to self-manage their health care needs, or just ignored their health, to avoid having to seek care from a HCP. Their

experiences receiving health care were described as being overall negative. Several of the participants described the effects of these interactions as the reason for their increased depression, feelings of worthlessness, increased drug usage, and avoidance of seeking health care when it was needed.

### **Young Enough To Be Saved**

Only one participant described an experience of receiving care in the hospital and receiving a lot of attention from both the doctor and nurses in regard to her substance use. “They spent a lot of time trying to get me to say that I wanted to get clean.” Hillary, at 22, was the youngest of the participants; she shared that her most recent experience at the hospital was different from any other visit due to the attention from the doctor and nurses.

Although the doctor came in and gave me a list of all the detox’s in the area and told me—he didn’t really have a lot of time to sit down with me—but he felt like considering my using time and my age and my mindset I guess he thought that I could get clean and like that. .... He wanted to see me do that.

Hillary also reported that one of the nurses said this to her: “Oh, my son is a heroin addict and he’s not going to get clean. It makes me so sad to see people your age come in.”

During our time after the tape was stopped, Hillary made the comment, “I think that the nurse was trying to save me because she couldn’t save her son.”

Hillary described her latest visit to the ED as being different from previous experiences due to this influx of attention and personalized treatment:

I had person after person come in and every person you talk to—I guess now that I think of it they were nice to me and treating me. They were treating me nice, but I don’t know if they were treating me with respect. I could tell they were sad for me and were pitying me, but I don’t know that they weren’t really treating me like I was a person with agency. .... like I felt it was more like pity than empathy. But it was preferable to other hospital visits I’ve had.



During the interview, Hillary reflected that although this treatment was preferable to prior interactions with HCPs, she felt that the doctor and nurse's behavior was disrespectful.

“It made me feel like kind of a little kid the way they were talking to me—their pity, a lot of pity in their voice.”

Like I was a young person in a situation that no one would ever want to be in or chose to be in. I felt like they were under the assumption that somehow I had been tricked into becoming a heroin addict. That I was really misled and that they needed to show me the way.

Hillary's experience of receiving patient-centered care was in stark contrast to the other participants. Four other participants had used this hospital and none of them mentioned having had this experience. The physician's statement that considering Hillary's age, length of drug use, and mindset, suggests that she was “worthy of being saved.” At the age of 22, Hillary was the youngest of the participants but had been using illicit substances since the age of 14.

### **Summary of Findings**

Listening to the stories of the participants allowed them a rare opportunity to be heard. Their stories, the terms they used, and their struggles were similar in so many ways despite differences in their ages, races, genders, and geographic locations. Their descriptions of the themes of *Marginalization*, *Defensiveness*, and *Repeated Victimization* were evident in the telling of their experiences.

The subthemes that fell under the overarching theme of *Marginalization* included *Feelings of worthlessness*, *Mistrust*, and *Unpredictability of care*. The meaning ascribed to these subthemes focused on the participants' feelings of being treated as if they were worthless. Many of the participants described similar experiences of being labeled and treated differently due to their drug use. Three of the participants demonstrated the same

look that they saw on the nurse's face after they had disclosed their IDU status; a physical withdrawal and verbal sound of disgust occurred in all three examples. All three of the participants were demonstrative, showed facial expressions of disgust, and raised their voices while describing this event.

The expectations of care to be received in the hospital typically followed the participant's belief and knowledge of what a nurse is and does in health care. The unpredictability of care was a result of their treatment after disclosing they were an IDU. For the three participants who had chronic illnesses, this unpredictability of care was a paradigm shift from their experiences receiving care before they disclosed their addictions. Previously, these three individuals had not hesitated to seek care and had an ongoing relationship with their primary provider. The comparison cases differed from the rival case in that all of the participants stated that they either did not have a trusting relationship with their nurses or other HCPs, or did not trust the hospital in general. This mistrust led to the overarching theme of *Defensiveness*.

All participants either described or verbalized their defensiveness as a result of the care received in the hospital from the nurses. This defensiveness was manifested in behaviors such as verbal outbursts toward the nurse, withdrawal from the nurse, and confrontation of the nurse. Descriptions of physical abuse, rough handling, and intentional neglect led the participants to become angry. This often resulted in statements made by the nurse that the individual was responsible for their illness due to their drug use. The participants became angry because they believed that the nurse didn't understand addiction and didn't understand where the person was coming from in their life.

The overarching theme of *Repeated Victimization* emerged as a result of the participants' statements, to avoid being subjected to further marginalization by their HCP, they would delay seeking care for their health care needs. The subtheme that fell under this category was *Self-care management and delay in seeking care*. Although this study attempted to focus just on the nurse encounter, the participants often clumped all HCPs into one group. If one encounter was negative, often the entire hospitalization was viewed as a negative experience. Several of the participants stated that they would try to not judge the behaviors of one, or a few of their HCPs, but that they now had to stop to think about seeking care for their illnesses and this was viewed as being unjust.

All of the participants had a history of a mental health disorder and a history of trauma. They described their feelings of being victimized after each negative encounter they experienced. These feelings manifested as descriptions of increased depression, increased anxiety when they were ill, and verbalizations of the feelings that they needed to use more of their drug to escape from their present reality. Several participants described being fatalistic about their present health condition and addiction. None of them verbalized an intention to follow up on their chronic conditions or the acute illness that had brought them to the hospital. As one participant stated, "This is my stamp."

The outlier theme of *Young Enough To Be Saved* that emerged from one participant's experience differed from the other eight participants' stories. Hillary's interactions with the HCPs included in-depth questioning about her history and drug use, education, and referral for treatment options. None of the other eight participants cited this holistic care when telling their stories.

The next chapter will present a discussion of the findings and my interpretation of the cases. The use of the researcher as an observer, the experience of the researcher as a nurse, and the nonverbal cues witnessed during the interviews will be examined. In addition, the application of Travelbee's (1971) phases of orientation, emerging identities, sympathy, empathy, and rapport will be discussed.

## CHAPTER 5

### DISCUSSION

#### Introduction

This chapter will present a discussion of the findings and my interpretation of the cases based on my analysis and reflection of the findings. I will examine the participant's experience with the nurse during a hospitalization and the meaning of this experience. I will also examine and describe the participant's intention of seeking care the next time care is needed. For the rival case, I will discuss my interpretation of the physician as understanding of addiction and as a humanistic role model. I will discuss my interpretation of the nurses' response as being influenced by the physician's humanistic role modeling and leadership qualities. I will also present an alternative view of "doing something to help yourself."

The following interpretive themes will be discussed from the comparative cases: *Marginalization, Defensiveness, and Repeated Victimization*. The subthemes of *Feelings of worthlessness, Mistrust, Unpredictability of care, Self-care management and delay in seeking care* will also be interpreted and discussed. Moreover, the outlier theme of *Young Enough To Be Saved* will be examined and interpreted.

Additionally, the five phases of Joyce Travelbee's (1971) theory of human-to-human relationship will be examined and interpreted in light of the descriptions of the IDUs' interactions with nurses in the hospital. Both the rival and comparison cases will be examined using Travelbee's (1971) interlocking phases of (a) the original encounter, (b) emerging identities, (c) empathy, (d) sympathy, and finally (e) the phase of rapport. This approach follows Yin's (2014) comparative structures of analyzing case studies.

This requires the same case study material to be repeated two or more times, “comparing alternative descriptions or explanations of the same case” (Yin, 2014, p. 188).

The following is my interpretation of the rival and comparison cases. The interpretation is based on the single interview of the IDU and their recollection and interpretation of the events that had occurred. Analysis of this data includes objective and subjective data and my experience as a nurse working with substance users for 16 years.

### **Interpretation of the Rival Case—Jane**

#### **Understanding Addiction**

Jane’s description of her most recent experience of receiving care from a nurse during an inpatient hospital stay was interpreted as “understanding of addiction.” From the moment the emergency technicians contacted the buprenorphine naloxone-certified physician, Jane’s initial treatment was specialized for a person in active withdrawal from an opiate addiction. The provider ordered Ativan (lorazepam) to be administered immediately, which assisted Jane with the acute withdrawal process before reaching the ED. Jane reported that she had been aware that treatment did not usually begin until the individual was physically in the ED.

This initial treatment set Jane up for a positive interaction with her provider once she arrived at the hospital. The provider stated that he was “waiting for this to happen,” as this was the first time he had treated a patient with this condition. The provider’s statement implies that he was aware of the common abuse of buprenorphine naloxone and recognized that she had been using the drug to avoid withdrawals (Bazazi, Yokell, Fu, Rich, & Zaller, 2011). Currently, prescribers of buprenorphine naloxone must receive training specific to addiction in order to prescribe this medication. Because the provider

was trained in addiction treatment, he was able to approach Jane's case holistically as he considered her substance dependence history, her take-home methadone program, and her risks related to the buprenorphine naloxone. The physician's knowledge obtained from his certification in addiction treatment was significant in the initial care and subsequent care that Jane received.

Fortunately for Jane, she received her initial treatment from a provider who understood the withdrawal process, addiction, and the best plan of treatment for her, as this is not the case for many individuals with substance dependence. As of April 2014, there were 444 providers or centers in Massachusetts where certified Suboxone (buprenorphine and naloxone) providers could be located (Opiate Addiction and Treatment Resource, 2014). As of 2012, Massachusetts was number one in the United States for active physicians, with 21,542 practicing patient care physicians (American Association of Medical Colleges [AAMC], 2013, p.11). Although the number of trained prescribers is a significant fraction of the total number of providers, the AAMC does not break down the providers by specialty. However, a significant difference exists in the number of trained providers and the number of potential providers for buprenorphine naloxone. According to the literature, physicians have cited barriers to administration of buprenorphine as lack of institutional support, lack of specialty backup, time constraints, and lack of confidence in their ability to manage opioid addiction (Hutchinson, Caitlin, Andrilla, Baldwin, & Rosenblatt, 2014). Jane was the only participant who reported receiving care from a provider educated in addiction treatment.

## **The Humanistic Physician as a Role Model**

Jane's attending physician in the ED demonstrated behaviors of a humanistic physician. "Humanist beliefs stress the potential value and goodness of human beings, emphasize common human needs, and seek solely rational ways of solving human problems" (Humanism, 2015). In Chou, Kellom, and Shea's (2014) study, physicians with highly humanistic attitudes and habits demonstrated behaviors such as "humility, curiosity, and a desire to live up to a standard" and "self-reflection, connecting with patients, teaching and role modeling, and achieving life work balance" (p. 1252). None of the other participants described their physician encounter as being positive or patient centered.

Jane's physician demonstrated humility and curiosity by sharing that she was his first case of a person injecting buprenorphine naloxone while taking methadone. He sat with her to listen to her story and her rationales for the decisions that she made. Jane trusted him and stated that she was "honest and told him everything." The physician demonstrated a desire to live up to a standard by treating Jane "by the basic values of how people should be cared for" (Chou, Kellom, & Shea, 2014, p. 1252). Jane's physician demonstrated the practice of connecting with patients and teaching and role modeling (Chou et al., 2014). He connected with Jane by "sitting with me for over 15 minutes" and explaining the plan of treatment. He understood how diligent and law abiding Jane had to be to be able to take home four days of methadone at a time. He reportedly told Jane that he didn't want to take that away from her. This connection demonstrated that the provider treated Jane with empathy, and not just as a person with a disease or illness. Studies suggest that a humanistic physician's empathetic treatment has



a positive effect on the physical health of the patient (Del Canale et al., 2012; Neumann et al., 2007; Rakel et al., 2011).

Jane reported that this experience meant a great deal to her and she referred to the physician as a “God” being sent to her. Jane was asked if this experience made a difference in when she would seek care the next time it was needed and she responded “Yes!” before I could even finish asking the question. She reported that the care she received made her feel comfortable and that for the last 2 years she had been telling others about her experience. Although Jane recognized that the next time she went to the hospital her experience might be different, she stated a number of times before, during, and after the interview that she wouldn’t hesitate to go back to that facility.

The provider’s habit of teaching and role modeling can only be assumed. Demonstration of humanistic attitudes and habits in the presence of nursing staff may certainly influence the nurse’s care of the patient. The literature suggests that role support is the strongest predictor of a positive attitude toward the substance-using person (Ford, Bammer, & Becker, 2009). As Jane was hospitalized for 3 days on several units, the only constant that remained during her time in the hospital was the physician. The physician may have acted as a strong influence and leader for the group of nurses caring for Jane. The nurses conformed to the leadership due to their “depersonalized social attraction processes” (Hogg, 2001, p. 184). “Depersonalization is the basic process underlying group phenomena; it perceptually differentiates groups and renders perceptions, attitudes, feelings, and behaviors stereotypical and group normative” (Hogg, 2001, p. 187). The nurses may have been practicing from an expected group focus of addiction-based care instead of a personal belief system about addiction. This type of modeling (Wallace,

Davis, & Liberman, 1973) and social identity behavior can be found within the psychology literature and organizational behavioral literature (Hogg, 2001).

### **Jane's Received Nursing Care**

Jane's most recent hospital stay was 3 days, and she reported receiving "excellent" care from "all of the nurses." Despite a number of prompts by the researcher to be more descriptive of the received nursing care, Jane focused more on a rich description of the care received from the physician. Jane defined excellent care received from the nurses as the following behaviors: checked in on her, were prompt with her medications, asked her how she was feeling and if she was doing okay, offered her counseling and resources, were concerned about her care, didn't judge her, and didn't treat her differently. The meaning of this experience was evident in Jane's verbal and nonverbal responses to my questions. When asked about the meaning of this experience, Jane moved forward in her chair, her eyes widened, and she spoke excitedly in a higher voice. She believed that this experience meant that health care providers were finally beginning to understand addiction as a disease. She repetitively told me that she had received "excellent" care throughout her stay at the hospital. Her demeanor was significantly different when describing other health care encounters she had experienced during her time of active substance use. Her previous interactions with nurses were similar to the experience described by the comparison cases. Jane would go back and forth between her negative experiences with prior nurse encounters and the care that she received during her latest hospitalization.

Understanding the definition of nursing is important, as this description represents what the public expects of a nurse. Nursing, as defined by the American Nurses

Association (2015) is “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations” (p.1). Trust is implicit and care based on ethics is essential. According to Jane, her nurses met her needs throughout her hospitalization. Jane’s nurses met the criteria for the definition of a nurse by checking in on her to ensure that she was comfortable, offering social service resources, referring her to a counselor trained in addiction treatment, educating her about area resources including Narcotics Anonymous, and treating her with respect.

Jane’s experience with the nursing staff was in stark contrast to other participant experiences at the same hospital. It is unknown if Jane’s team of nurses were the same nursing staff as other participants who had used the same hospital. The behavior of Jane’s nursing staff throughout the 3 days may best be explained by the social identity theory of leadership (Hogg, 2001) or Bandura’s (1977) social learning theory. Bandura (1977) considers modeling to be a strong determinant for the outcome effects of the person watching the behavior. In effect, the nurses learned vicariously through the role modeling of the buprenorphine naloxone-certified physician and witnessed the positive interaction between Jane and the physician. Unfortunately, due to the need for medication as an intervention to relieve the distress from withdrawal, the nurse is hampered in his/her/zir ability to respond effectively without the assistance of the HCP. In addition, because her physician was managing Jane’s withdrawal symptoms, it may be possible that Jane did not display drug-seeking or manipulative behaviors that often cause the nurse to avoid the patient (Neville & Roan, 2014).

The nurse has the ability to serve as a role model and leader in providing culturally sensitive care to the substance user. Demonstration of caring behaviors, patient-centered care, and active progression through Travelbee's (1971) phases of the human-to-human relationship model is essential for addressing the biopsychosocial needs of the substance user. The nurse has the ability and ethical responsibility to care for the substance user in a humanistic manner. The American Nurses Association (2011) Code of Ethics provides the guidelines for nursing care and notes it is inclusive of all individuals and is not based on the nurse's preconceived beliefs or feelings about any person or population group.

### **Doing Something to Help Yourself**

An alternate explanation for the nursing care provided to Jane during her hospitalization is that the nurses may have viewed Jane as being worthy of help as she was "doing something to help herself" by being enrolled in the methadone program. Many nursing schools focus on the application of one nursing theory to guide the students throughout their education. Popular nursing theorists for nurse education that focus on promoting self-care, stability, and the interpersonal process for the patient include Orem's theory of self care (Denyes, Orem, & Bekel, 2001), Neuman's system model (1982), and Peplau's theory of interpersonal relations in nursing (1991). Nursing is intervention laden and outcome driven by nature. Nurses expect to put their skills to work to "fix" the patient when at all possible. By educating nursing students and nurses about harm reduction interventions, the nurse may experience satisfaction of "fixing" a problem experienced by the IDU.

Complications of this outcome-driven focus occur when the nurse cares for an IDU receiving care in the hospital. Since the IDU was not “fixed” during their hospitalization, the nurse may view this as a failure of self. Avoidance of substance users can translate to not having to experience this “failure to fix” the patient. Since Jane was on a methadone program and only had this event occur due to an act of kindness, the nurse may view her hospital stay and discharge as a success for “fixing” the patient. Interestingly, I was able to view recent track marks on her neck and wrists during our interview. Jane currently sees a counselor every 4 days at the methadone clinic. Jane shared that she injected her methadone several times a day, which is a violation of the methadone program regulations. It is unknown if Jane had been injecting her methadone prior to her hospitalization, but this may have resulted in a different outcome for Jane. The route of ingestion significantly impacts the stigma of IDUs (Surlis & Hyde, 2001). Therefore, Jane’s behavior of injecting her methadone would be viewed negatively by the HCP.

Jane had been on methadone for several years and was on a “take home” program. In order to be allowed take-home methadone, an individual has to be compliant with all rules of the treatment program and have negative urine drug tests. Jane was allowed take home methadone for three doses per week. According to SAMHSA (n.d.), this equates to being compliant in the methadone maintenance treatment program for 181–270 days. As Jane had not relapsed by taking mind-altering drugs (i.e., heroin, cocaine), her nurses may have found her willingness to assist her friend as an acceptable error in judgment. However, this interpretation of the nurses’ behaviors is in stark contrast to what is being reported by other studies. A review of the literature does not support the HCP’s view of

an IDU in recovery to be perceived any differently than an active user (Earnshaw, Smith, & Copenhaver, 2013; Link et al., 1997).

Jane's personality may have influenced her received nursing care. She was charismatic, talkative, and engaging in her conversations. During our interview, I was struck by the fact that anyone who looked at her would not believe that she had been a heroin addict as she had a "grandmotherly" appearance. Jane was amenable to sitting wherever was convenient, she was appreciative of being offered a beverage, and she quickly expressed gratitude for having the opportunity to talk with me. She asked questions about the study and made sure to praise me for the work I was doing. As a patient, she may have demonstrated similar behaviors, which would have been in contrast to the societal view of an IDU being demanding, drug seeking, and difficult to work with. For Jane, having this positive hospitalization experience meant that the times were changing in regard to treatment modalities for substance users. Although Jane recognized that her experience was unique, her willingness to seek health care had increased because of this experience.

### **Interpretation of the Comparison Cases**

The other eight participants, who comprise the comparison cases, did not have the same experience that Jane had when receiving care from a nurse. The following interpretive themes will be discussed from the comparative cases: *Marginalization*, *Defensiveness*, and *Repeated Victimization*. In addition, the subthemes of *Feelings of worthlessness*, *Mistrust*, *Unpredictability of care*, and *Self-care management and delay in seeking care* will also be interpreted and discussed with the intention of delivering the participant's meaning of the experience. The outlier theme of *Young Enough To Be Saved*

will also be examined. The findings were reported with an emphasis on the participant's experience, meaning, and impact.

## **Marginalization**

### **Feelings of Worthlessness**

The subtheme of *Feelings of worthlessness* was not a surprising finding as this descriptor of the IDU is quite prevalent in the literature and is also apparent in my practice as a nurse. Substance users are shunned by society, and this has changed very little over the last several decades (Durham, 1994; Palamar, 2013; Simmonds & Coomber, 2009; Sleeper & Bochain, 2013). The language used by the participants to describe themselves was derogative and reflected a mirror image of societal views. Listening to participants refer to themselves as “just an addict” and “just a junkie” was difficult for me. This proclamation of self was often accompanied by a defeated look, a lowering of their voice while saying the phrase, a slump in the chair, and avoidance of eye contact. These verbal and nonverbal behaviors spoke loudly to how the participants viewed their place in society.

The HCPs contributed to this feeling of worthlessness through demonstrations of avoidance and non-caring behaviors. This approach had a significant effect on the development of the nurse-patient relationship. Travelbee (1971) describes the phase of emerging identities as a point when each person recognizes the other as a unique individual. Most all of the interactions described by the participants illustrated that the IDU and nurse were unable to get past this phase of the interpersonal relationship. The nurses demonstrated the marginalizing behaviors of “othering,” which has been described in the literature as “a process that identifies those that are thought to be different from

oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination” (Johnson et al., 2004, p. 253). Examples of these othering behaviors described by the participants included verbal stigma and discrimination, nonverbal behaviors of avoidance, negative facial displays, care that interferes with the IDU’s dignity, failure to provide education or information to improve the IDU’s health and well-being, and failure to treat the IDU with respect.

The transformation from being marginalized in society to verbalizations of feeling valued occurred as soon as I met the individual and told them the purpose of my study. As the IDUs entered the NES in city A, most of them looked at me but then quickly turned their gaze away. In the city B NES, I barely received a second look as they entered the door. Once I approached the individuals and informed them of my study, I was often met with a surprised look and a response such as “You want to know what I think?” or “I’m really happy you are doing this.” As the individuals shared their stories, their demeanor changed in how they responded to the questions or even sat in the chair. During analysis, I reflected on these visual changes in my field notes and noted that in a number of the interviews, I had written how the participant appeared to be standing taller, appeared relaxed, and was smiling as they left the interview room. Three of the participants began to tell me stories about other IDUs’ experiences in the hospital and stated that they would inform these individuals about my study. It is important to note that according to the counselors and director at the city A NES, the clients typically visit the NES immediately prior to their drug use, as “they don’t want to get caught with anything on them and then get hassled by the police.” This time spent sharing their story also represented a time that they were refraining from drug use. The meaning of this was



important to me as both a nurse and researcher as it exemplified the importance of “being heard.”

All of the participants thanked me for allowing them to share their story for my study. I found this interesting because six of the nine offered their appreciation prior to my thanking them for their participation in the study. Five of the nine participants had to be reminded as they stood up to leave that they would be receiving a gift card to compensate them for their time. Three of these five participants stated that they would have done the interview even if they hadn't been given the gift card. The meaning of being able to tell their story was therapeutic according to Alex, David, Grace, and Jane: “I feel so much better now that I talked with you.” The use of storytelling as a therapeutic method (Holloway & Freshwater, 2007; Lakeman, McAndrew, MacGabhann, & Warne, 2013) was not the intention of this study, but it was an unexpected and welcoming outcome for the participants and the researcher. The meaning of being acknowledged and asked to share their story was significant for the IDU, as this opportunity allowed them the experience of not being marginalized in society.

### **Mistrust**

The examples provided by the participants who illustrated mistrust of the nurse primarily focused on expectations of the nurse's role and perceptions of how the nurse should behave. When the nurse failed to meet the expectation of the participant, the participant automatically assumed that the care they received was because they were an IDU. This represents parallelism of social psychology's explanation of self-concept in that the IDU responds to how they believe they are perceived by the other (Mitchell, 2009).

Listening to the stories, I could clearly hear that the participants didn't trust that their HCP would help them with their withdrawals while they were being treated for their acute condition. All of the participants in the comparison case had been admitted for a reason other than substance use. Although none of the participants articulated this as mistrust, the language they used and examples they provided illustrated that mistrust was present. Alex left AMA because he knew that he would be going through withdrawals and he said he had money in his pocket and, therefore, he could avoid withdrawals by purchasing drugs. He stated that when he first started to withdraw, the nurses told him that they couldn't give him anything because "this isn't a detox." Ella avoided withdrawals because she was being medicated with an opioid for her chronic back pain. Avoidance of withdrawal symptoms is ever present in the substance abuser's mind. Recognizing, understanding, and addressing the IDU's anticipated withdrawals while hospitalized is imperative for the nurse and health care team in order to provide care that meets the needs of the individual. According to the Gallup (2014) poll, nurses rated number one for honesty/ethics in a profession. Unfortunately, this societal perspective was not the experience of the participants. The experience of the comparison cases exemplified the lack of ethics the nurse demonstrated while caring for the IDU.

The nurses' lack of knowledge of drugs and drug use was evident in the stories shared by the participants. Both Christopher and David confessed to actively injecting while in the hospital. The participants reported a concern about going through withdrawals while hospitalized. However, Christopher was receiving opioids for his meningitis, which would have prevented him from experiencing severe withdrawal symptoms, but he shared that he wanted to be overmedicated. Christopher stated that the

nurses should have known that he was overmedicated because he was “always in a nod” (a state in which the person is alternately wakeful and drowsy). He believed that he could have been harmed by this inattention to his mental status. When Christopher was asked about his role in being honest, he became defensive and stated that if he told them he was still using, he would have received “lesser” medications. He lacked trust in the nurse and doctor to provide him with the medications he believed he should receive.

David stated that after he had disclosed that he was an IDU, he was told that he would not be receiving opioids for treatment. David shared how he became defensive because he hadn’t even asked for pain medication. David was insistent in his explanation to me that he had to use his illicit substances to avoid experiencing even more pain than he already had been experiencing due to his severe constipation. The hospital was not meeting David’s needs of receiving medication to avoid withdrawal symptoms, so he exerted avoidance of the facility and resisted the institutional power of the nurse and physician being in control, by leaving and going to a different hospital to receive care (Szott, 2014).

According to the U.S. Department of Justice Drug Enforcement Administration (n.d.), physicians may dispense opioids for up to 72 hours for the purpose of relieving acute withdrawal symptoms while an individual is awaiting a referral for treatment. Implementation of this code would improve the experience of the IDU being treated for a medical condition. None of the participants reported receiving opioids in advance for their withdrawal symptoms. Grace reported receiving 5 milligrams of methadone to assist her with her withdrawal and stated that this was ineffective. Grace’s dose of 5mg was

below the usual starting dose of 10mg to 30mg per day given to individuals to avoid experiencing withdrawal symptoms (Baxter et al., 2013).

The participant's disclosure of their use of illicit substances in the hospital is certainly worthy of attention by the administrators and legal department of the hospital. Drug interactions may be potentiated by the use of illicit substances and the disease or illness the individual is being treated for in the hospital. The participants' examples clearly demonstrate that the nurse must be aware of illicit drugs and their effects on the patient. Many of the participants did not believe that their nurse was knowledgeable about illicit substances. This may result from a lack of role support and education from an administrative standpoint and is evident in the literature as being common and problematic (Ford, 2011; Monks, Topping, & Newell, 2013).

The participants recognized that the nurses didn't interact with them very much throughout their stay. This further emphasized the IDU's feeling of worthlessness. The literature reinforces that nurses feel unprepared to care for the substance-using patient (Chang & Yang, 2013; Ford, Bammer, & Becker, 2008; Michaelsen, 2012; Monks et al., 2013; Neville & Roan, 2014; Tran et al., 2009). Avoidance is the most common tactic used by the nurse while caring for a substance user (Monks et al., 2013; Natan et al., 2009; Peckover & Chidlaw, 2007). Unfortunately, nurses recognize that the withdrawing substance user is a burden on an already heavy workload (Monks et al., 2013). David clearly illustrated how the nurse avoided him after he was caught setting up his drugs to inject while in the hospital. He reported that the nurse didn't really check on him after that incident. He made it clear that there was a significant change in the nurse's behavior toward him after discovering he was injecting in the hospital.

The examples shared by the participants in regard to mistrust of the nurse, their provider, and the hospital are clearly parallel with the findings of a recent concept analysis of the phenomenon of “feeling safe as an inpatient in the hospital” (Mollon, 2014). The attributes of “trust, cared for, presence, and knowledge” were found to be the components needed for a patient to feel safe in the hospital (Mollon, 2014, p. 1729). David mentioned several times that “the hospital is the one place that you should be able to feel safe in.” Absence of these attributes was articulated during all of the interviews. Feeling unsafe, being vulnerable, and not having trust in your nurse does not allow for the development of a trusting relationship between the nurse and patient. The lack of an interpersonal relationship between the IDU and the nurse can have a significant impact on the physical, emotional, and social well-being of the IDU.

### **Unpredictability of Care**

The *Unpredictability of care* was, in many ways, the most significant subtheme of the participant interviews. All of the participants had experienced marginalization behaviors during an encounter with a nurse or other HCP during their trajectory as a substance user. All of the participants made statements about the negative care they had received and made statements such as “You get used to it.” For David, Ella, and Hillary, their chronic conditions allowed them to compare the received care before and after the period they began to use illicit substances. When asked if their care was different during a time they were hospitalized and not using, all emphatically stated that they received significantly better care when they were not using illicit substances.

The care received from the nurses ranged from blatant stigma, discrimination, and refusal of treatment to random interactions with nurses who provided harm reduction

advice and demonstrated empathetic behaviors. The unpredictability from nurse to nurse made it difficult for the participants to be able to initiate a relationship with their nurse or trust that they would be well cared for. The participants verbalized that they recognized that a negative encounter with a nurse did not mean that all encounters would be negative. However, this perspective wasn't always acted upon, as both Alex and David reportedly refused to return to a hospital in which a few nurses had treated them poorly. In light of the participants' histories of trauma and abuse, nursing care should have been based on the principles of trauma-informed care. Avoiding triggers that re-traumatize an individual is an important part of trauma-informed care (Brown, Harris & Fallot, 2013). Unfortunately, examples of this evidence-based practice of patient-centered care were not evident in any of the interviews.

Many of the participants used the term "the look" to refer to how they assessed the nurse and the anticipated response of the nurse from the moment they interacted with each other. The nonverbal behaviors such as a scowl on the nurse's face, a curled lip, physically distancing themselves from the IDU once the person disclosed their addiction, and avoidance of eye contact all set the participant up to become defensive. These nonverbal behaviors have been cited in the literature as examples of "othering" (MacCallum, 2002). This prejudgment of the IDU began a cycle of marginalization, defensiveness, and repeated victimization that emerged in all nine participant interviews.

It was interesting to note that six of the participants made excuses for the nurses' harsh behaviors. Alex spoke the most about being able to empathize with the nurse having to care for a substance abuser. He recognized that the nurse might be fearful of being harmed physically, verbally, or by a needle stick injury from a person infected with

a communicable disease. Alex spoke of the nurse behaving the way she did because she was “going through her change in life” or that she “could have had a fight with her husband.” Other stated rationales for the nurse’s behaviors included, “having a bad day,” “getting ready to retire,” and “can’t deal with stress.” This acknowledgement of the nurse as a unique individual is the second phase of Travelbee’s (1971) human-to-human relationship model. It was noteworthy that the participants offered an explanation for the nurse’s behavior without being prompted as to why they think the nurse behaved a certain way.

Interestingly, Isaac was the only participant who failed to enter this phase. He was unable to recognize the vulnerability of the nurse caring for a substance abuser who had been shot by an unknown person during the early hours of the morning. Isaac admitted to “looking scary and bad” due to blood on his hands, hair, and a gunshot wound to his leg. During our interview, Isaac was very loud, demonstrative, and constantly in motion. He spoke quickly, passionately, and at times had an intense stare. These behaviors may be interpreted as intimidating and unpredictable. Workplace violence has increased and is often seen in patients with a history of mental illness or being under the influence of a substance (Gillespie, Gates, & Berry, 2013). Fear may have caused the nurse to be more task driven and less involved on an interpersonal level (Ford, 2011; Peckover & Chidlaw, 2007). Several of the participants described how they attempted to ease the fear of the nurse by initiating conversation, being polite, thanking them for their care, and praising them.

However, all six of the participants who provided an excuse for the nurse’s behavior also pointed out that this was the nurse’s job and that separation of work and

personal life issues was crucial to the patient experience. As David stated, “It’s her job to care for me, not judge me.” Emotional labor has been described as the engagement or detachment to a client and the associated benefits and gains (Henderson, 2001), and the dissonance of having to behave opposite of the way one feels (Morris & Feldman, 1996). The emotional labor occurs because nurses are expected to act within an accepted level of caring despite their beliefs and feelings about the situation or individual. The literature provides research studies illustrating the nurse’s dissatisfaction and lack of desire caring for substance users (Brener et al., 2010; McLaughlin et al., 2006). This disagreement between the expected response and demonstrated response was unacceptable to the IDU.

Not all experiences with the nurses were negative. This confounded the predictability aspect, as the care was different from one nurse to the next. It is important to illustrate these examples of an interpersonal relationship as these encounters set the stage for the participant to have an expectation that they will experience similar interactions with their future nurse. The following section will describe three participants’ experiences of a positive interaction in which they described nurse encounters where they were not subjected to marginalization.

### **Nurse Encounters Without Experiencing Marginalization**

Although Jane was the only participant who had an entire hospitalization stay without being subjected to marginalizing behaviors, other participants cited isolated examples of what can be described as a positive encounter because the IDU did not experience marginalization from the nurse. Several participants provided examples of how this positive nursing encounter resulted in a change in their behavior.



Alex provided an example of a nurse going through what he calls “the three hurdles.” These hurdles include acknowledgement of a patient’s distress and a desire to relieve this distress, actively doing something to relieve the distress (such as advocating for the patient), and recognition that the nurse did all that they could do to relieve the distress. Alex described the three hurdles by sharing a recent hospitalization in which he had been experiencing withdrawals and the provider refused to give him medication to alleviate the discomforts. The nurse recognized that Alex was in distress and stated she would go talk to the doctor about getting something to help him. This was what he termed the “first hurdle.” The second hurdle was that the nurse returned with a medication to relieve his withdrawal. He stated that this could have been a placebo but it was the fact that the nurse followed through in her intended action that was meaningful to him. Alex described the final hurdle as being accomplished by recognizing that the nurse did all she could do to help him with his distress. Alex provided this sequence of events as an example of a positive nursing interaction in the hospital. This example demonstrates Travelbee’s (1971) phases and development of rapport. For Alex, this nurse demonstrated what he believed a nurse was, and should be. Although Alex didn’t have a change in his drug use behavior because of this interaction, he stated that he changed in that he would seek emergency care because of this encounter.

Hillary’s experience with a nurse who recognized the importance of providing harm reduction education and referral to available resources was unique. Hillary was the only participant who clearly described the nurse recognizing that Hillary was unable or unwilling to cease her substance use but that the nurse had the ability to provide Hillary with information to make her drug use less harmful. Hillary’s experience with the nurse

teaching her how to properly cleanse and inject, as well as referring her to a facility that offered free syringes to reduce the blood-borne diseases from sharing syringes, resulted in fewer abscesses and visits to the ED for treatment. Hillary is only one of three participants who had not been infected with HCV, a chronic blood-borne disease spread by sharing syringes.

Grace's experience with the nurse who advocated for Grace to receive medication for her withdrawal symptoms, provided her with information and education about HCV, and referred her to a detoxification unit was another example of Travelbee's (1971) phases that result in rapport. Until this facilitator of perceived care interacted with Grace, she had been withdrawn, angry, and had planned to LAMA despite being quite ill from her newly diagnosed HCV. The meaning and impact of this experience for Grace was profound, as she became quite emotional discussing the nurse who "saved my life," and the impact this encounter had on her admittance to a detoxification unit and 6 months of sobriety.

My interpretation of the positive nurse interactions is that all of the encounters demonstrated the nurse going through Travelbee's (1971) phases with the ultimate development of rapport. In each instance, the nurse demonstrated an interest in the IDU as a person worthy of care. Each of the examples demonstrates that the nurse was knowledgeable about addiction and treated the IDU as a person deserving of time and education. By not approaching the IDU with bias and an attitude of dominance, the nurse was able to interrupt the cycle of marginalization, defensiveness, and repeated victimization experienced by the participant. The stories told by the participants echoed Travelbee (1971) with regard to the importance of the nonjudgmental care and the effect

that interactions with nurses in the hospital setting can have on the IDU's emotional, physical, and psychological well-being.

### **Defensiveness**

As the participants shared their stories, evidence of their defensiveness emerged. This coping mechanism was always in response to (a) verbal and nonverbal displays of stigma and discrimination after disclosure or awareness of drug use, (b) perceived inadequacy of received care, and (c) passive accusations of drug seeking without provocation. The defensiveness often began when the participant disclosed their IDU status. The nurse's response of physically pulling away, displaying a disgusted look, or making an inappropriate comment caused the participant to experience anger and disbelief and to respond by becoming defensive. This nonverbal exchange often resulted in a verbal altercation that further demarcated the differences of the nurse and the IDU.

Another common time period during which the participant would demonstrate defensiveness was during insertion of an intravenous catheter or during a blood draw. This visibility of track marks as evidence of their drug use was a time of vulnerability for the IDU. Statements made by the nurse or phlebotomists were often condescending and unhelpful. Several of the participants also noted that the HCP was "rough" during this task. The participant would become verbally defensive, and this may have contributed to further stigma and discrimination from the nurse, as these behaviors were parallel to societal views of the IDU.

I noted that all of the participants kept their jackets on throughout the interview despite the warm room. Hillary wore two long-sleeved shirts and long pants on a day that was abnormally warm for the season. The participants spoke of how they hid their track

marks (areas where they had injected into the skin) because of embarrassment and “it’s nobody’s business.” Several participants would gaze at the area when speaking about an abscess but none showed me the site, which is in contrast to my presence in the NES working as a nurse and having many IDUs show me healing, or healed, abscess sites.

Skin abscess is a common, painful, and potentially dangerous consequence of injection drug use. Many of the health care encounters described by the participants involved treatment for this condition. Accusations of drug seeking often occurred during this care. A skin abscess is known to be painful, and current studies are attempting to determine an effective pain-relieving intervention (Bourne, Brewer, & House, 2014). When seeking treatment for this complication, three participants stated they were informed abruptly by their nurse or HCP that they would not be receiving opioids for the procedure. This resulted in an immediate defensive verbal response as the participants stated that they had not even asked for pain medication. Although current treatment for skin abscesses lacks an effective pain-relieving medication to be used during the incision and drainage process, none of the participants reported being informed by the nurse or HCP of this fact.

The outcome of this communication may have further reinforced to the nurse that the IDU reflected the societal image of being a drug seeker, demanding, and a difficult patient (Brener et al., 2010; McCaffrey et al., 2005; McCreaddie et al., 2010). This interaction led to a further decline in the nurse-patient relationship that was described by the participants. The participants were quick to tell me that this was not “how they got their drugs” and “you think I want to deal with that to get my drugs?” The participants exerted an avoidance of social control by becoming defiant and brutally honest in their

thoughts toward the HCP (Szott, 2014). Both Jane and Isaac verbalized how each had confronted their nurse about inappropriate behavior. It did not go unnoticed that both Jane and Isaac were white, of similar age, and were educated.

### **Repeated Victimization**

Most of the participants spoke of their feelings of being victimized not only by their HCPs, but also by their families and society in general. After experiencing marginalization from their nurse, the IDU would either immediately be verbally defensive or would withdraw from interacting with the nurse. This differential of the nurse being in power and the IDU being powerless could be heard in the participants' explanations. The longer lasting effects of this repeated victimization resulted in the IDU attempting to manage their own health care needs and, therefore, they delayed seeking care to avoid being marginalized again.

### **Self-Care Management and Delay in Seeking Care**

Several of the participants voiced their dismay with seeking treatment not only from the hospital, but also from their primary health care provider. Avoidance of being treated poorly, experiencing withdrawal symptoms, and a belief that most drug related illnesses could be self-treated were commonly cited as reasons for a delay in seeking care. David and Grace shared that their drug use increased after these negative encounters with the nurse and other HCPs. Grace didn't follow up with treatment for her newly diagnosed HCV due to her experience of being marginalized. The trauma experienced from negative nurse or other HCP interactions further traumatized the IDU and brought the cycle of marginalization, defensiveness and repeated victimization full circle.

The participant's shared self-care management techniques primarily focused on harm reduction. The use of new "works" (syringe, cooker, cotton, water, and alcohol wipe) for each injection was common knowledge among the IDUs because of the NES. All of the participants reported the effectiveness of the NES during the interview, or in a conversation before or after the interview. Hillary used an online support group for IDUs to obtain advice on how to self-treat her symptoms, which was ultimately diagnosed as sepsis. A search on Google using the term "drug forum" resulted in a mix of recovery options and harm reduction forums. Within these forums, other IDUs offered advice and treatment options for a variety of drug related complications. A review of some of the treatment topics offered helpful information for the IDU to recognize when self-care treatment was no longer an option. Users of the forum acknowledged the anticipated stigma and discrimination and offered helpful hints for the user to implement while receiving care.

I was able to witness several clients asking the counselors about how to avoid or care for an abscess. In my experience as a nurse working with substance abusers, I have been asked many questions related to self-care for not only drug related illness but also for non-drug related health care needs. A disheartening event occurred that clearly illustrated this attempt at self-care management in order to avoid a HCP encounter. One of the clients that I approached at the NES was visibly ill. She was wearing a winter coat, two sweaters, and was hugging herself in an attempt to get warm. She declined the offer to participate in an interview but asked me if there was anything else she could take to "feel better." Upon further discussion, this 19 year-old female had been in the hospital the day before, diagnosed with endocarditis and sepsis. She left AMA after a few hours due

to the onset of withdrawal symptoms that she was experiencing. Despite education about the consequences of not being treated, this young female declined to return to the hospital.

Self-care management techniques and a delay in seeking care were the direct result of prior traumatic health care encounters and experiences. It was interesting to note that David and Hillary had the strongest reactions to not seeking care. Hillary was the youngest of the participants and David was the “youngest” in his time of using drugs. This may be the result of maturational development and the lack of coping skills surrounding illicit drug use. All of the other participants verbalized that they did not want to go to the hospital but would do so if necessary.

### **Young Enough To Be Saved**

Although this theme emerged from only one participant’s interview, the importance of the concept is crucial to understanding the trajectory of the substance user. Hillary provided several examples of statements made by the nurse and other HCPs about her age and chance at abstinence and recovery. At Hillary’s most recent visit to the ED, she reported that the nurses and doctor spent a “lot of time” talking to her about her drug use, her personal life, and resources for addiction treatment. Hillary reports that these HCPs also spent a great deal of time “trying to get me to say that I wanted to get clean.” The doctor informed Hillary that he didn’t have a lot of time to sit with her, but he shared area detoxification resources with her.

He said considering my using time and my age and my mindset I guess he thought that I could get clean and like that... he wanted to see me do that. Then the nurse came in and said—oh, my son is a heroin addict and he’s not going to get clean. It makes me so sad to see people your age come in.

Hillary reported that these interactions made her feel good because she wasn't being treated as she normally would have been, or expected to be, by the HCPs. The demonstrated HCP behaviors may also represent countertransference. The nurse was treating Hillary in a way that she was unable to do for her son. However, Hillary stated she also felt that the nurses and doctor were disrespectful because they treated her with pity. "I could tell they were sad for me and were pitying me, but I don't know that they weren't really treating me like I was a person with agency... like I felt it was more like pity than empathy." She detailed that they talked to her as if she had been "tricked" into starting her drug use instead of being cognizant of her actions and consequences.

Hillary, age 22, was the youngest of the nine participants but was in the top five for length of drug use. The HCPs appeared to be responding to Hillary based on her age, rather than her substance use history. Research has shown that the earlier the initiation of drug use, the longer the substance use history and delay in initiation of treatment (Dennis, Scott, Funk, & Foss, 2005; Evans, Libo, Grella, Brecht, & Hser, 2013; Scott, Dennis, Laudet, Funk, & Simeone, 2011). From a research perspective, David had the best chance at recovering from his addiction as he had been using for only 6–8 months at the time of his hospital admission. Not only was David not offered the same resources as Hillary, he ultimately left AMA due to his received treatment.

The health care disparity of treating someone based on age has a significant impact on the IDU's drug use trajectory. Although it can't be determined for certain that Hillary's HCPs treated her differently because of her age, this is what happened according to Hillary's perspective and recall of statements verbalized. The notion of one substance user being more "worthy" than another only adds to the stigma and



discrimination currently experienced by substance users. This discrimination results in health inequity and has a significant financial cost to societies (World Health Organization [WHO], 2015). The WHO (2015) determines health inequities to be differences in fairness, access to resources, and the fundamental basic rights of human beings due to avoidable differences in an individual's social, economic, or geographic grouping. Formal equality implies that individuals in similar situations be offered the same fundamental rights and not classified according to a social hierarchy (Yamin, 2009). Optimal health status should be the goal for all individuals and should not be impacted by intentional or unintentional discrimination, or marginalization (Braveman et al., 2011).

### **The Unidirectional and Bidirectional Cycle of the Nurse/IDU Interaction**

The manner in which each participant interacted with the nurse that demonstrated behaviors of health inequities varied as well as the defensive mechanisms used during the encounter. All of the participants described a nurse encounter that illustrated a cyclic process that was either unidirectional or bidirectional. In the next section, an example and model of each cycle will be described. A comparison of the participant's use of the unidirectional and bidirectional model will also be explored.

#### **Unidirectional Cycle**

Grace shared an encounter that illustrated the unidirectional cycle of marginalization, defensiveness, and repeated victimization. During her second day of hospitalization for acute HCV, Grace used her call bell to report that she was experiencing severe abdominal pain. Upon arriving at the room and hearing Grace's complaint, the nurse stated, "Well, it's withdrawals and if you didn't do drugs then your stomach wouldn't hurt." Grace did not respond to this statement and also stated that the

nurse immediately left the room after the statement. Grace shared that she became so angry because she knew what withdrawals were and she knew that her abdominal pain was different from what she had experienced in the past. Grace felt that the nurse was only treating her as an addict and attributed everything to her drug use instead of looking at her as having something else wrong. Grace reported that in response to this “ignorant bitch,” she just stayed under the covers and refused to talk to her for the remainder of the shift. Grace also experienced increased depression and sadness and would not use the call bell for the rest of the shift in order to avoid having to interact with the nurse—“I just suffered.” Grace reported, “To them, I’m just another addict.” This avoidance and withdrawal behavior caused Grace to experience an increase in physical and emotional discomfort. The nurse’s marginalizing behaviors toward Grace resulted in her defensiveness and in repeated victimization as other nurses and aides who entered her room also did not acknowledge her. Grace shared that the nurse only came into the room when “she had no choice” and reported that the nurse wouldn’t talk to her; “she just did what she needed to do,” which illustrates the cyclic process. See Figure 1 for a model of this unidirectional process.

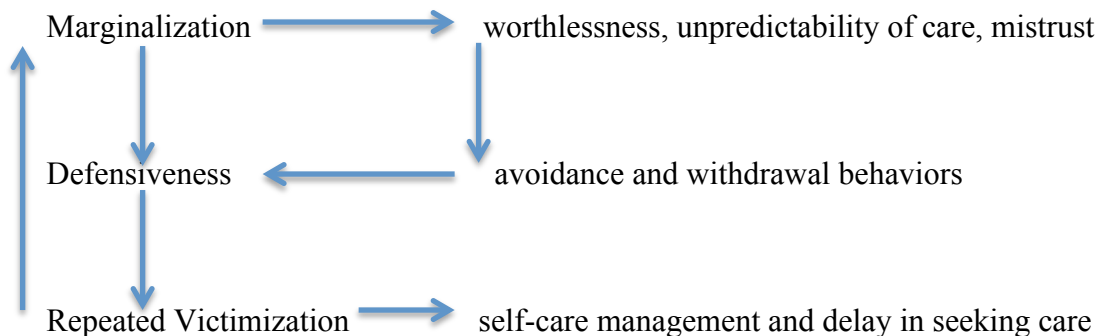


Figure 1: Model of a unidirectional cycle.

### **Bidirectional Cycle**

The bidirectional cycle of marginalization, defensiveness, and repeated victimization was complex, but often apparent in the participant’s stories of their encounters of received nursing care. In this cycle, the participant would become verbally confrontational, and this resulted in increased marginalization from the nurse due to the power differential of the nurse and patient. The nurse and participant would have a verbal exchange that ended with the participant being angry and always ended with either the participant LAMA or withdrawing from and avoiding the nurse. In response to this, the nurse would continue to avoid or withdraw from the participant.

An example of this bidirectional cycle was illustrated by David’s experience of informing the nurse upon admission that he was an IDU and being told, “This isn’t a detox.” Ultimately, the nurse caught David as he was starting to inject while in the hospital. The nurse became angry and told him that he shouldn’t be doing that and would need to be reported. This resulted in David becoming defensive and verbally retaliating that the nurse shouldn’t disrespect him because he didn’t disrespect her, and that he just couldn’t deal with the withdrawals. This interaction resulted in the nurse further marginalizing David by not checking in on him and responding slowly to his call bell

requests. This resulted in David becoming more defensive and verbally confrontational toward the nurse. The nurse further demonstrated marginalization by stating, “If you didn’t do drugs, you wouldn’t feel this way.” This repeated victimization resulted in David continuing to use while in the hospital, increasing his drug use, and ultimately leaving AMA. David shared that he no longer followed up with his primary care provider because he “didn’t need to be hassled.” This example of a confrontational mode of communication illustrates the IDU’s attempt to exert a sense of control of the situation. Ultimately, the power differential of the nurse and IDU results in an impaired therapeutic relationship. See Figure 2 for a model of this bidirectional cycle.

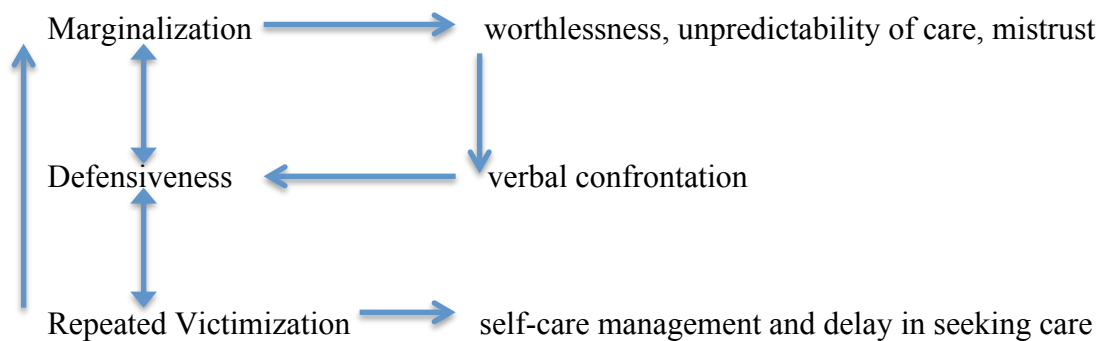


Figure 2: Model of a bidirectional cycle.

An examination of the defensive response for each study participant was performed to discover if there were commonalities between those that demonstrated the unidirectional cycle and those that demonstrated a bidirectional cycle. There was no relationship between any of the participants' age, gender, education, length of drug use, or geographic status in either the unidirectional or bidirectional cycle of defensiveness behaviors. In addition, an examination of the participants' mode of defensive behaviors revealed avoidance and withdrawal for the unidirectional model and verbal

confrontations for the bidirectional model (see Table 7 for evidence of the unidirectional or bidirectional cycle demonstrated by each participant).

Table 7: Evidence of unidirectional or bidirectional cycle of participants.

	Unidirectional cycle	Bidirectional cycle
Alex	✓	
Bob	✓	
Christopher	✓	
David		✓
Ella	✓	
Grace	✓	
Hillary		✓
Isaac		✓
Jane		✓

All of the participants demonstrated defensive behaviors in response to the nurses' marginalization of them. Whether the defense mechanism was internally or externally focused, the result was always the same with the participant experiencing a repeated victimization. This continuing trauma resulted in the participant avoiding further interaction with the nurse. Several participants made comments about "expecting" to be treated poorly. It is unknown how the participants interacted with the next nurse after experiencing this cycle. By using Travelbee's (1971) interpersonal nursing process theory, the nurse has the ability to interrupt the vicious cycle noted in both the unidirectional and bidirectional cycle models. In the next section, Travelbee's (1971) phases will be briefly defined and examples of how this phase was accomplished will be described.

## The Human-to-Human Relationship

The phases of Travelbee's (1971) theory emerged during my analysis. A brief review of the interlocking four phases will be described, and examples of these phases will be provided.

1. Original Encounter—Judgment made about the other person based on observations, “first impressions,” verbal and nonverbal inferences. “Generally both nurse and other person are stereotyped and categorized” (Travelbee, 1971, p. 130). All of the participants described completion of the first phase, original encounter. Unfortunately, this is the phase where most of the difficulties in the IDU and nurse relationship began. As previously described, the nurses' personal beliefs, values, and prior experiences caring for a substance abuser interfered with further progression of the phases. It was difficult to determine progression of this phase from the participant's perspective and description of their stories. However, “the look,” the facial grimacing, physical withdrawal, and sounds such as “Phft” were described by the participants as being displayed within the first few minutes of their interaction with the nurse.

2. Emerging Identities—During this phase, the nurse and patient begin to form a bond and “perceive another less as a category, and more as a unique human being” (Travelbee, 1971, p. 132). Six of the participants were able to enter into the phase of emerging identities by providing justification for the nurse's behaviors. However, this phase was not completed, as the nurse did not partake in this phase as required by the model. There were three examples of the nurse entering the phase of emerging identities. This occurred when the nurse would advocate for the participant (for Grace and Bob), offer harm reduction information (for Hillary), or initiate referrals to counseling and

treatment for the IDU (for Grace). According to Travelbee (1971), both the nurse and patient must engage in this phase to move forward toward the development of rapport.

3. Empathy—A conscious process in which one is able to share in the thoughts and feelings of the other without being submerged by the involvement (Travelbee, 1971). Bob and Grace described this phase when the nurse recognized the distress from the withdrawal and attempted to provide comfort to the participant. Hillary's nurse demonstrated empathy by not only recognizing that she had returned to the ED, but also inquired about the reason for the continued abscesses.

4. Sympathy—A distinguishing characteristic of sympathy is the “basic urge or desire to alleviate distress” (Travelbee, 1971, p. 141–142). Bob's and Grace's nurse demonstrated sympathy by advocating for the IDU to receive medications to alleviate the distress of the withdrawal symptoms. In Bob's case, the provider had initially refused to prescribe a medication but ultimately did so after being contacted by the nurse. For Hillary, the nurse alleviated Hillary's distress of not having clean syringes by providing her with information about a free NES in the area.

5. Rapport—represents the final phase of progression of the interlocking phases. This culminates in the development of the human-to-human relationship (Travelbee, 1971). As described earlier in the description of nurse encounters where the participant was not marginalized, Alex, Hillary, and Grace all described examples of the development of the human-to-human relationship with the nurse. Jane best described development of the human-to-human relationship with the provider. Her story is not rich in description of the various phases of Travelbee's (1971) theory, but she was the only

participant who was not marginalized by her nurses at any point during her 3-day hospital stay.

Table 8 illustrates the phases achieved by all participants during a hospitalization. For all of the participants who progressed through the phases to reach rapport, each described accomplishment of the interpersonal process with only one nurse during their hospitalization. This encounter was not necessarily the most recent hospitalization for the participant. The significance of the participant having had this experience is that the individual has an awareness of how a nurse should behave. There were no discernible demographic differences between those who developed rapport with their nurse, and those who achieved only one or two phases of Travelbee's (1971) theory.

Table 8: Completion of Travelbee's (1971) phases by the participants.

	Orientation	Emerging Identities	Empathy	Sympathy	Rapport
Alex	✓	✓	✓	✓	✓
Bob	✓				
Christopher	✓				
David	✓				
Ella	✓				
Grace	✓	✓	✓	✓	✓
Hillary	✓	✓	✓	✓	✓
Isaac	✓				
Jane	✓	✓	✓	✓	✓

### **Implications for Nursing**

Implications for nursing, organizations, and society are overwhelmingly present. With the growing increase in the number of substance users, it is imperative that a new approach to caring for the substance user be developed. The literature supports the evidence presented here that nurses lack the training to care for the substance abuser



(Chang & Yang, 2013; Ford et al., 2008; Michaelsen, 2012; Monks et al., 2013; Neville & Roan, 2014; Tran et al., 2009). However, training alone has not been shown to be enough in changing the nurses' attitudes and behaviors toward the substance abuser (Ford, Bammer, & Becker, 2009). Role support for the nurse and a change in the culture of health care for the substance abuser must occur.

Nonjudgmental assessment upon admittance to the hospital is essential.

Understanding what drugs are being abused in a geographical area is critical for the nurse to be able to identify signs of the drug being used, the slang terms associated with the drug, associated side effects, withdrawal symptoms and onset, as well as area resources for referral and treatment for the drug. This training must be performed regularly, as the drug commonly abused and slang language for the drug is ever changing. Knowing which are the most commonly abused drugs in a geographic area is important for HCPs. The signs of drug use, withdrawal symptoms, and onset are significantly different between heroin and crystal methamphetamine. Being aware of the various drugs will allow the nurse to anticipate and to respond in a knowledgeable manner. Hospital involvement with local police departments for training about the locally most commonly abused drugs should be ongoing and collaborative.

Recognition of the individual under the influence of an illicit substance is imperative in the acute care setting. Nurses, physicians, and hospital administrators must be invested in keeping all patients safe while hospitalized. Addressing withdrawal symptoms early in the admission may ease the patient's concern about experiencing the painful withdrawal symptoms that accompany illicit drug use. Demonstrating compassion and empathy to relieve this pending distress is essential to the development of an

interpersonal relationship. Early consultation with mental health services or an addiction specialist will ensure that the patient is being cared for using evidence-based practice. Nurses should be trained in addiction, trauma-informed care, and motivational interviewing to further enhance the interpersonal relationship with the substance-dependent person.

The incorporation of physicians trained in addiction medicine is a fundamental part of the health care team; as David stated, “It all begins with the doctor.” The nurse can be the leader in advocating for current evidence-based addiction treatment. Treating patients from a holistic view should be an expectation in health care. Incorporating training and education for all ancillary health care providers (phlebotomists, technicians, etc.) should be a yearly requirement and may easily be conducted by the nurse. The use of role model behavior has been shown to be an effective tool and must be demonstrated from top administration to the staff who interact directly with the substance user (Wallace et al., 1973). Since the nurse spends the majority of the time with the patient, the nurse should be the role model of expected behavior. Self-reflection of personal biases, values, and beliefs is imperative to avoid transference of negative perspectives.

Trauma-informed care must be implemented when treating the substance abuser, as a history of childhood adverse experiences is common among the users (Mersky, Topitzes, & Reynolds, 2013; Wu, Schairer, Dellor, & Grella, 2010). This approach to care allows the individual to have a sense of control and empowerment during their treatment. All of the participants in this study cited a history of physical and/or emotional trauma or PTSD. The nursing staff and other HCPs who come into contact with the substance abuser should implement frequent self-reflection exercises for biases toward

the substance abuser. Collaboration with area mental health practitioners will assist the nurse in providing care that is compassionate, patient centered, and within boundaries that are clear for both the nurse and patient. Training on implementation of trauma-informed care should be performed thoroughly and regularly. Specialized teams in the health care environment made up of addiction experts should be a resource readily available for all HCPs. Avoidance of further traumatization is crucial when working with the substance abuser.

Implementation of harm reduction education should be part of standard nursing care for the substance abuser. Harm reduction education does not mean to tell the substance user to stop using, but focuses on the individual's rights to self-determination and their autonomy to make informed decisions regarding their drug use. Strategies may include education about safe injection, avoidance of overdose, care of abscesses, safe sex practices, and available treatment services such as methadone and buprenorphine and naloxone.

Opportunities for harm reduction education can easily be implemented during tasks that require visualization of the arm. Hillary reported a change in her injection habit after being educated by the nurse in regard to properly cleaning the injection site, and the one-needle/one-use concept. This resulted in a decreased number of abscesses and safer drug use for Hillary. This behavioral change can lead to a reduction in the number of emergency room visits, less harm to the user, a decreased amount of public funds being spent on abscess care, and avoidance of lengthy and costly stays in the hospital for untreated infections and comorbid diseases such as HCV and HIV. Providing oral antibiotics is significantly less costly than an intensive care unit stay for sepsis. Harm

reduction education during these tasks has been shown to be an effective teaching method (Harris & Rhodes, 2012; Wilson, 2013). Regularly scheduled evidence-based harm reduction training should occur in order for the nurse to become competent in providing this education and care for the substance user.

The human-to-human relationship model (Travelbee, 1971) provides a framework in which to educate, support, and further develop the role of the nurse in an interpersonal relationship, beginning in the academic setting and continuing in the hospital and community health care settings. Education, practice, and an expectation of a nonjudgmental approach to the substance user must be taught and role modeled beginning in the nursing curriculum and practicum. Exposure to individuals with a substance use disorder is imperative in order to develop a sensitivity and understanding of the health care disparities of this vulnerable population. Further education and role support for the nurse and other health care team members must be part of ongoing staff education and support in the health care setting. Collaboration between disciplines trained specifically to care for the substance user can provide role modeling and support to the nurse. Incorporation of harm reduction education, brief motivational interviewing, and trauma-informed care should be part of the nursing curriculum and further developed and strengthened throughout the nurse's career. The interpersonal relationship between the nurse and patient is a monumental part of health and wellness.

### **Implications for Future Research**

Several initiatives and recommendations for future research aimed at caring for the IDU emerged from this study. Research from the perspective of the substance user is limited and is primarily found in the Public Health and Sociology literature. With the rise

in the use of illicit substances, the need to provide evidence-based care to reduce health care disparities for the substance user is a priority. Continuing to examine and understand the genetic relationship of addiction may assist in identifying and intervening from a prevention focus for those at high risk of substance dependence. Addressing the environmental factors of exposure and initiation of substance use is also a critical area to be examined for identification and prevention for individuals at high risk for substance dependence.

Understanding the educational and support needs of the nurse in the acute care setting is of primary concern in order to address the nurse's ethical erosion illustrated in the stories of the participants. The development and use of health care teams trained in addiction services can serve as an interventional study with the aim of humanistic, patient-centered care for the substance abuser. The development and implementation of tools is needed to assist the nurse to identify the use of illicit substance use, recognize the slang terms for various illicit substances, and to recognize and intervene prior to the onset of withdrawal.

Since all of the participants had a history of trauma, further research for the development of in-depth education, training, and application of trauma-informed care, harm reduction education, and motivational interviewing beginning in nurse education is an area to be explored. Further research that includes a breadth of the substance users' experiences in health care will provide greater insight for improving care to the individual throughout their addiction trajectory. The use of a mentor for a person actively using illicit substances is another area to be explored. Most importantly, the essence of nursing lies in the interpersonal relationship. Further research exploring implementation

of this process as a fundamental part of nursing education may lead to an increase in nonjudgmental nursing care.

### **Strengths & Limitations**

The findings of this study may not represent the experience of all IDUs. The stories told by the participants represent their recollection, perspective, and interpretation of the event. However, it was this recollection that informed each IDU's present mental and physical well-being. This study cannot generalize the experience of all IDUs' experiences receiving care from a nurse on a medical unit. Instead, the findings of this study add to the nursing knowledge base of caring for the substance-abusing individual.

Strengths of this study included the diverse participant sample and the fact that four women agreed to share their stories, as this population is difficult to obtain. Other strengths included the richness of the participant stories, the eagerness of the participants to share their perspectives, and their willingness to be respectful of the researcher's boundary of not being impaired by a mind-altering substance during the interview. The researcher's experience as a nurse—a nurse who has worked with substance-dependent persons—was helpful while observing and interacting with the IDUs. My attempt at being as transparent as possible with all written materials proved to promote trust. I noted that the participant sat more forward and would look at what I was writing during the collection of the demographic data, but then would become more relaxed and sit back in the chair while I made notes during the interview. The use of a qualitative approach was important, as the participants displayed nonverbal behaviors that emphasized their spoken words. Additional strengths included the inadvertent therapeutic effect of storytelling that

resulted in a number of the participants stating they felt better at the conclusion of the interview.

Limitations to the study were present. Participants were only interviewed once due to their transient and chaotic lifestyle; therefore, they were not able to offer input on the researcher's findings. This limitation made it difficult to follow up on questions gleaned after listening to and reading the transcripts. The participants were eager to tell their story and it became challenging to discern when the experience occurred, and if the care received was from a nurse. Details of the experiences differed and at times, it was difficult to get in-depth information due to lack of memory recall. A limitation in the design included the difficulty with identifying a rival case that provided enough information to be markedly different from the comparison cases.

### **Conclusion**

This study was important because of the high rates of morbidity and mortality associated with injection drug use. Individuals who are IDUs have a much higher rate of death due to overdose and AIDs-related mortality, than non-injecting users (Mathers et al., 2013). IDUs continue to receive marginalized care that has an effect on their physical, emotional, and psychosocial well-being. The nurse has the ability to assist the IDU in making incremental changes to reduce the harm from the drug use. Evidence of the nurse as a motivator for change was seen in the positive encounters with resulting behavior changes noted in the Alex, Grace, and Hillary interviews. Along with prevention and treatment education and intervention, incorporation of harm reduction strategies by the nurse is one way to demonstrate compassion toward a marginalized population. Developing an interpersonal relationship with the substance user can decrease the harm

related to substance use, the societal cost for treatment, and decrease the long-term effects from the chronic conditions related to substance abuse. Incorporation of a team of health care providers educated and trained in addiction is imperative to improve the care received by this vulnerable population.

The use of Travelbee's (1971) human-to-human relationship model can improve the interpersonal relationship between the nurse and IDU. The development of a therapeutic relationship has been shown to have positive effects for both the patient and nurse. Nurse-patient connectedness has been shown to have a positive effect on nurses and their nursing care through a reflective process (Kendall, 2006). When the nurse forms a connectedness to the patient, the nurse becomes more invested in the patient's outcome and has increased job satisfaction (Foster & Hawkins, 2005; Mitchell, 2007).

The complexity of caring for the IDU requires the nurse to avoid prejudging the individual in order to deliver high quality, competent care. Understanding the experiences of the IDU receiving care from a nurse is imperative for nurses and researchers to gain insight into new ways to expand care for this vulnerable population. Nurses have an ethical and moral responsibility to provide compassionate care to the substance dependent person. Recognizing the role of the nurse in providing patient-centered care, improving the IDU's hospital experience, and decreasing health care disparities is paramount. It is essential that the nurse receives education and role support to implement addiction and trauma-informed care to the IDU. The nurse has the ability to serve as an influential motivator and change agent. To restate Grace's powerful statement, "I have plenty of excuses to get high, plenty of them. I can come up with a million reasons to get high. I'm trying to find a reason not to."



**APPENDIX A**  
**CASE STUDY PROTOCOL**

**A) Overview of the Case Study**

- 1) **Audience-** dissertation committee and nurses
- 2) **Research Question-** What is the experience and meaning attributed to care by nurses, received by adult substance abusers during a health care encounter in the acute care medical setting?
  - 2a) **Aims-** 1- Describe the IDU's most recent experience receiving care from a nurse
    - 2- Describe the IDU's interpretation of the meaning of this experience
    - 3- Describe if the IDU feels this experience has, or will have, an effect on when the IDU will seek care the next time it is needed
- 3) **Theoretical Framework-** Joyce Travelbee's (1971) Human-to-Human Becoming Model. The four phases of the framework, 1) original encounter, 2) emerging identities, 3) empathy, and 4) sympathy will be used to code the transcripts.
- 4) **Role of the Protocol-** the protocol will be used to guide the research study in a standardized manner and will be followed for each case.

**B) Data Collection Procedures**

- 1) **Contact site and person-** Tapestry city A and Tapestry city B- Tim Purington- Director of Tapestry Needle Exchange Service
- 2) **Data Collection Plan**
  - a) **Gaining access-** Researcher will spend time in the setting to allow for acclimation for researcher and participants. Staff will inform clients about study and refer them to posted flier. Fliers will be posted in the NES to inform clients of study.
  - b) **Resources-** researcher will have access to a private room to conduct the interview, contact summary sheet, and to write field notes. The researcher will supply her own computer, paper, pens, pencils, digital recorder, back-up recorder, and notebooks. These will be carried in a bag to each setting.
  - c) **Procedure for calling for assistance-** staff will be aware of when each interview will occur. Researcher will sit in chair closest to the door. Researcher will carry a bell to use to draw attention to assistance being needed, if necessary.
    - a) **Individuals to be interviewed using semi-structured questions-** Individuals 18 age and older, who have been hospitalized in the past year and were active IDU's at the time nursing care was received.
    - b) **Demographic sheet-** to be obtained verbally or in writing.
    - c) **Observations-** IDU's arrival and departure from clinic, interaction between IDU and counselor.

- 3) **Expected preparation prior to site visits-**
  - a) contact and meet with Tim Purington, Program Director of Tapestry
  - b) get approval from IRB for Tapestry health
  - c) review enrollment forms, referral information done at initial visit for IDU at Tapestry.
  - d) contact and meet counselors and staff at NES
  - e) complete any necessary trainings for facility (HIPAA, safety, etc.)
  - f) complete and submit required health forms
  - g) negotiate interview space, times, and procedure for referring IDU to counselor if necessary.
- 3) **Protection of Human Subjects**
  - a) fliers to be posted, and interviews to be held only at NES
  - b) informed consent to be either in writing or verbally on audio-tape
  - c) all contact sheets and digital recordings to use a number code
  - d) all digital audio tape recordings, contact sheets, field notes, code sheets to be kept in a locked filing cabinet
  - e) all electronic transcripts to be kept on a password protected laptop, written transcripts to have identifying data removed and stored in a locked filing cabinet. All audio tapes will be destroyed 5 years after the conclusion of the study

**C. Data Collection Questions (researchers internal inquiry questions)**

- 1) Do I know when this hospitalization occurred?
- 2) Was the individual injecting drugs at this time? What were they admitted for?
- 3) Do they need prompting to recall an event from the hospital? Do they need prompting to determine if a nurse was the other person during this interaction?
- 4) Do they always use this hospital, or do they go to a number of hospitals for care?
- 5) Was this admission related to their drug use or a medical problem?
- 6) What was the process that led them to seeking care at the hospital?
- 7) Is there anything different about this hospitalization compared to others?
- 8) Was the interaction being referenced an isolated event, or was this what occurred during entire stay?
- 9) Was the context of the meaning of the experience evident?
- 10) Was the context of the situation described so that behaviors of both individuals were recognizable?
- 11) Does the IDU recognize what the nurse's role is?

**D. Guide for the Case Study Report**

- 1) Introduction
- 2) Review of the Literature
- 3) Theoretical Framework
- 4) Methodology
  - a) case study as research strategy
  - b) multiple, holistic case studies

- 5) Data Analysis
  - a) individual case studies
  - b) participant checking
  - c) rival and comparison case
  - d) a priori codes
  - e) in vivo codes
  - f) Travelbee phases as codes
  - g) computer analysis (NVIVO 10)
  - h) pattern matching
  - i) explanation building
  - j) review of memos, notes, field notes
  - k) peer debriefing
  - l) use of an auditor
  - m) coding for concepts
  - n) coding for themes
- 6) Case Study Database (per case)
  - a) contact summary form
  - b) demographic form
  - c) transcribed interview data (de-identified)
  - d) field notes
  - e) auditor notes
- 7) Findings
  - a) dissemination to dissertation committee
  - b) journal articles
  - c) presentations



**APPENDIX C**  
**CONSENT FORM**

Consent Form for Participation in a Research Study

University of Massachusetts Amherst

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**Researcher:** Kimberly Dion

**Principal Investigator:** Donna Zucker

**Study Title: A Case Study of the Injection Drug Users' Perceptions of Received Nursing Care**

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**1. What is this form?**

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records. If you do not wish to sign this form, you may give permission verbally on the digital audio-recorder and still be able to participate in this study.

**2. WHO IS ELIGIBLE TO PARTICIPATE?**

You are eligible because you are over the age of 18, you speak and understand English, and you have had an encounter with a nurse while receiving care in a hospital during a time you were actively injecting drugs.

**3. WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of this research study is to describe what an injection drug user thinks or feels about the care received from a nurse in the hospital during a time that they were actively injecting drugs.

By interviewing individuals who have had this experience, the researcher will better understand the experience and meaning that the nurse-patient experience had on the individual, and if this experience has, or will have an effect on when the individual would seek care the next time it was needed. Understanding the experiences of the injecting drug user is important in order for researchers and nurses to learn more about new ways to improve nursing care.

#### **4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?**

The study will take place in a private room at the needle exchange service. The interview will last approximately 60-90 minutes. You will be audio recorded during the interview. You will not be contacted in the future by the researcher.

#### **5. WHAT WILL I BE ASKED TO DO?**

In order to be sure you understand why you were asked to participate in this study, you will be asked to answer some questions about the study. You will be asked to tell the interviewer what the study is about; why you were asked to participate in the study; what you will be asked to do for the study; what are the possible risks you might face from participating in the study, and what benefits you may get from this study. You will be asked, "If you want to, can you quit this study?" You will be asked to verbally state that you understand the informed consent. These questions must be answered before moving forward with the interview. Your participation in this study does not affect your ability to obtain services at the needle exchange site.

There are two parts to the research study. In the first part you will be asked to participate in an audiotaped interview where you will be asked questions about your experience with nursing care while in the hospital during a time when you were injecting drugs. You will **not** be asked questions about current drug use. You will be asked to describe your most recent experience of receiving care from a nurse while in the hospital, and what meaning this experience had for you. You will also be asked if this encounter had an effect on when you sought health care the next time that it was needed. For the second part of the study, you will be asked to answer questions asking information such as age, race, ethnicity, education level, income level, and the name of the hospital you used for your care. You can answer the questions on a paper or answer them on the tape. You may skip any question you feel uncomfortable answering.

#### **6. What are my benefits of being in this study?**

You may not directly benefit from this research; however, we hope that your participation in the study may help nurses and other health care providers to understand the experience of the injection drug user while receiving care in the hospital, and improve their care.

#### **7. WHAT ARE my RISKS OF being in THIS STUDY?**

There is minimal risk to participating in this study. There may be some emotions experienced while thinking about, or talking about your most recent health care experience in the hospital. There may be an unforeseen risk that talking about this experience may make you feel anger or sadness about care that was received, or having to think about your health status. The time that the interview takes may be an inconvenience for you. All efforts will be made to keep the conversation confidential. If you need to speak to a counselor, you will be given the contact information for one at the needle exchange center.

### **8. How will my personal information be protected?**

The following procedures will be used to protect the confidentiality of your study records such as audio recordings, consent form, and code books. We cannot guarantee complete confidentiality of the study data. The researchers will keep all study records, including any codes to your data, in a secure location, such as a locked file cabinet. Research records will be labeled with a code. A master key that links names and codes will be stored in a separate and secure location. The master key and audio recordings will be destroyed 5 years after the close of the study. All electronic files (such as wav files, databases, spreadsheets, etc.) containing identifiable information will be encrypted. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff (interviewer, her advisor, and a content expert) will have access to the passwords. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

### **9. WILL I RECEIVE ANY PAYMENT FOR TAKING PART IN THE STUDY?**

To compensate you for your time during this study, each participant will receive a twenty dollar gift card to a grocery store or bodega at the end of the interview.

### **10. WHAT IF I HAVE QUESTIONS?**

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researchers, Kimberly Dion at 413-545-1314, or Donna Zucker at 413- 545-1343. If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or [humansubjects@ora.umass.edu](mailto:humansubjects@ora.umass.edu).

### **11. CAN I STOP BEING IN THE STUDY?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. You can still use the services of the needle exchange even if you do not complete the interview.

### **12. WHAT IF I AM INJURED?**

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to this type of research, but the study personnel will assist you in getting treatment.

**13. SUBJECT STATEMENT OF VOLUNTARY CONSENT**

When signing or verbally agreeing to the contents of this form, I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

\_\_\_\_\_  
Participant Signature:                      Print Name:                      Date:

By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

\_\_\_\_\_  
Signature of Person                      Print Name:                      Date:  
Obtaining Consent



**APPENDIX D**  
**DEMOGRAPHIC FORM**

- 1- Gender
- 2- Race/Ethnicity
- 3- Age
- 4- Years of schooling
- 5- Income level
- 6- Work status
- 7- Whom do you live with?
- 8- Type of housing
- 9- Years of substance abuse
- 10- Age which substance use first started
- 11- Hospital where you received your care
- 12- Other medical conditions?
- 13- Do you have a mentor?

**APPENDIX E**  
**RECRUITMENT FLIER**



**University of  
Massachusetts  
Amherst**

**Looking for Research Study Volunteers!**

Are you 18 years or older?

Do you speak, understand, and read the English language?

Have you been hospitalized on a medical unit during a time that you were actively injecting drugs?

If you answered yes to the above questions, you may be eligible to participate in a research study that is looking at injection drug users' perceptions of received nursing care.

**What do I get?-** You will get to share your story and ideas about how to best care for substance users. You will receive a \$20 gift card to a grocery store or bodega at the end of the interview.

**What will I be asked to do?-** You will be asked questions during an interview that will last 60–90 minutes. Your voice will be recorded during the interview but you will remain anonymous in the data.

**Where do I do this?-** The interview will take place at the needle exchange site during a time that is convenient for you. Sign up for a time on the log. You don't need to use your real name.

**What are the risks?-** There is minimal risk to participate in this study. You may feel sad, upset, or angry about the hospitalization or your health status.

**What if I have questions?-** If you have further questions about this project you may contact the researchers, Kimberly Dion at 413-545-1314 or [kadion@nursing.umass.edu](mailto:kadion@nursing.umass.edu), or Donna Zucker at 413- 545-1343 or [donna@acad.umass.edu](mailto:donna@acad.umass.edu).

## **APPENDIX F**

### **INTERVIEW QUESTIONS**

- 1- Please tell me about your most recent experience of receiving care from a nurse while you were in the hospital and were an active injection user.
- 2- Please tell me/describe what this experience meant to you.
- 3- Please tell me how this encounter compared to other encounters you have had with nurses.
- 4- If you witnessed this, how did the nurses care for other patients?
- 5- Please tell me if this experience affected your decision of when to seek medical care the next time you needed it.

**APPENDIX G**  
**A PRIORI CODES**

- Original encounter
- Emerging identities
- Empathy
- Sympathy
- Rapport
- Being hospitalized
- Comparing hospitalizations
- Being cared for
- Deciding to seek treatment
- How to care

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