"A POSITIVE PERFECT STORM":

CREATION AND DEVELOPMENT OF HAWAI'I'S SYRINGE EXCHANGE PROGRAM-HARM REDUCTION IN ACTION?

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DEDICATION

This work is dedicated to the dynamic personalities that were instrumental in the creation of Hawaii's Syringe Exchange Program: Aaron Peak, The Hawaii AIDS Task Group, and The Governor's Committee on AIDS,

and

to "L," who experienced the stigma attached to the diagnosis of HIV and suffered and died from AIDS.

I submit my nursing dissertation today...because of you.

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I would like to extend my sincere appreciation to several individuals who supported me throughout my study.

To my husband, Neil—thank you for putting up with my ceaseless chatter. I am sure you could recite this dissertation from memory! To my children: Dennis (Mel), Kevin, and Connie (Ron)—thank you for your advice … yes, I tried to keep it simple.

A special thank you to the dynamic personalities that make up the CHOW project! Thank you for sharing your reports and answering my many questions.

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Yes … I did it!

ABSTRACT

Hawai'i has a syringe exchange program (SEP) that has been in operation for over 25 years. However, little is known of the factors that led to the creation, development, growth, and success of this program, while similar programs are actively opposed in many parts of the U. S. This study delves into the perceptions of the factors that led to the creation, development, and growth of Hawai'i's SEP. This study uses a purposeful sample, using a snowball technique, in which 22 key informants (K. I.) are recruited and interviewed. This is a mixed methods study; two methods of data collection are used, K. I. interviews and deductive directed content analysis. Discussions with K. I. provide perceptions about the factors leading to the creation, development, and growth of Hawai'i's SEP. The deductive directed content analysis, using a harm reduction (HR) approach of five principles—pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals—is tested against data from Hawai'i SEP annual reports. Statistical analysis is performed to measure the frequency HR principles are used. Study findings reveal dynamic personalities played a major role in the factors leading to the creation, development, and growth of Hawai'i's SEP. This study identifies two major themes—fear, and knowledge is power. A retrospective deductive directed content analysis is conducted on the annual reports of 1995 through 2015, plus the Operational Manual for 2016. The findings reveal the most common HR principle is priority of immediate goals; balancing costs and benefits ranked second in frequency; focus on harms ranked third; humanistic values ranked fourth, and pragmatism ranked fifth. This study provides recommendations that could improve public health in Hawai'i.

Keywords: syringe exchange programs, critiques, HIV, harm reduction

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ACP	American College of Physicians
ANA	American Nurses Association
APA	American Psychiatric Association
CNA	Canadian Nurses Association
CDC	Centers for Disease Control and Prevention
CHOW	Community Health Outreach Work
GCA	Governor's Committee on AIDS
HR	Harm Reduction
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HPD	Honolulu Police Department
HIV	Human Immunodeficiency Virus
IDU	Injection Drug Use
K. I.	Key Informant(s)
RN	Registered Nurse
PWID	Person/People Who Inject Drugs
STD	Sexual Transmitted Disease
SEP	Syringe Exchange Program

CHAPTER 1

GENERAL STATEMENT OF THE PROBLEM

In the summer of 2015, rural Scott County in Indiana saw first hand the deadly effects of people who inject drugs (PWID) sharing needles and injection equipment (Crowley & Millett, 2017; Ruiz, Allen, & O'Rourke, 2016; Toppa, 2015). In Scott County, Indiana, there were 79 human immunodeficiency virus (HIV) cases between mid-December 2014 and March 2015. "The county normally averages about five new cases a year" (Goldschmidt, 2015, p. 2)—new cases of HIV continued to spiral out of control. According to May (2016), "Since the start of the outbreak, 210 people in Scott County have been diagnosed with HIV, and most are concentrated in Austin, which has a population of fewer than 2,500. Nearly 95 percent of the infected also have Hepatitis C" (para. 2). This rapid spread of HIV among PWID is not uncommon (Des Jarlais, Pinkerton, Hagan, et al., 2013). Furthermore, Des Jarlais, Feelemyer, Modi, et al. (2012) and Des Jarlais, Pinkerton, Hagan, et al. (2013) stated the HIV increase among PWID could be as high as 50% per year; Scott County clearly exceeded these numbers.

Vice President Pence, then Governor of Indiana, reluctantly agreed to allow the local health department to begin a syringe exchange program (SEP) for PWID. The reluctance was in part due to his often quoted self-described beliefs: "I am a Christian, a Conservative and a Republican in that order" (Rodrick, 2017, para. 24), and allowing an SEP was seen as condoning or even encouraging illegal usage. The Scott County SEP continues to operate today.

To people living in Hawai'i, the outbreak of HIV cases in Scott County, and the associated reluctance of the Indiana state government to set up a SEP, comes as somewhat of a surprise, as a Hawai'i state-supported SEP has been in effect since 1990 (Adamski, 1997; Lichty, 1990). Each

year, the analysis of the operations of the SEP in Hawai'i demonstrated that the SEP is associated with a low incidence of HIV and acquired immune deficiency syndrome (AIDS) among PWID, and it is also cost effective. According to the Centers for Disease Control [CDC], each HIV/AIDS patient annually costs approximately $23,000 (2010 dollars), with an estimated lifetime cost of $379,668 (2010 dollars) (CDC, 2015). On November 25, 2014, the CDC reported,

> The average lifespan of a person without HIV is 79 years. The average lifespan of a person with HIV diagnosed at age 20 taking current HIV medicines is 71 years. The average lifespan of a person with HIV diagnosed at 20 not taking current HIV medicines is 32 years. (para. 7)

The state support for the SEP has annually varied between approximately $750,000 and $1 million, and the support was there even through the great recession of 2009.

The average person might well wonder if Scott County is an anomaly or whether Hawai'i is the anomaly. Regrettably, it is the latter case. This dissertation will therefore attempt to answer the overall question as to why the Hawai'i SEP seems to have been so acceptable and successful. To do so, this dissertation examines the overall distinctive nature of the State of Hawai'i. It uses key informant (K. I.) discussions, explores literature from local publications, with a focus on the political parties in Hawai'i, and also examines the personalities that appear to have made possible the creation of the SEP in Hawai'i. The complicated manner in which the program was set up is detailed in Chapter 4, based on interviews with K. I. and backed up by contemporary articles. Additionally, the input of the K. I. presents a rich trove of comments as to why, though successful, the Hawai'i SEP still appears to be not as effective as it might be. Finally, because a SEP are usually seen as part of an overall harm reduction (HR) approach to

social/medical problems, this dissertation examines whether the Hawai'i SEP followed, and is following, HR principles.

This chapter briefly describes four areas that help account for Hawai'i's uniqueness: (1) the *geographical* reality of Hawai'i, (2) a brief *history* of Hawai'i before the takeover of the Kingdom in 1898, (3) *demographic influences* and the *immigration patterns* into Hawai'i that helped create a socio-cultural approach to some community problems that do not exist in any of the other 49 states, and (4) the very different form that *religion* has taken in Hawai'i. Following these four areas, a discussion on HR, with special emphasis on SEPs, and a short introduction to the Community Health Outreach Work Project (CHOW) is presented. After the discussions on SEPs and HR, the Theoretical Framework, Statement of the Problem, Significance of the Problem, Research Questions, and Implications for Nursing Research, Practice, and Policy, as it pertains to this study, is included.

Organization of the Study

This dissertation is divided into five chapters. Chapter 1 examines the State of Hawai'i as being unique among the 50 states by focusing on a variety of perspectives including its *geography*, its *history*, its *demographics*, and its *religion*. In conclusion, the chapter presents an overview of the State's SEP.

Chapter 2, Literature Review, reviews HR in the civic community and SEPs in general. Chapter 3, Methodology, details the methodology that is used to show how politics and personalities operating in the State in the 1970s, 1980s, and 1990s led to the creation of a successful SEP. It includes the methodology of the study, as well as the design, target population, data collection, data analysis, and research findings.

Chapter 4 presents the findings and attempts to use the findings to answer three questions: (1) what made Hawai'i a hospitable home for the creation of an SEP, and (2) how did the sociocultural situation and personalities use that foundation to craft an SEP. Further, the chapter describes the links between the SEP and HR, and using material supplied by the K. I. attempts to answer the question (3) what factors are preventing Hawai'i's SEP from being more effective in the area of needle exchange, its core function.

Chapter 5 ties together the material from the previous chapters and suggests some ways in which health policy in Hawai'i could be set up to improve overall health in Hawai'i, especially for PWID.

Hawai'i is Unique

Influence of geography. As the map indicates, Hawai'i is almost in the dead center of the Pacific Ocean.

Figure 1.1. Geographical location of Hawai'i. The red circle on the map pinpoints the location of Hawai'i in comparison to the West Coast, placing it almost dead center in the Pacific Ocean. Adapted from "Hawai'i in the Pacific," 2017.

Hawai'i is approximately 2,500 miles from the major West Coast cities from Anchorage to San Diego, and is approximately 4,000 miles from Japan— Hawai'i is indeed very isolated.

This isolation is not merely the distance in miles but also the distance in time. Even with travel by jet plane, it takes approximately five hours of flight time to reach the West Coast. However, because of the time zone difference between Hawai'i and the West Coast, two hours in the winter and three hours in the summer, it takes almost half a day to reach the West Coast. To reach the East Coast and Washington D.C. is another 2,500 miles and three more time zones. As a result, when Hawai'i is getting underway at about 9:00 a.m., it is 3:00 p.m. on the East Coast, and some agencies are already closing for the day. When Hawai'i is at the "end of the day," the day has already been completed in Asia and Europe.

The overall result is that people in Hawai'i are more concerned with what is happening in the state than what is happening in other parts of the world. The major newspaper may well indeed carry news of a local high school football coach's contract on the front page, often as a headline. National news and international news are generally carried deeper in the newspaper. Similarly with the local radio and TV stations, local news is more important than national news. It is not easy for people from Hawai'i to move to the mainland, as one cannot simply pack one's belongings in a rental truck and drive a few 100 or even a few 1,000 miles. Overall, there is the feeling that if Hawai'i residents do not take care of a problem themselves, no one else will do it for them. This geographic isolation is one factor that makes Hawai'i different from the other 49 states.

Influence of history. Just as geographic isolation helped shape Hawai'i and its approaches to problems, so too has its history. When the Mayflower landed near Cape Cod in 1620, Hawai'i did not exist as an entity. Rather, a different leader ruled each of the main islands (Kame`eleihiwa, 1992). It was not until over 150 years later that the Hawaiian Islands were first visited by a "westerner," when Captain Cook first landed in Hawai'i in 1778. Thus, Hawai'i was

never a part of the mythology of the foundations of the United States through the thirteen colonies, the War of Independence, and the Declaration of Independence. Within 20 years of Captain Cook's arrival, the islands of Hawai'i had united under King Kamehameha I, and had also seen a variety of arrivals from the United States. However, these visitors—missionaries, traders, and whalers—were not visiting a part of the United States, rather an autonomous Kingdom. Though these various peoples had many effects on the indigenous population, perhaps the most devastating effects were the various infectious diseases, such as smallpox, against which the local population had no immunity. The population of Native Hawaiians crashed from what some estimated at a peak of about 1.2 million to fewer than 300,000 by 1860 (Blaisdell, 1989). Power in the islands was transferred in 1848 with the Great Mahele: land that had formerly been used in common could now be bought and sold (Blaisdell, 1989; Hawaii History.org, 2017; Kame`eleihiwa, 1992).

After the Great Mahele, the new law allowed foreigners to buy, sell, and lease land, with the trading in land primarily between some of the nobility and the foreigners. Hawai'i rapidly moved from the original *a`hupua`a* system of land use primarily for subsistence farming, to sugar plantations that displaced the indigenous population in favor of imported labor and machinery. Sugar became an extremely valuable commodity crop because of events on the United States, such as the Civil War, and favored the rise of the "the Big Five": Castle & Cooke, Alexander & Baldwin, C. Brewer, Theo Davies and American Factors (Blaisdell, 1989; Daws, 1968; Economic History of Hawai'i , n.d.; Hawaii History.org)

The most traumatic event of the history of Independent Hawai'i was the overthrow of Queen Lili`okulani in 1893: an event which was spearheaded by the 'Committee of Safety,' against the wishes of President Grover Cleveland, overthrowing the monarchy of Hawai'i

(Greenspan, 2013; History.com, 2010). Though many urged the Queen to resist, she felt that it would be dangerous for the Native Hawaiians to resist.

The new, predominantly white, government placed Sanford Dole as Hawai'i's first and only President. He served in this position from 1894 to 1898, and along with heading the new government, offered Hawai'i to the U. S. for annexation. Although President Grover Cleveland first opposed this annexation, the Spanish-American War and conflicts in the Philippines increased Hawai'i's value to the United States. The islands were annexed in 1900 by the succeeding president, President William McKinley (Blaisdell, 1989; U. S. History, 2016). Dole then became the first Territorial Governor of Hawai'i (Economic History of Hawaii, n.d.). The Overthrow became permanent with Hawai'i becoming a Territory of the United States and closely tied to the United States through trade, especially in sugar, and through the opening up of Pearl Harbor as a naval base. However, it is important to note that Hawai'i did not share in the common history of the United States, most notably the Civil War. Further, Hawai'i did not seem to have a backlash against immigrants from China, Japan, Korea, and the Philippines as similar to the backlash on the mainland against the immigrants from Ireland, Italy, and 'less desirable countries' of Europe in the late 1880s and early 1900s.

The attack on Pearl Harbor in 1941 linked Hawai'i very closely to the Mainland states, as all became involved in the common war effort to defeat the Fascist powers (Hawaii History.org, 2017). However, part of the historical memory for Hawai'i post Pearl Harbor was the denial of many rights to Japanese citizens and the forced interment of many in internment camps in Hawai'i and on the Mainland (Daws, 1968). Hawai'i was formally admitted into the Union in 1956 as the fiftieth state. Though Hawai'i was now permanently part of the United States, the way in which it moved from an independent kingdom to being a State in the Union ensured that

its history was sufficiently different from the other 49 states, as will be described in Chapter 4—this difference helped shape a radically different approach to dealing with social problems.

Influence of demographics. Not only does Hawai'i differ from the other 49 states in terms of history and geography, it is one of four states where Caucasians are a majority-minority of the population (DeVore, 2015). For example, in 1980, Hawai'i's population by ethnicity identified 318,770 Caucasians out of a total of 964,691 people (Schmitt, 2011). Similarly, in 1990, Hawai'i's population by ethnicity identified 369,616 Caucasians out of a total of 1,108,229 people (Schmitt, 2011). This is not to say that the Caucasians had very little influence. On the contrary, they exercised far more power than the simple numbers represent—a power that came to its peak with the Overthrow in 1893. In particular, Caucasians owned large tracts of land, and, in a state where useable land was at a premium, ownership of land went hand in hand with power (Daws, 1968). Nevertheless, like any other movement in history, stability is rare, and so it was for the Caucasians. The Asian populations, who had been brought over to work the plantations, gradually moved out of the plantations into other work and were slowly, but surely, amassing power.

Beginning about 1852, the Chinese workers were brought in to assist in the sugar crop. From 1872 through 1892, Hawai'i's sugar industry expanded while the Native Hawaiian population declined. The result of the sugar industry expansion created a demand for plantation laborers (Maclennan, 1997). By 1885, additional workers were brought in from Japan, followed by the Portuguese, to work as plantation contract workers (History of Labor in Hawai'i, n.d.).

It is important to note that though the conditions under which the workers lived were not ideal, these workers, however, were free men, and there is no comparison with the use of slave labor in states of the South. Indeed, workers were free to return to their native lands, although

many instead preferred to bring wives from their homeland, and then moved out of the plantation into other jobs and small businesses in the islands.

The 1970s also saw something akin to a renaissance among Native Hawaiians who had seen their language, culture, and traditional land usage all lost or at least driven into hiding (Blaisdell, 1989). Gradually, under the influence of a few strong individuals, such as Dr. Kekuni Blaisdell and Myron B. Thompson, the glories that were present before the arrival of Captain Cook were revived, including the building and sailing of the *Hokuleia* that conclusively demonstrated that it was possible to sail a Hawaiian style vessel to and from any of the island chains in the South Pacific. The University of Hawai'i encouraged Native Hawaiians to undertake study at the university by setting up special programs, such as that in the John A. Burns School of Medicine Imi Ho' Ola Post Baccalaureate Program and the Native Hawaiian Center of Excellence. In the same vein, the Hawai'i State Legislature set up the W. R. Richardson School of Law, which was named in honor of the Hawaiian Supreme Court Justice William Richardson, a notable scholar in Native Hawaiian law, and who was a Native Hawaiian.

The political landscape of Hawaii also saw dynamic changes. Many of the Chinese, Japanese, Koreans, and Filipinos fought in World II and came back eager not only to take advantage of the GI Bill and further their education, but also began to take on the established politicians (Daws, 1968). Possibly the most notable were the emergence of U. S. Senator Matsunaga and U. S. Senator Inouye, who both enjoyed long careers in the U. S. Senate. Similarly, Patsy Mink represented District Two in Hawai'i; while a Caucasian, Neil Abercrombie, represented the first District for many years. All of these individuals were Democrats and helped establish Hawai'i as the most Democratic state in the Nation.

What is of special importance for this study is not that the Caucasians were a minority in Hawai'i, but, as previously mentioned, that the majority of the population had not adopted the "myths" of the creation of the United States with its emphasis on the ability of the individual to succeed on his or her own. Instead, the Asian populations brought with them an understanding of the importance of community, something that the indigenous community also accepted (Casken, 1995). Further, it was this understanding of the importance of community that helped provide the radical approaches to dealing with drug usage associated with HIV/AIDS, as will be detailed in Chapter 4.

Influence of religion. Religion was the final major influence for the development of Hawai'i's SEP, partly because Hawai'i's history was primarily driven by groups that felt there was only one approach to religion—the Christian religion. The Christian religion relied on the Bible for its theoretical base, a base that emphasized sin and repentance, and sins of the flesh—the stance of the East Coast missionaries. These missionaries, in the early nineteenth century, helped shaped some of the initial politics in Hawai'i. Under the missionaries' influence, the indigenous religion was driven underground, and sociocultural activities, such as hula dancing, were banned. Also banned was the style of dressing that showed a little too much flesh, especially for the *wahini* (Daws, 1968; Kame`eleihiwa, 1992).

Other mainline religions also established themselves, but they tended to be more tolerant than on the mainland. For instance, the Catholic Church gained considerable influence through the work of St. Damien and Blessed Marianne Cope among the Hansen disease patients on the island of Molokai. For them, it was important to treat the sufferers as human beings basically in a nonjudgmental manner. The possibility that the disease had been spread through immorality was not of concern to them, rather the focus was on consequence of the harm. Perhaps the most

public expression of this tolerance was in 1970 when Governor Burns, a pious Roman Catholic, refused to veto legislation permitting legalized abortion (Diamond, Palmore, Smith, & Steinhoff, 1973). By not signing the abortion bill, Governor Burns honored his own beliefs, as well as demonstrating that there was no state religion in Hawai'i—not signing the bill allowed it to become law.

More important to the influence of religion was the arrival of the Asian populations. These groups brought a variety of non-Christian religions with them: a different canon than the Bible to buttress their approaches to life, thereby demonstrating that there were many other religions that had equally long histories and high idealism. Most of the Asian religions did not have the notion of a single omnipotent god whose wishes and directions could be found in the Bible. Most Asian groups had an approach to life that stressed community and tolerance, which was in direct contrast to the more Calvinistic nature of much of Christianity in the United States where there were sharp differences between right and wrong, especially in matters of sexual morality. Even though the Native Hawaiian religion had been driven underground, it had not disappeared; it was a very tolerant religion, especially in terms of sexual morality; for example, homosexuality was not banned (Kame`eleihiwa, 1992).

The four factors discussed in this section—the *geography*, the *history*, the *demographics,* and the *religious* nature of the Hawaiian population—are all interrelated, and they all helped provide a suitable climate for dealing with what was seen as the scourge of PWID and the dangers of HIV/AIDS to them and the civic community.

This portion of Chapter 1 demonstrated that the first state to support SEP was Hawai'i, and that the Hawai'i SEP has been in operation since June 25,1990 (Adamski, 1997; Lichty, 1990).

Harm Reduction through Syringe Exchange Programs

A typical SEP provides PWID free sterile syringes, drug paraphernalia, and condoms as a means of reducing the transmission of blood borne pathogens (Burris, Finucane, Gallagher, & Grace, 1996; Centers for Disease Control and Prevention [CDC], 2010; Crowley & Millett, 2017; Des Jarlais, McKnight, Goldblatt, & Purchase, 2009; Get the Facts, 2016; Institute of Medicine, 2006; Needle Exchange Programs Promote Public Safety, 2006; Palmateer et al., 2010; Vlahov et al. 2001; WHO, 2004). Furthermore, the Department of United States Health and Human Services (2017) identified SEPs as effective ways of not only reducing drug abuse but also reducing HIV transmission, and posted the following quote from the U.S. Surgeon General Dr. Regina Benjamin on their website: “SEPs are widely considered to be an effective way of reducing HIV transmission among individuals who inject illicit drugs” (para.1). In 2014, there were 34 states and 196 cities in the U. S. that operated SEPs, with Hawai'i being one of these 34 states (North American Syringe Exchange Network, 2014). The primary aim of a SEP is on decreasing, or eliminating, the sharing of injecting equipment, thereby reducing, or eliminating harmful consequences of IDU. To put it simply, a SEP is a tool that is used to reach PWID and educate them on the consequences of risky IDU in an effort to keep not only the PWID but also the civic community as safe as possible. Education is provided at these SEPs on HIV prevention, drug treatment referrals, overdose prevention and treatment; additionally, basic hygiene products are provided.

Introduction to the Community Health Outreach Work Project

The Community Health Outreach Work (CHOW) Project, Hawai'i’s statewide SEP, has been in operation for over 20 years and provides Hawai'i’s at-risk population syringe exchange, health education, outreach, safer sex supplies, hygiene kits, HIV and Hepatitis C (HCV)

counseling, testing, and referral and overdose prevention services (CHOW, 2014, para. 1). The purpose of CHOW is simple: provide a SEP to the civic and PWID community as a way to decrease the harmful consequences of the risky behavior of IDU (Des Jarlais, Johnson, Rustvold, Lenze, & Lusk, 2010).

The CHOW project is evaluated through data collection by CHOW outreach workers, surveys, treatment referrals, and surveillance databases (Des Jarlais et al., 2010). The four surveillance databases are used to monitor both CHOW services, including counseling and testing for HIV and HCV, and PWID demographics and referrals to treatment (Des Jarlais et al., 2010). The CHOW project has exchanged more than 9,600,000 syringes at five mobile van units operated by seven outreach workers, and it provides services to PWID on the four major Hawaiian Islands: Hawai'i, Maui, Kauai, and Oahu (Community Health Outreach Project, 2012; Des Jarlais, Lenze, & Lusk, 2015). The CHOW project disposes these used syringes according to the Blood Borne Pathogens Standards; the procedure for safe disposal of these syringes is clearly identified in the operational manual (Community Health Outreach Project, 2016).

According to the current Executive Director of CHOW, the outreach workers have the "ability to connect with PWID in *a non-judgmental*, *respectful and empowering* way which fosters relationships within which behavior change occurs *when people are ready, willing* and able to make changes in their lives" (Lusk, 2015, para. 9). This suggests the CHOW project is following a HR approach because they not only connect with the PWID in a nonjudgmental way, but they also meet these people where they are at with their addiction. Harm reduction programs implement strategies that are aimed at a behavioral change, knowing that change takes time, begins with one step, and PWID often relapse.

Theoretical Framework

This dissertation uses the HR approach for its framework. In HR, a common sense approach in dealing with drug users provides a way to reach PWID with compassion as well as respecting their rights and dignity (Keane, 2003).

A common belief about drug use is that it is both a lifestyle option and a normal part of society (Mangham, 2007; Virdo, 2012). According to the HR Coalition (n.d.), a HR approach "accepts, for better and or worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them" (p. 1). Furthermore, Catholic Charities AIDS Services (2010) acknowledges,

> There are certain behaviors, which people will always engage in for a variety of reasons. Harm Reduction interventions allow that these behaviors will take place and aim to minimize or in some cases eliminate the risks that these behaviors may pose to the individual, their loved ones, the community and society. (p. 1)

According to Sulmasy (2007), "Those being treated in needle-exchange programs are overwhelmingly suffering from drug addiction, not abusing drugs" (p. 7). Drug addiction is described as "compulsive drug seeking and use despite the harmful consequences;" whereas, drug abuse refers to "using a drug inappropriately" (National Institute of Drug Abuse, 2016, para. 1). The Diagnostic and Statistical Manual of Mental Disorders [DSM-IV-TR] (2000) includes a section on *substance dependence* and further defines dependency as including tolerance and withdrawal. Tolerance refers to a need for greater amounts of the substance to achieve the desired effect; whereas, withdrawal refers to "distress or impairment in social, occupational or other important areas of functioning" (DSM-IV-TR, 2000, p. 116). With physical addiction, the body craves for the substance and gradually requires an increased amount

of the substance in order to obtain the same feelings. Many PWID turn to crime, such as prostitution, to pay for their addiction. According to Veit (2000), "Homelessness, physical and sexual abuse, criminal behavior and involvement with law enforcement and justice systems are closely connected with illicit drug use" (p. 458). Simply put, the addicted person dependent on a substance, no longer has the freedom of choice (Sulmasy, 2007). Therefore, according to Sulmasy (2007), the HR strategy of a SEP will not only benefit the PWID, by helping to reduce the harm associated with IDU, but also at same time benefits the community.

Consistent throughout the literature are five values/principles that form the basis of using a HR approach. The five main guiding principles of a HR approach, identified in the literature, include the following: (1) pragmatism, (2) humanistic values, (3) focus on harms, (4) balancing costs and benefits, and (5) priority of immediate goals (Beirness, Jesseman, Notarandrea, & Perron, 2008; Hilton, Thompson, Moore-Dempsey, & Janzen, 2001).

The principle of pragmatism refers to taking a common sense approach when dealing with the high frequency of risky drug use and sexual behavior among many substance use disorders. According to Ashton and Seymour (2010), " It was simple common sense to many in the alliance that such a service should be non-judgmental and treat drug users with respect" (p. 95). The second identified HR principle is humanistic values, which includes simply being non-judgmental when working with PWID (Des Jarlais et al., 2013; Hilton et al., 2001; Keane, 2003; Pauly, 2007; Tiderington, Stanhope, & Henwood, 2013; Virdo, 2012). A basic belief is to treat each PWID as worthy of the same dignity and rights of any other member of society, that is with respect and without judgment (Hilton et al., 2001; Pauly, 2007).

The third principle, focus on harms, merely refers to viewing the extent of drug use as less important than the adverse consequences of drug use. The focus of HR is on avoiding harm

associated with drug use rather than the elimination of the drug itself (Keane, 2003), and whether or not the drug use behavior is morally right or wrong is not a priority (Hilton et al., 2001). In fact, the drug user may choose to continue with drug use; however, some of the negative consequences of this choice may be prevented (Tiderington et al., 2013).

Injecting drugs is a well-known method of spreading blood-borne diseases, such as HBV, HCV, and HIV (Beletsky, Grau, White, Bowman, & Heimer, 2011; Vogel, 2013; Voon et al., 2015; World Health Organization [WHO], 2014). In 2015, according to the Centers for Disease Control and Prevention (2017), 2,392 of the 39,513 diagnoses of HIV occurred as a consequence of sharing needles. Therefore, PWID sharing used needles continues to be a concern (Voon et al., 2015). With such high statistics, the consequence of shared needles poses a potentially greater threat to both the PWID and the public than the simple abuse of drugs (Hilton et al., 2001; World Health Organization [WHO], 2013).

The fourth principle of the HR approach is balancing costs and benefits. According to Inciardi (2009), “Some pragmatic process of identifying, measuring, and assessing the relative importance of drug-related problems, their associated harms, and costs/benefits of intervention is carried out to focus resources on priority issues” (p. 7). For example, the cost and dangers associated with the spread of HIV is greater than simply dealing with the cost of drug use alone (Ashton & Seymour, 2010; Guinnes et al., 2010; Hilton et al., 2001; Needle Exchange Programs Promote Public Safety, 2006). As previously stated, the lifetime cost of providing medical care for a person infected with HIV is estimated to be $379,668 (2010 dollars) (CDC, 2015). The equivalent amount of money spent on SEP would prevent at least 30 new HIV infections (Harm Reduction Coalition, 2000; The Foundation for AIDS Research, 2013). According to Vogel

(2013), “A clean needle costs 97 cents” (p. 1); therefore, the cost associated with the diagnosis of HIV far outweighs the expense of a single syringe.

The last HR principle is priority of immediate goals. According to WHO (2009), “A ‘priority’ is, simply, a fact or condition that is more important than another” (p. 2). The priority goal is an immediate reduction in harm for not only the drug user but also the community, and is based on what is considered right or wrong at any particular moment in time. A good example of how goal prioritization can change with a difference of opinion is Indiana’s implementation of a SEP. What was originally banned because there were concerns that the SEP encouraged drug use is now available for PWID because Governor Pence considered the outbreak of HIV a public health emergency (Philpott-Jones, 2015). However, the formation of Indiana’s SEP was too late for the drug users who had already been exposed to HIV. Simply put, HR is a *pragmatic* and *nonjudgmental* approach that *focuses on harm reduction*, taking into consideration *cost effectiveness,* and *goal prioritization* for not only the civic community, but also the PWID community.

Statement of the Problem

Despite the accessibility to a SEP by the target population of PWID in Hawai'i, and the awareness of the civic community about the negative consequence of the risky behavior associated with IDU, little is known about the effect of the socio-political conditions that facilitated the creation of Hawai'i’s SEP. A paucity of research has been conducted that investigates the overall question as to why Hawai'i’s SEP seems to have been so acceptable and successful. Lastly, because SEPs are usually seen as part of an overall HR approach to social/medical problems, this dissertation examines whether the Hawai'i SEP actually followed, and is following, the HR principles as identified in the literature.

Significance of the Study

A HR approach is not unlike the concepts identified in Florence Nightingale's environmental theory. A major concept in her theory of nursing is "what nursing has to do… is to put the patient in the best condition for nature to act upon him" (Nightingale, 1859/1992, p. 75). Similar to Nightingale's theory, the HR model seeks to place an individual in the best possible condition to maximize health by reducing the consequences of some form of risky behavior. The unconditional acceptance generated by the HR strategy of a SEP, aimed at a target population and focused on minimizing harm from risky behavior, has the potential to affect the health of the civic community, as well as the community of PWID.

Research Questions

This study examines the sociopolitical conditions that facilitated the creation of Hawai'i's SEP and investigates how that program influenced public health policy in Hawai'i. The findings of this study will contribute to a better understanding of how the SEP improved public health and public health policy in Hawai'i. The study is guided by three research questions.

RQ1: What were the factors that led to the creation, development, and growth of the syringe exchange program in Hawai'i?

RQ2: How has the syringe exchange program in Hawai'i incorporated the five principles of harm reduction?

RQ3: What barriers currently impede the delivery of the syringe exchange program in Hawai'i, and what recommendations could strengthen the syringe exchange program and further improve public health in Hawai'i?

Implications for Nursing Research, Practice, and Policy

The consequences of risky behavior with IDU impact not only the civic community but also the PWID community. Therefore, it is pertinent to address the changing needs of the target population that frequent CHOW's SEP, ultimately meeting the health needs of the entire community. Furthermore, the results of this study may demonstrate changing health needs that can further address human care by putting "the constitution in such a state as that it will have no disease" (Nightingale, 1859/1992, p. 1).

This dissertation study uses the HR approach, and its guiding principles, as the main theoretical framework in an effort to capture perceptions of K. I. and socio-political conditions that facilitated the creation and development of Hawai'i's SEP. Further, several recommendations will be presented in which health policy in Hawai'i could be set up to improve overall health in Hawai'i, especially for PWID.

CHAPTER 2

REVIEW OF THE LITERATURE

According to Garrard (2011), "A literature review is defined as an analysis of scientific materials" (p. 5). Conducting a literature review involves synthesizing previously conducted scientific research (Fink, 2005; Roberts, 2010), and also includes identifying "key variables for study" (Roberts, 2010, p. 87). This literature review explores the scientific research focusing on the history of harm reduction (HR), with a primary focus on HR and the target population of people who inject drugs (PWID). It is structured to identify topics of study pertinent to Hawai'i's syringe exchange program (SEP).

A review of the literature was conducted using a search builder using the following major key words: syringe exchange program, harm reduction, human immunodeficiency virus (HIV) and harm reduction. The inclusion criteria were articles that focused on the historical content of HR, SEP, and HIV, HR. The inclusion publications had to be written in English, but they did not have to be published in the United States. Publications not in English and conference abstract publications were excluded.

A thorough search of the scientific literature consisting of relevant articles and books published between 1987 and 2017 was completed through PubMed, Google, Google Scholar, and Electronic Journals at the University of Hawai'i at Mānoa. Google was included because it is commonly used by the public and by researchers to find up-to-date drug education materials from other researchers and/or governmental agencies (Farrugia, 2014). As of March 2017, searching Google's main site and using the terms "harm reduction, HIV, public health, and defining harm reduction" yielded 541,000 results. Searching under the PubMed site using the same words yielded only five results, and even the phrase "critics of harm reduction" yielded

only nine articles. However, a search of PubMed for the term "harm reduction" yielded 6,168 articles. Filtering the search by limiting the articles based on the year of publication (1981-2017), and public health as an additional key word, reduced the number to 4,189 articles. Concentrating on articles relevant to the historical nature of HR resulted in 86 references, including websites, newspaper archives, journals, and books, that met the inclusion criteria. Of these, three books, originally published in 1597, 1737, and 1859, one article published in 1973, four published in the 1980s, and 37 articles published in the 1990s were included in this literature review because of their historical implications resulting in a total of 207 references.

Harm Reduction in the Civic Communities

Harm reduction deals with many aspects of human behavior. When used within a program that is designed to address risky behaviors, the focus ranges from the more serious consequences of risky behavior to less harmful ones. According to Wodak (1999), "The term harm reduction has never been defined by an official body" (p. 169). Des Jarlais (1995) stated, "It must be emphasized that the HR perspective is still under active development, and there is as yet no consensus on its fundamentals" (p. 10). According to Allen, Ruiz, Jones, and Turner (2016), "While there is no universal definition for harm reduction, the Harm Reduction Coalition (2015) states that 'Harm reduction is a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use'" (p. 2). Harm reduction approaches have been described in the literature as principles, concepts, strategies, interventions, programs, policies, and a movement (Ball, 2007; Newcombe, 1992; Weatherburn, 2009). Elsewhere, both risk reduction and harm minimization have been implied (Marlatt & Tapert, 1993). Although there is no agreed-upon definition of HR, there are many common elements to the definitions that have

been proposed. Regardless, the purpose underlying the use of a HR approach is simply to reduce the consequences of risky behavior.

The literature review suggests that HR is a relatively new concept or social policy that has only recently gained acceptance in society (AddictionInfo Alternatives to 12-Step treatment, 2017; Hobden & Cunningham, 2006; Wodak, 1999). However, there are also data showing that HR has been used for decades (Wodak, 1999). Moreover, according to Erickson et al. (2002), "The origins of harm reduction lie in the more than a century old public health movement at protecting the entire community from harm" (p. 1). Examples of long-standing, well-established public health initiatives or strategies to protect the community from harm include "mandated safety standards for motor vehicles, sports equipment, and needle exchange programs" (MacCoun, 1998, p. 1201). MacCoun (1998) identified risky behaviors associated with the policies as simply "driving a vehicle, drinking by alcoholics, participation in sports and intravenous drug use " (p. 1201). MacCoun further identified the harms that these polices try to reduce; these include "physical injury, and HIV transmission" (p. 1201). Likewise, other studies suggested that the change in cigarettes to low-tar content is also a HR approach (Ahmad & Billimek, 2005). Whereas, Lusk (2012) expands on motor vehicle safety standards (seat belts) and sports equipment (motorcycle/bike helmets) by suggesting "holes in pen caps, padded edges of bar/bar with stools, sunscreen and crosswalks" (para. 5) are all additional HR examples used to protect the community from harm.

Therefore, policies broadly acknowledged by society as successful in reducing harm to individuals and the civic community include education on the dangers of drinking and driving, and mandated safety standards for motor vehicles to reduce injury-related mortality. Within the sporting world, policies include the stress on protective sports equipment to prevent sports-

related injuries, such as the use of helmets to prevent concussion, (ACP, 2016; MacCoun, 1998). There are additional standards for toys, food, and pharmaceuticals, and all are aimed at reducing harm in the forms of physical injury, illness, and death (MacCoun, 1998). Because a HR approach does not focus on changing or stopping the harmful activities, the emphasis would not be focused on stopping the participation in sports, smoking, drinking, drug use, or even operating a vehicle, rather the focus would be on reducing the harmful consequences of the activity to not only the individual but also to the civic community.

Although mandated safety standards for motor vehicles and sports equipment to protect from injury may be seen as pragmatic, simple common sense, a SEP carries some opposition. Some studies in the literature suggested stigma surrounding drug use may play a large part in the reluctance of the public to accept SEPs, as a HR strategy, as a way to influence health (Anderson, 1991; Erickson et al., 2002; Friedman et al., 2007; Islam, Day, & Conigrave, 2010; Tempalski, Friedman, Keem, Cooper, & Friedman, 2007).

Most literature suggests that the practice of HR to influence health is guided by the previously mentioned five principles: pragmatism, humanistic values, focus on harm, balancing costs and benefits, and priority of immediate goals (Ashton & Seymour, 2010; Beirness et al., 2008; CDC, 2010; Denning, 2000; Erickson, 1995; Foley, 1997; Fowler, 2010; Governor's Committee on AIDS: Interim Report 1988; Guinnes et al., 2010; Hilton et al., 2001; Inciardi, 2009; Keane, 2003; Lichty, 1990; Marlatt, Larimer & Witkiewitz, 2012; Newcombe, 1987; O'Hare, 2007; O'Rourke, Ruiz, & Allen, 2015; Pauly, 2007; Peak, 1990; Riley et al., 1999; Tiderington et al., 2013; Virdo, 2012; Vogt, Breda, Des Jarlais, Gates, & Whiticar, 1998; World Health Organization [WHO], 2009).

These five principles can also be identified within the duties of nursing practice. The Canadian Nurses Association's [CNA] Code of Ethics for Registered Nurses 2002 identified nursing duties that "are consistent with the principles of harm reduction" (Pauly, McCall, Gold, & Payne, 2007, p. 21). Furthermore, according to the CNA (2011):

> Nursing values related to the provision of safe, ethical, competent and compassionate nursing care; the promotion of health and well-being; the promotion of and respect for informed decision-making; the preservation of dignity in which care is provided on the basis of need; and the promotion of justice are compatible with the values of harm reduction. (p. 14)

That the CNA has actively embraced HR is demonstrated by their actions in opening and operating Insite, a supervised injection facility in Vancouver, Canada, in response to the ongoing health and social crisis resulting from dangerous injection drug use (IDU) (Lightfoot et al., 2009).

Similarly, the American Nurses Association [ANA] (2016) position statement identified some of the principles of a HR approach, stating that SEPs are supported by

> . . . education about the transmission of HIV disease… access for referral of IDUs to treatment and rehabilitation services… continued research of the effectiveness of SEPs, and the utilization of qualified health care providers including nurses as resources for quality, cost-effective program outcomes. (para. 2)

The ANA's (2016) overall support for the availability of SEPs in the United States suggested an embracement of this HR strategy as a way to minimize harm to the community.

In addition to the two nursing organizations ANA and CNA, both the American College of Physicians [ACP], and American Psychiatric Association [APA] identified the use of HR

strategies to help decrease the harms associated with IDU. According to ACP (2016), in an effort to help control the spread of AIDS, the "provision of clean needles/syringes to drug addicts . . . exchange programs for needles/syringes are warranted as a means of AIDS control" (p. 1). Furthermore, according to the APA (2016) position statement on SEPs, "Psychiatrists can help foster the success of SEPs by supporting efforts to remove government restrictions on the availability of sterile syringes specifically within the structure of organized needle exchange programs" (p. 1).

Without a doubt, HR does deal with many aspects of human behavior in the civic community. Regardless of where HR is used in the civic community, including the medical profession, the underlying focus ranges from the more serious consequences of a risky behavior to less harmful ones.

Harm Reduction in the Community of People Who Inject Drugs

In the late 1880s, some physicians in England identified the "disease model of addiction and the need for treatment" (Johnson, 2001, p. 1). By the 1920s, England's drug problem had escalated and the need for consensus by physicians regarding treatment and narcotic control was identified. The result was the formation of the Rolleston Committee (Johnson, 2001). Based on its recommendations, government-endorsed guidelines were implemented that allowed doctors to legally supply opiates to addicts (Ashton, 2006; Johnson, 2001). However, by the 1960s, with the ready supply of opiates, England was faced with the "public spectacle with queues of junkies forming outside all-night chemists" (Ashton, 2006, p. 2)—addiction had spiraled out of control. Some addicts were maintained on heroin for years obtained from local pharmacies, which also provided clean needles and syringes, a clear example of HR in action (Johnson, 2001).

By 1980, Rotterdam, the Netherlands, was also confronted with the negative consequences of addiction for many drug users. A self-identified junkie, Nico Adriaans, developed the Rotterdamse Junkiebond, a group of drug users who sought to educate not only drug users but also the general public on substance use and the associated risks (Grund, 1992; Lane, 1993). In 1981, the Rotterdamse Junkiebond began distributing clean syringes to help prevent the spread of hepatitis (Grund, 1995). When HIV was recognized as an additional threat to Dutch PWID, the first SEP was opened in 1984 (Anderson, 1991; Grund, 1992; Grund, 1995; Lane, 1993; Marlatt et al., 2012). According to Engelsman (1991), "The Dutch believe, however, that a pragmatic approach aimed at seeking solutions is more effective than one that is emotional and dogmatic" (p. 484).

It was also during the 1980s that increasing heroin use was noted in Liverpool, England, with additional concern because of the associated risk of contracting HIV. At the same time, a connection "between heroin use and unemployment and deprivation" (Ashton & Seymour, 2010, p. 94) led to the recognition of a vulnerable population made up of individuals at risk for contracting HIV: the homeless and the unemployed, often with a history of substance abuse and psychiatric disorders (Ashton & Seymour, 2010; Bussing-Birks, 2014; Dual Diagnosis, 2014; Evans et al., 2012; Gelberg et al., 2012; Grebely et al., 2014; Harris & Rhodes, 2013; Kerr et al., 2009; Marin-Navarrete et al., 2013; O'Rourke et al., 2015; Strehlow et al., 2012). By 1985, out of a need to meet the needs of this vulnerable population in Liverpool (Merseyside), the Mersey Model of Harm Reduction was established.

According to Ashton and Seymour (2010), the three guiding principles of the Mersey Model include:

> *Make contact* with the whole population at risk, not just the few who were already in touch with health care services; *maintain contact*, in the belief that, at the very least, if they are in contact drug users may be influenced to change their behaviour, and *make changes* in their behaviour. (p. 95)

These three guiding principles of the Mersey Model are similar to the principles of a HR approach: pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals. According to Ashton and Seymour (2010),

> The spread of HIV is a greater danger to the individual and public health than drug misuse. . . . it was simple common sense to many in the alliance that such a service should be non-judgmental and treat drug users with respect. . . . making contact with the target group, those hard to reach so as to be able to deliver primary care interventions. (p. 95)

The goal of the Mersey Model was simple: reduce the harmful consequences of drug use. This was accomplished by providing “information, advice and clean injecting equipment” (Ashton & Seymour, 2010, p. 95). These three principles helped guide the provision of user-friendly and non-judgmental services to people who continue to use drugs.

The English developed a system for dealing with addiction in a “humanitarian medical approach” (Ashton, 2006, p. 1) and developed a system of drug control that considered ‘medical values and public health considerations’ of the addict (Johnson, 2001). In contrast, the United States “created criminals out of addicts who could have led law-abiding lives in Britain” (Ashton, 2006, p. 1). According to Blume and Lovato (2010), the disease model commonly used in the United States has been “historically aligned with an abstinence-only approach” (p. 190). The abstinence-only approach fails to consider that relapse is common. Whereas, HR programs

implement strategies that are aimed at a behavioral change, knowing that change takes time, begins with one step, and that PWID often relapse. A HR approach with addiction “differs from current models in that it does not require individuals to remove their primary coping mechanism until new coping mechanisms are in place, thus, creating an easier more obtainable avenue for desired behavioral change" (Scavuzzo, 1996, p. 5).

A shift from an abstinence-only approach resulted in a new and developing approach to addiction, and treatment strategies developed from a need to decrease the harmful consequences affecting not only the addict but also the community. This new approach is based on HR, although "HR can include abstinence” (Foley, 1997, p. 2). It is not a 12-step model, which uses a progression of 12 separate steps focused on spirituality that guides a person from addiction to recovery (Twelve Step Program, 2012). It is also not about whether the PWID is unable or willing to reduce or abstain from the risky behavior. Rather, the HR approach to addiction seeks to reduce the risk of injury to the PWID or the consequences of his or her risky behavior, while at the same time reducing harm to the community (International Harm Reduction Association, 2010; Ostrow, 2010; Wodak, 2011).

Critiques of Harm Reduction and Syringe Exchange Programs

Not everyone supports HR approaches and SEPs. Criticism of both may derive specifically from the type of services provided by some HR programs. Indeed, while there is no public objection to the use of seat belts or helmets to prevent injury, or the removal of outdated perishable food products in grocery stores to prevent illness or death, HR strategies that include SEPs often meet with objections.

Debates for and against SEPs have sparked controversial arguments between the Democrat and Republican parties of the United States government. The ban for federal funding

to support SEPs began in 1988 and resulted in the Public Health and Welfare Act, section 300ee-5, which addressed the prohibition of federal funds (Weinmeyer, 2016). In the 1990s, a recommendation by the Institute of Medicine requesting the federal ban be lifted was presented to the U. S. government. As a result, in 1997, Congress passed Public Law 105-78 amending the language to allow for the removal of the ban, providing that the Secretary of Health and Human Services could not determine SEPs encourage illegal drugs, and, at the same time, could determine that they are effective in preventing the spread of HIV (Lopez, 2016; Weinmeyer, 2016). However, before the Secretary of Health and Human Services could hold a press conference to announce the lifting of the ban, the Republican opposition interposed. The federal ban for funding remained in effect until the Democrats successfully, although temporarily, were able to lift the ban in 2010. The following year, when the Republicans again took control, the ban was once again reinstated. According to Weinmeyer (2016), "In 2015 the proposal for funding was again discussed, this time because of the outbreak of HIV infections in Indiana" (p. 253). Congress passed federal funding for SEPs at the end of December 2015; however, the funding is still prohibited for sterile syringes, and federal funds can only be used to pay to keep SEPs operational.

On one end of the spectrum of debate is that SEPs reduce drug use and protect the entire community. Whereas, on the other end of the spectrum is that by providing funding for SEPs, the federal government is sending mixed messages: drug use is not all bad because drug paraphernalia is provided to inject illegal drugs, thereby contraindicating law enforcement efforts against drug use (Weinmeyer, 2016).

Through the literature review, three main reasons for the controversies associated with SEPs were identified: *morality*, *enabling,* and *legality and ethical considerations* (Harm

Reduction of Harm Maintenance, 2005; Keane, 2003; Kleinig, 2008; Lusk, 2012; Sulmasy, 2012). The first objection is based on the concept of social morality. Iyer (2003) defined morality as the "common societal conceptions of what is right and what is wrong. Our morality and morals are reflected in how we live, the decisions we make and, and what we hold as valuable" (p. 1091). A testimony given by Mrs. L. Smith, a representative from Toughlove Inc., before a Subcommittee of the Australian House of Representatives acknowledged that SEPs are a valuable asset; nonetheless, the question was asked, "But what is the real message being conveyed? That it is okay to use illegal substances? That it is okay to harm or kill yourself?" (*Impact of Illicit Drug,* 2007, p. 111). On the contrary, a principle of HR is a humanistic value that employs a strategy of treating PWID non-judgmentally and avoids the approval or disapproval of drug use—it respect the rights and dignity of PWID (Beirness et al., 2008; Keane, 2003). As such, Sulmasy (2012) suggested that many of the PWID come from a background of poverty, and many grew up as children of addicts or began using drugs at an early age through influence of older siblings or friends (p. 8).

A second objection to HR is based on the concern of enablement. According to a testimony by W. J. Roques, a special agent-retired from the U.S. Drug Enforcement Association, given to the Government Reform Subcommittee on Criminal Justice, Drug Policy, Human Resources of the U.S. House of Representatives on February 16, 2005, "Harm reduction is nothing more than enabling. . . . enabling and/or encouraging continued drug use leaves the addict/user trapped in the enslavement that drugs impose on them" (*Harm Reduction or Harm Maintenance,* 2005, p. 178). On the contrary, "Best evidence suggests that NEPs do not lead to increased drug abuse in the community" (Sulmasy, 2012, p. 7). The priority goal of using HR strategies or offering education on the harms associated with IDU is to reduce the likelihood of

the consequence of the risky behavior; the drug use itself is of secondary importance (Beirness et al., 2008; Farrugia, 2014). Hawai'i's SEP not only targets PWID who are motivated to stop IDU, but it also aims to connect with those engaging in other risky behaviors, potentially stimulating behavioral change, while being fully aware that change takes time and begins with a single step. According to the Executive Director of Hawai'i's SEP, providing an outreach service, such as an SEP, may help stimulate behavioral change in the target population.

The third objection is related to legal and ethical reasons. According to the Merriam-Webster dictionary (2014), legality is the "attachment to or observance of law." Iyer (2003) defined ethics as "the systematic investigation of questions about right and wrong" (p. 1084). According to the testimony of Roques, "HR is just another segment in the sophistic tapestry that 'drug policy reformers' have woven to lead society to their ultimate goal: drug legalization" (*Harm Reduction of Harm Maintenance,* 2005, p. 178*).* Perhaps the Rolleston Report of 1926, and the drug policy that followed thereafter, contributed to the concern that HR and SEP could lead to an increase in drug use and promote drug legalization. Regardless of the question about right or wrong, the consequence of IDU can affect the entire community:

> Preventive measures for infectious diseases not only prevent the individual addicted persons themselves from succumbing to these infections, but also that an addict infected with HIV or Hepatitis B can infect other addicts and even non-drug users, such as spouses or sexual partners. (Sulmasy, 2012, p. 1)

A priority of goals should then be focused on the elimination, or, at the very least, minimization of the harmful consequences of IDU to the entire community.

Summary

Within the HR literature, HR strategies are mostly discussed with respect to drug use. However, it can be argued that HR is a broader public health strategy that can be implemented within the community, in which case it sheds the negative connotations it has when connected with just drug use. When safety standards for motor vehicles and sports equipment are suggested as HR strategies, there is little argument. Conversely, when HR refers to drug use, the discussion shifts, as society's objections are based on the context of morality, ethics, and the law. It should be noted that HR priority is not a strict set of actions. A HR priority that can be successfully implemented in one generation may not be effective, and may even increase harm, in another generation, as can be seen from the English example with its implementation of the Rolleston Committee's recommendations. According to Paine (1737/1999), "The circumstances of the world are continually changing and the opinions of men change. . . . that which may be thought right and found convenient in one age, may be thought wrong and found inconvenient in another" (p. 12). Furthermore, "Different people have different values: what one person prioritizes, another might ignore" (WHO, 2009, p. 2). Regardless of where HR strategies are used within the community, the priority of immediate goals is simple: do no harm. Data from the literature identified HR as playing a significant role in reducing the harmful consequences of risky behavior in both the civic community and the community of PWID.

This integrative review suggests three key concepts. First, the use of mandated safety standards for motor vehicles and sports equipment to protect from injury were discussed as examples of ways to minimize harm to the public, demonstrating that HR approaches have been used for decades. Thus, the negative association between HR and a SEP may be the role played by drug use. Data were included that were not peer reviewed and not necessarily published

within the past decade. Second, a reference provided by Paine (1737/1999) was included to reiterate the idea that change is necessary, and what is considered appropriate for one generation may not be appropriate for another generation. Finally, the integrative review was done with the intention of providing a general history of HR and drug use and its role as the foundation for Hawai'i’s SEP.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

Chapter three describes the methodology of this study, including the research design, study population, administration, and data analysis. Two methods of data collection are used: key informant (K. I.) interviews and a deductive directed content analysis of the annual reports of the Hawai'i syringe exchange program (SEP).

Harm reduction (HR) is a key part of public health policy. A HR approach involves accepting that there are risky behaviors in which people may engage that could result in harm to an individual and/or the community, and then implementing strategies to avoid or minimize harm to both the individual and the community. The SEP is an example of a HR strategy in the state of Hawai'i.

Research Design

The research design for this study uses a mixed methods approach. First, historical data were obtained through the archives of the Mānoa Library at University of Hawai'i, the Hawai'i State Library, the Honolulu Advertiser, the Honolulu Star-Bulletin, and by qualitative discussions with K. I.. Discussions with K. I. aimed to discover perceptions about the factors leading to the development and growth of the SEP in Hawai'i.

Second, a deductive directed content analysis was conducted to examine existing references related to the SEP in Hawai'i. Finally, a statistical analysis was conducted, looking at frequencies and percentages of the five HR principles. Typically, qualitative research uses inductive methods and frequently begins with the accumulation of specific data; the analysis of which leads to a more general understanding of the topic and generates theory directly from the data. In contrast, a deductive approach tests a theory against data (Cavanagh, 1997, p. 1277;

Downe-Wamboldt, 1992; Hsieh & Shannon, 2005). In this study, the HR principles were tested against data from the Hawai'i SEP annual reports. This was achieved by looking at the frequencies and percentages of the five principles in the reports, therefore determining how the SEP incorporated the five HR principles over the past 20 years.

Population

Protection of human subjects. Exempt approval was obtained from the Office of Research Compliance Human Studies Program (University of Hawai'i's Human Studies Program) on April 7, 2016 (CHS #23841) (Appendix A). The risk of loss of privacy and confidentiality was addressed by explaining to potential informants that their name may appear as an interviewee and any information they provide may be used in this dissertation. Informants were offered the option to respond anonymously. Informants were also told that they were free to withdraw their consent and discontinue participation in the study at any time, without any negative consequences.

Participants. This study included discussions with K. I. who were part of the Hawai'i Governor's Committee on AIDS (GCA) in the late 1980s and early 1990s, current or past board members, and individuals currently involved with the Community Health Outreach Work Project (CHOW). This study did not include drug-using participants. All data for people who inject drugs (PWID) were obtained from a review of data published in the SEP annual reports for 1995-2015. Approval to access these reports was obtained from the CHOW project (Appendix B).

Power of analysis. According to Onwuegbuzie and Leech (2007), "All qualitative research studies should involve some form of qualitative power analysis" (p. 117). Some studies identified six interviews as a sufficient number from which to identify themes (Guest, Bunce, & Johnson, 2006; Mason, 2010; Morse 1994). The final sample size in this study was 22 K. I. This

sample size was sufficient to identify themes, and provide insight into the formation of the SEP in Hawai'i.

Inclusion criteria. The inclusion criteria for study participants was: K. I. who were part of the Hawai'i's GCAs in the late 1980s and early 1990s, current or past board members, or individuals involved with the CHOW project. The K. I. had to be English speakers and willing to participate in a recorded interview. No interviews were conducted with individuals that used the services provided by the CHOW Project.

Exclusion criteria. Exclusion criteria were individuals who were unwilling to be recorded or interviewed, and individuals who were not currently, or previously, involved with the Hawai'i Syringe Exchange Program (Figure 3.1).

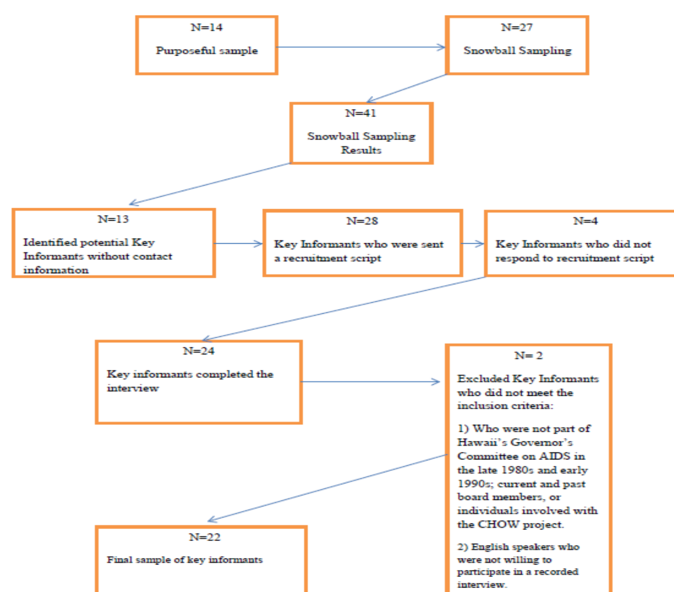


Figure 3.1. Snowball sampling results. As a result of the purposeful sample and snowball technique, 41 potential key informants were identified—13 were unable to be located; 28 were sent a recruitment script, of which four did not respond, resulting in 24 key informants to be interviewed. Of the 24 interviewed, two did not meet the inclusion—22 key informant interviews were included in the study.

Administration

Key informant discussion. The sampling method used to recruit participants combined purposeful sampling and snowball sampling. Initially, potential participants were K. I. publicly identified as having direct experience with the formation of the Hawai'i SEP or being currently involved with the Hawai'i SEP. An email was sent to potential K. I. with a brief explanation of the study and an invitation to participate in the study (Appendix C). Interviews were scheduled at a time and location convenient for the participant. The purpose of the research was explained to each participant, and the consent form was reviewed. Each participant was given the opportunity to decline to have his or her name used in the publication of this research.

The first interview of the purposeful sample of K. I. was conducted on May 31, 2016. Snowball sampling occurred when the purposeful sample of K. I. identified additional participants. According to Burns and Grove (2005), "Saturation of data occurs when additional sampling provides no new information, only redundancy of previously collected data" (p. 358). Saturation of data for this study occurred with the 20th K. I. Therefore, the number of K. I. (n=22) was adequate for this study because the additional two K. I. provided no new information. The last interview was conducted on June 30, 2016. Permission to record the discussion was obtained before recording each informant's interview (Appendix D).

K. I. interviews were guided by a series of nine questions (Appendix E). The filtering question was: What is your past or present connection with Hawai'i's syringe exchange program? After the ninth question, participants were provided with opportunity to share any thoughts that they had not already verbalized.

The recorded interviews were carefully listened to and reviewed to capture the informants' key comments and ideas. The tapes were transcribed, with each transcript worked

on separately. Repeated ideas were identified from each transcript, and repeated ideas from all transcripts were combined. An idea that was repeated two or more times in an interview was considered a repeated idea. Repeated ideas were organized and placed under a heading "Significant Statements." Each idea under this heading was labeled with page, line, and transcript number. This procedure was repeated for each transcript, resulting in groups of relevant text selections of repeated ideas that could be organized into common themes.

The common themes were then evaluated to clearly distinguish between related ideas. At this point, any repeated ideas that belonged under a different theme or significant statement section were moved. The significant statements were examined and further divided into "formulated meanings," and finally, a theoretical narrative retelling the K. I. stories was derived from two major themes. The K. I. discussions provided perceptions of the sociopolitical conditions that existed when the SEP was established in addition to its current operations. These discussions were used to answer Research Question 1: *What were the factors that led to the creation, development, and growth of the syringe exchange program in Hawai'i*?

Content analysis. The collection of annual reports began with 1995, the report to the Needle Exchange Oversight Committee pursuant to Hawaii Revised Statute 325-116 and covered subsequent years up to and including 2015. The 2016 CHOW Operational Manual was analyzed, along with the 20 annual reports, because the annual report for 2016 was unavailable. Permission to access the SEP annual reports was obtained from the current Executive Director of the CHOW project (Appendix B). The collection was physically obtained. Each report was read and then converted to a PDF file to allow the report to be uploaded. Mayring's qualitative software solution was used to work through the text passages of the reports, based on the "strict

content-analytical rules for the whole process and for the specific steps of analysis" (Mayring, 2014, p. 10).

The first step was uploading Research Question 2 for the deductive directed content analysis: *How has the syringe exchange program in Hawai'i incorporated the five principles of harm reduction*? This question met the site criteria to be classified as a deductive category application.

The second step necessary to use this program was linking the research question to theory, with the theory in this study being the HR theory. The third step was defining the research design, and the fourth step involved defining the documents to be analyzed (the SEP annual reports). Each report had to be divided into different text files and converted in Unicode (txt). The final step was defining clear methods of data collection. Mayring (2000) categorical coding was used as a guide to complete the deductive directed content analysis of the reports.

Principles. The five HR principles were identified and defined based on the definitions used by previous researchers, and coding rules were created. These coding rules assisted in "determining exactly under what circumstances a text passage can be coded in a category" (Mayring, 2000, p. 4). Subsequently, examples of the HR principles were extracted from the annual reports based on the coding rules, until data saturation for each year was reached (Appendix F—Table 3:1). After the first coding, the QCAmap software automatically provided a hint to revisit the "central content-analytical rules (category definitions, level of abstraction, coding agenda)" (Mayring, 2014, p. 12). The coding examples and coding rules were reexamined, but no changes were made. Next, statistical analyses were used to compare the categories across the years. Finally, a sample of coding for each category was discussed with a

PhD prepared neutral researcher, first providing the definition and coding rules for each principle. No additional refinements were made for the development of this study.

Statistical analysis. Statistical analysis was performed with SPSS Version 23 (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.), which provided a means of measuring the frequency of HR principles used in the operation of the SEP in Hawai'i. The statistical analysis of the annual reports identified the “registration of the occurrence of the HR principles and categories, in a nominal way and the category frequencies” (Mayring, 2014, p. 12).

Data analysis. Validity, reliability, and generalizability concerns were of less importance in evaluating the qualitative data (e.g., the K. I. interviews) in this study. However, validity and reliability were addressed in the deductive directed content analysis section of this study by obtaining primary data (Burns & Grove, 2005). Primary data were the SEP annual reports for 1995–2015 (inclusive).

Four components were considered to establish credibility: trustworthiness, transferability, dependability, and confirmability. Trustworthiness was established for the deductive content analysis using software that had “strict content-analytical rules for the whole process” (Mayring, 2014, p. 10). The results of this study cannot be generalized, as the study sample was not a representative sample of all SEPs in the United States. Transferability was not possible as no other state has the same history of SEP as Hawai'i. According to Auerbach and Silverstein (2003) for “data analysis to be justifiable it must be transparent” (p. 84). The steps taken to complete this study have been transparent. Dependability was not possible, as this study cannot be repeated. Conformability addresses the aspect of bias. One source of possible bias in this

study was adopting preconceived ideas as a result of the HR approach. A deliberate effort was made to analyze the data in an unbiased manner.

CHAPTER 4

FINDINGS

Research Questions

In this chapter, the results of the mixed-methods study are presented, which were obtained from the literature of events around this period, discussions with key informants (K. I.) and deductive directed content analysis. The following research questions are addressed:

RQ1: What were the factors that led to the creation, development, and growth of the syringe exchange program in Hawai'i?

RQ2: How has the syringe exchange program in Hawai'i incorporated the five principles of harm reduction?

RQ3: What barriers currently impede the delivery of the syringe exchange program in Hawai'i, and what recommendations could strengthen the syringe exchange program and further improve public health in Hawai'i?

A chronological framework of the events leading up to the creation, development, and growth of Hawai'i's syringe exchange program (SEP) helps to answer the first research question. An explanation of how the SEP in Hawai'i incorporated the five principles of harm reduction (HR) emerged from discussions with the K. I. and with the deductive directed content analysis of 20 years of Hawai'i's SEP annual reports. In the discussions with all of the K. I. (n=22), two major themes emerged; additionally, barriers were identified that currently impede the delivery of the SEP in Hawai'i. Recommendations from the K. I. are discussed in Chapter 5.

Creation, Development, and Growth of Hawai'i's Syringe Exchange Program

As indicated in Chapter 1, the geography, history, demographics and spiritual approaches of Hawai'i are different than all the other 49 states. This difference naturally extended to health

care. For example, social-political moves unique to Hawai'i included being the first state to legalize abortion. Hawai'i also introduced a series of sex education programs on television. It was also the first state to cover most of its inhabitants with health care insurance through the Prepaid Health Care Insurance Act (Diamond, 2010).

In 1970, the Hawai'i legislature completed passage of a bill giving a woman the right to have an abortion on her request. The bill was sent to Democratic Governor Burns to sign. The Governor, a Roman Catholic, would not sign nor veto the bill, and as a result, within 10 days, the unsigned bill became law. Hawai'i became the first state in the nation to legalize abortion at the request of a woman (Diamond, Palmore, Smith, & Steinhoff, 1973).

In 1973, the University of Hawai'i and Hawai'i PBS station KHET-TV created a television series, titled *Human Sexuality*, in response to Hawai'i's communities reporting a series of risky sexual behavior, such as unwanted pregnancies, venereal disease, and abortions (Diamond, 2010). According to Diamond (2010), the television series presented "sexuality as a science and art of natural process, common or at least of interest to all, rather than a set of problems relevant to a minority" (p. 4). The series addressed sex-educational content in a nonjudgmental way, exploring topics such as prostitution and homosexuality (Diamond, 2010). In 1973, the National University Extension Association awarded the title 'Creative Programming Excellence' for the series, which was instrumental in bringing sex education into schools (Diamond, 2010).

In 1974, George Ariyoshi, another Democrat, became the third Governor of Hawai'i and served until 1986. Given the social make-up of the state and its political history, it was not a surprise that in 1974 the state was the first in the nation to introduce the concept of requiring that most of the population be covered by health insurance. The Prepaid Health Care Act was the

only legislation of its kind in the U. S., and required Hawai'i employers, with a few exceptions, to provide health insurance to any employee who worked 20 hours or more a week (Hawai'i's Prepaid Health Care Act, 2003; Neubauer, 1993). The act was challenged by the Chevron corporation "on constitutional grounds because the Federal ERISA (Employee Retirement Income Security Act) prohibited such a mandate" (Hellrich, 1994, p. 2). However, "President Nixon intervened and granted Hawai'i an exemption from ERISA. This [was] the only exception given to any state" (Hellrich, 1994, p. 2).

In the 1980s, Hawai'i's population grew more than 25% from the previous decade. According to discussions with a K. I., "Hawai'i was doing pretty well economically, and that really allows people to think out of the box and it allows them to just be more positive about things too" (K. I. 24). Another K. I. described Hawai'i as being in a position where "there was lots of money, lots of Japanese tourists during that time and hence the economy was really good" (K. I. 5). K. I. described Hawai'i at the onset of the SEP as a liberal and progressive state (K. I. 2; K. I. 9; K. I. 24). A similar description of Hawai'i as a progressive state was also identified in the literature (DeGiacomo, 2013; Montes, 2015; Newport, 2013; Rucker & Goldfarb, 2014). According to Montes (2015), "Hawai'i's legislature regularly backs the most 'progressive' policies of any state, imposing heavy taxes, massive bureaucracies and lavish government programs, and leading the leftward charge of social issues from same-sex marriage to abortion" (p. 2). This progressive approach, in part, comes from the factors that make Hawai'i unique among the 50 states and is an additional reason that helps explain the emergence of the SEP.

In 1981, acquired immune deficiency syndrome (AIDS) was officially recognized by the Centers for Disease Control and Prevention [CDC], and the same year, the first AIDS cases were reported in Hawai'i (K. I. 17; D. McEwan, personal communication, June 24, 2016). According

to K. I. 11, “At that time, so many fingers were pointed at the homosexual group.” However, according to the CDC, human immunodeficiency virus (HIV) can be transmitted through not only sexual activity, but also parentally. During the early 1980s, Hawai'i experienced an increase in injection drug use (IDU), specifically heroin (K. I. 17). According to K. I. 17, users “were having difficulty finding needles [and so] they would often share them because the people using [them] were desperate.” In addition, during this time the homeless population was expanding and there was a “very strong misperception that everybody that was homeless was an injection drug user and probably had HIV” (K. I. 24).

Also, in 1981, anticipating that Hawai'i would be “hit soon” with more HIV cases, a few concerned individuals decided to start an organization to support people with HIV. The Jewish term ‘Lchaim,’ which means ‘to life,’ was the inspiration for the name of this support group, and the name agreed upon was the ‘Life Foundation’ (D. McEwan, personal communication, June 24, 2016). In 1983, the Life Foundation became a legal charity, a nonprofit, tax-exempt organization (Life Foundation, 2015; D. McEwan, personal communication, June 24, 2016). Today, the Life Foundation continues to provide support for people living with HIV/AIDS (Life Foundation, 2015). The Life Foundation would later become a major player in the establishment of Hawai'i’s SEP.

In 1985, Hawai'i’s AIDS Task Group was established. This group materialized because there were already several individuals who were interested in and working on AIDS issues. Initially, this group was called “the HHHH” (the 4 Hs)—Hemophiliacs, Homosexuals, Haitians and Heroin—however, the name was soon changed because “it was said that was really not a good acronym for it” (K. I. 11). The name was changed to the “Hawai'i AIDS Task Group, and it became very active and we literally had individuals representing all four of the major islands

that came together" (K. I. 11). Further, K. I. 11 stated, "The Hawai'i AIDS Task Group was instrumental in opening up the whole State of Hawai'i to deal with HIV/AIDS."

Dr. M. Diamond, a University of Hawai'i at Mānoa professor, was chosen to be the Executive Director of the Hawai'i AIDS Task Group, and the meetings were held monthly on campus at the University of Hawai'i (K. I. 1; K. I. 2). The Hawai'i AIDS Task Group's meetings became a "brainstorming place where people from the community could come together on a monthly basis and talk about all the AIDS-related issues from the legislative standpoint, from a public standpoint, from a legal standpoint" (K. I. 2). Another K. I. reported the Hawai'i AIDS Task Group included "people from the University, people from the military, everyone who was addressing the nature of AIDS" (K. I. 3). K. I. 2 described the Hawai'i AIDS Task Group as made up of "different voices from different groups," including importantly "law enforcement and legislators." Additionally, K. I. 2 acknowledged that Hawai'i at that time had some "progressive police officers."

The presence of a police officer at these meetings represented the growing concerns of the Honolulu Police Department (HPD). The HPD realized it had limited knowledge on how to deal with processing suspects that were HIV positive. In 1985, the first known incident of processing a person with HIV was dealt with by having the officers 'draw toothpicks' to see who would be the officer to complete the process, which included taking photographs, fingerprints, and putting the suspect in a cell. The officers who did not draw the short toothpick were told to leave the area (K. I. 17). Lack of knowledge had created fear in the department, and a letter of concern regarding the need for proper police training was sent to the Chief of Police. The response from the Chief of Police to the writer of the letter of concern was, "Fine, you see a problem; you see there's a need for a solution. You do it" (K. I. 17). Training, education,

practical equipment, and different ways of patting people down evolved as a way to keep officers healthy and safe. In addition, the female police officer who wrote the letter of concern that stimulated change in the HPD was appointed the law enforcement liaison for the Hawai'i AIDS Task Group. This young progressive police officer started attending all the Hawai'i AIDS Task Group meetings (K. I. 17). Having the support of the HPD was incredibly important to the Hawai'i AIDS Task Group because it provided a medium: a way to "work from the inside, and get them [HPD officers] to understand the benefits of needle exchange and not arrest people for paraphernalia" (K. I. 2). This same police officer would later accompany Aaron Peak, with his outreach work, in Chinatown, Honolulu, which will be detailed later in this chapter.

One K. I. acknowledged that during the Hawai'i AIDS Task Group meetings "everything was open and was able to be discussed, so we tried to come up with, you know, best practices, but we listened to everyone who was there" (K. I. 2). "Although the Hawai'i AIDS Task Group was not a government agency, it was a recognized entity that brought community leaders and voices into the dialogue" (K. I. 2). "We were looking at how to reduce AIDS transmission. And that was the only aspect that we were concerned with" (K. I. 11).

Meanwhile, on Maui, Dr. John Lewin, a physician, was becoming increasingly aware of the health care needs of a growing population of HIV-positive people in the community, as one of his first patients had HIV (K. I. 22). As a result, Lewin saw the need for anonymous testing sites, programs to provide care, and the importance of patient confidentiality for this clientele (K. I. 22). HIV had become a concern for this physician.

Other people in Hawai'i were becoming aware of and concerned about the growing HIV epidemic. The extent of the epidemic was clear in 1985 when the world was stunned by the death of American actor Rock Hudson, known as the 'heartthrob of the Hollywood Golden Age,'

who died of AIDS (Historian Insight, 2016). K. I. expressed feelings that HIV was a ". . . scary epidemic. This is happening on the Mainland. We don't want this to happen in Hawai'i. We don't want to let it get ahead of us" (K. I. 3). According to K. I. 5, "Our friends were dying." While K. I. 11 said, "I certainly remember the death toll, the literal death toll that was being taken and that was horrendous." K. I. 22 further stated,

> HIV was kind of a death sentence with a lot of stigma attached to it. It was a frightening disease. There was no therapy for it. Virtually everybody who contracted it died within a few years from fully manifested AIDS and so that was causing a lot of hysteria.

A consensus among the K. I. was the feeling that something had to be done to prevent the disease from spreading throughout the islands.

In 1986, John Waihee, another Democrat, became the first governor of Hawaiian ancestry since Sam King was selected as Territory Governor in 1953 (Info Grafik Inc., 2016; Soylent Communications, 2014). According to Neubauer (1993), "Hawai'i's quest to become a health environment began with the election of John Waihee as Governor in November 1986" (p. 1). Governor Waihee began his quest to address the health environment by appointing Dr. John Lewin as Hawai'i's Director of Health; he held the position until 1994 (K. I. 22; Neubauer, 1992). When Lewin was appointed, he had already practiced medicine in Hawai'i for ten years and came to office not only with a background in politics, but also with experience in the Indian Health Service (Neubauer, 1992). During his term as Director of Health, Lewin was described as being a young, very progressive leader, extraordinary energetic, dynamic, visionary physician committed to public health (K. I. 24; Neubauer, 1992; Nissen & Douglas, 2006).

As the Director of Health, Dr. Lewin was faced with a variety of serious community health concerns, among them “the spread of HIV and Hepatitis B, C, and the sharing of needles among people who were addicted to various drugs” (K. I. 22). According to Neubauer (1992), “Lewin’s dynamism was focused on an activist role for government in addressing social problems of which health was but one interrelated component” (p. 169). Governor Waihee and the Director of Health became part of a team “sympathetic toward the policy initiatives that were to occur” (Neubauer, 1992, p. 170). The change that was about to occur would help make Hawai'i the cutting edge in health care with the development of innovative HR programs and the formation of committees that would address the threat of HIV.

Meanwhile, the Hawai'i AIDS Task Group was still conducting monthly meetings and expressing their concerns, “And we thought, we know that there’s a large contingency of drug users in Hawai'i, how could we prevent the transmission among drug users to their partners” (K. I. 3). K. I. 22 identified feelings that there was a need to protect society, in general, because the infected PWID could transmit the disease through sexual relations. K. I. 17 noted, “One of the Surgeon Generals said this was a health problem. We have to deal with this as a health problem.” K. I. 22 expressed feelings that the ‘war on crime’ is not the way to deal with HIV. Rather, according to K. I. 22, that it was “more of a medical issue and trying to treat it as a crime, coalescing disease with other more associated morbidities and trying to reduce those associated morbidities, especially as HIV and the AIDS epidemic were heating up was pretty important.” Cost effectiveness was also identified during the discussions with the K. I., as in “the cost of HIV in terms of health care costs was also significant” (K. I. 22). The Hawai'i AIDS Task Group, according to K. I. 1, served as a precursor for the Governor’s Committee on AIDS (GCA)

because collaboration and coordination already existed in the community and the HIV community.

There was a consensus that it was time to bring these concerns up to the Director of Health (K. I. 5). A group of people presented these concerns as an issue that needed to be addressed by the Director of Health "with a great deal of passion" (K. I. 22). Subsequently, Governor Waihee was lobbied by the Director of Health and "various others that this was a HUGE issue that required a Governor's level of oversight, and he agreed to go forward with the committee" (J. C. Lewin, personal communication, Nov. 7, 2016).

In 1987, the GCA was formed: "The Governor really wanted to do something about HIV" (K. I. 24). The GCA was formed out of the need to address the growing concern regarding HIV/AIDS and "was created via Fiscal Appropriates Act 216, Section 53 of the 1987 state Legislature" (GCA Interim Report, 1988, p. 1). This GCA policy-making group was made up of 19 individuals who were appointed by the governor, including a hospital administrator, physicians, President of the Blood Bank, President of the Hemophilia Foundation, and representatives of Life Foundation, and the gay community (Lichty, 1990; Vogt et al., 1998). Although the literature consistently listed the number of GCA members as 19 individuals, a report submitted to the Governor identified up to 25 members (Governor's Committee on AIDS, 1992).

According to the GCA Interim Report (1988), the mission statement for this policy-making group was "to be a community and government-based body which develops and recommends public policy that assures the initiation, coordination, promotion, implementation and evaluation of the State Plan to address the AIDS crisis in Hawai'i" (p. 1). The key members of the GCA were Nancy Partika, M.P.H., as the Executive Director; Pamela Lichty, M.P.H., the

planner; and Nancy Kern, M.P.H., as the program specialist (GCA, 1989; K. I. 3). According K. I. 24, Partika "managed to bring together relatively high level people from almost every sector of society." The committee later divided into the following subcommittees: *Education, Human Services, Health Care* and *Epidemiology, Research* and *Control*. Examples of subcommittee participants were Reverend Pam Vessels (*Education*), Mario Ramil, J.D., later a Hawai'i Supreme Court Justice (*Human Services*), Steve DeMaggio, M.S.W. (*Health Care*), Dr. John Lewin the Director of Health and Dr. Kim Thorburn a 'prison doctor' (*Epidemiology, Research* and *Contro*l) (GCA, 1989; K. I. 2; K. I. 21). Thus, the GCA was dealing with HIV/AIDS on many fronts simultaneously.

The presence of Dr. Thorburn on the GCA reflected the growing concerns of the Hawai'i prison system regarding HIV/AIDS. A known IDU inmate died of Hepatitis B, the consequence of his risky behavior, and he had most likely contracted the infection while incarcerated (M. Thorburn, personal communication, October 2, 2016). According to Thorburn (2016), syringes and needles were not easily accessible and

> . . . were heavily shared and re-used. We'd hear stories about sharpening dulled needles on matchbook cases. We decided to offer preventive intervention to inmates who thought they may have been exposed to the deceased person through needle sharing and sent out a written notice inviting inmates to make an appointment to receive the prophylaxis. More than 100 inmates came forward. (Personal communication, October 2, 2016)

According to K. I. 21, the HR intervention SEP seemed to be a pretty obvious prevention approach at that time, perhaps a SEP in prisons would have helped save lives.

In 1987, HIV/sexual transmitted disease (STD) outreach workers out of the Waikiki Health Center, and funded by the State Department of Health, began working on the streets of

Waikiki and Chinatown in an attempt to build up trust with the PWID (K. I. 2; K. I. 5). According to K. I. 5, it took “at least a year before anyone would talk with me” and eventually the trust was gained. The purpose of outreach at that time was to provide HIV-STD education to sex workers, as well as to provide health information, condoms, alcohol wipes, and even little bottles of bleach, from the perspective that “we only need to make sure that the people that we knew who were using were being as safe as they could be” (K. I. 5). Providing bottles of bleach to keep PWID safe is a clear example of HR in action without being so labeled.

In May 1989, the GCA presented to Governor Waihee the *Implementation Plan for HIV in Hawai'i: Report and Recommendations of the GCA*. *Policy: HIV and Sterile Needles*. “The GCA recommends that the State of Hawai'i shall study the possibility of developing and implementing a program to provide opportunities for IV drug users to acquire or exchange sterile needles anonymously and at no cost” (GCA, 1989, p. 30). The recommendations from the GCA to Governor Waihee became another important keystone of Hawai'i’s SEP.

In 1989, another community agency was established to help deal with AIDs. The Community Health Outreach Work (CHOW) to Prevent AIDS Project was set up as a “contracted organization through the Research Corporation of the University of Hawai'i with the purpose of not only ‘working with peer educators,’ but also distributing condoms, safe sex education, and bleach kits” (Marten, Qui, Borthakur, & Whiticar, 2005, p. 159; additionally, K. I. 24; Lusk, 2015). Although Sena Gates was not only the person who started CHOW, she was also the first executive director for CHOW. Gates, a Democrat, had the reputation of being “very political, very savvy” (Altonn, 1998; K. I. 24). Gates was active in the community, and she founded Hawai'i Women’s Political Caucus and also was a member of the Community

Housing Resource Board Affordable Housing Alliance and the city's Special Needs Committee (Altonn, 1998; K. I. 24).

Elsewhere, in June 1989, an international AIDS conference was held in Montreal, Canada, with the theme of *The Scientific and Social Challenge of AIDS* (AIDS 20th International AIDS conference Melbourne, Australia, 2014). Interested individuals from Hawai'i attended this conference (K. I. 24). Other attendees included the national leader of the needle exchange movement, Dave Purchase, who would later be invited to Hawai'i to help with Hawai'i's SEP (Hevesi, 2013; K. I. 21; Purchase, 2012). Also in attendance was Aaron Peak, who later became one of the driving forces behind Hawai'i's SEP (Purchase, 2012).

Influence of Two Men: Peak and Purchase

A combination of personalities helped shape how HIV/AIDS was managed in Hawai'i, and the arrival of Peak and Purchase added further depth to the picture. There is limited data on when Peak first moved to Hawai'i; however, there is some reference to his arrival in the mid-1980s because of his attendance at a Hawai'i AIDS Task Group meeting (K. I. 17). Also, there is no reference to the year Peak left Hawai'i; although, it is known that he moved to India where he "worked with Mother Theresa" (K. I. 17) and started a needle exchange in Kathmandu (N. Crofts, personal communication, June 1, 2016). There is also no specific date when Purchase arrived in Hawai'i to help Peak; yet there is reference to his arrival following the 1989 AIDS conference in Montreal, Canada. Crofts (2016) said,

> I heard about a man [Dave Purchase] 'who started the needle syringe program on the streets of Tacoma,' and he took me to the first North American Syringe Exchange Program in Tacoma in 1990. That was where I first met Peak. . . . and this wonderful

> little bit of drama where Peak said. . . . 'I had a dream.' (Personal communication, June 1, 2016)

Those were the words of Peak when discussing how he had first become involved in SEPs. Peak, originally from San Diego, was considered a wild child who experimented with different drugs (N. Crofts, personal communication, June 1, 2016). Peak's friend, Purchase, and K. I. 17 described him (Peak) as

> . . . around 6 feet tall, 220 pounds, with reddish hair and a creamy complexion; he had a gold tooth; he had a heart for people; he was just a ball of light; he was just very, very real, very compassionate, very loving; he was fascinating, bright eyes, a great smile, and had very unusual, long, tubed shaped earrings, an incredibly warm spirit.

Peak's partner died from HIV as a result of exposure to IDU. Peak, himself, was infected with HIV and spent his life trying to prevent others from contracting the same disease (N. Crofts, personal communication, June 1, 2016; K. I. 17). In Peak's words, "I wasn't out to change anything. HIV found me; I didn't find HIV" (Crofts & Purchase, 2012, para. 7).

Although there is no reference to a date when Peak began outreach work in the community, there is reference that he was indirectly funded to do the outreach work through the Life Foundation, an organization dedicated to stopping the spread of HIV and AIDS (K. I. 5; K. I. 23; K. I. 24). Peak would obtain condoms from the State Health Department and, in turn, give them out to anyone who wanted them (K. I. 2). It was at this time that HIV-STD outreach workers, who began outreach in 1987, were also on the streets alongside Peak. The Life Foundation and the State Department of Health were working toward a common goal: harm reduction, and decrease HIV/AIDS among drug users.

Purchase was a well-known advocate for handing out sterile syringes to prevent HIV transmission (Hevsi, 2013). In 1988, Purchase was responsible for starting the first legal needle exchange program in the United States in Tacoma, Washington. Purchase was described as a rather tall, bearded biker, often wearing a black leather jacket; he would set-up a fold-up chair, and a television table, on a street close to a site where known heroin users frequented, and it was there he distributed equipment such as syringes, bottles of bleach, and condoms (Hevesi, 2013). Though it was not officially sanctioned by the government and did not receive financial backing, there was support from the Tacoma police force and the Mayor, and also the Tacoma county health department (N. Crofts, personal communication, June 1, 2016; Hvesi, 2013).

After establishing a working relationship, Peak invited Purchase to visit Hawai'i, and Purchase brought him (Peak) syringes. Peak then started a quiet underground exchange in Honolulu's Chinatown, out of what was called the Rubber Room at 61 N Hotel Street, which was funded and operated by the Life Foundation (Vogt et al., 1998). The Rubber Room was a place where sex workers and other people could come and relax for a while and get information and referrals (Purchase, 2012). "It was sort of a respite for prostitutes . . . gave them condoms and other kinds of stuff" (K. I. 23). Having an HPD officer on the Hawai'i AIDS Task Group demonstrated the importance of having police support. According to K. I. 17, the officers and plain-clothes officers unofficially "agreed to give [PWID] safe passage" to the Rubber Room. The Rubber Room was an example of HR in action: PWID were treated non-judgmentally, and educational material was dispersed as a way to keep the PWID as safe as possible, and all without expecting the PWID to stop using drugs.

A picture, probably from early 1990s, that was taken outside the Rubber Room "showed the profusion of needles that were around" (K. I. 11). According to two K. I.,

> We went up onto the roof and there was . . . the diaper and the needles and that . . . the picture was made into a poster that showed needles being discarded and a baby diaper and the legend on the photo was 'The Point is to Save Lives.' (K. I. 2; K. I. 3)

In an attempt to bring the underground syringe exchange to the surface of public knowledge, the Life Foundation approached Keith Kaneshiro, Honolulu City Prosecutor, with a plan to distribute sterile syringes with the proposed site for the program to remain at the Rubber Room (K. I. 2; Lichty, 1990; Life Foundation, 2015). Since Peak had been threatened with arrest if he continued operating the underground exchange, the only way to have an exchange was to make it legal by legislation. The threats of arrest motivated a move towards a legal SEP in Hawai'i (Purchase, 2012).

Plan: Syringe exchange program. In the summer of 1989, HIV was still a somewhat new threat to the community. K. I. 3 discussed how a plan was formed by the GCA to solicit support:

> . . . the purpose being to draft a bill to propose this syringe exchange program for the State of Hawai'i, support it with funding by the State. . . . The first meeting was held in a room in the Department of Health Building on Punchbowl Street, Honolulu, Hawai'i.

There were approximately 25 people in attendance at the first meeting (K. I. 3; Lichty, 1990) with representatives from the medical community, the Life Foundation, Hawai'i Medical Association, State Director of Health, Hawai'i Nurse Association, Hawai'i Chapter of the American Academy of Pediatricians, and the civic community (K. I. 3; Vogt et al., 1998). Dr. G. Starbuck, a pediatrician with the Hawai'i Medical Association, was in attendance and was concerned that the HIV epidemic was moving from the PWID to their sexual partners who, in turn, could transmit the virus to innocent children (K. I. 9).

K. I. 9 stated,

> At the time there was a very conscious discussion among HIV advocates about the consequence to innocent victims, because the implication was that PWID 'deserved what they got,' if you will. And they were choosing their path and choosing to put themselves at risk. But their sex partners and their children were not. So this concept of the innocent victim, especially the children, came up and was politically very palatable.

The concern of innocent victims remains a concern today (Des Jarlais et al., 2009). According to Drash and Blau (2016), "Babies—are the youngest, most vulnerable victims of a raging epidemic" (p. 2).

This same group of 25 people assembled with the shared purpose of decreasing HIV transmission through legislation, and people came because they were interested in this idea. According to K. I. 3, there was only one person at this meeting who stated, "I really don't think this is going to happen," and suggested waiting for one more year before implementing the plan. However, there was the attitude that "If you got a very simple and relatively inexpensive way of decreasing HIV transmission among drug users you should do it" (K. I. 3). This group of 25 people "wanted to see it happen. And even though this whole group was basically as one, we really wanted to write this bill and have it passed in the Legislature" (K. I. 3).

Subcommittees emerged from this first meeting of 25 interested people. These sub-committees differed from the larger GCA subcommittees (*Education, Human Services, Health Care and Epidemiology, Research* and *Control*) because there were only three: *Community at Large* (legislature) led by P. Lichty because of her familiarity with the state legislature; the *Medical Community* led by N. Partika, and the *Media Committee* led by N. Kern (K. I. 3). The *Community at Large* committee had political support, and, according to K. I. 21, there were

"allies in the legislature who were open to harm reduction vs. punishment and criminality." The third subcommittee, the *Media Committee,* focused on providing weekly or bi-weekly stories to news outlets, along with helping to develop a five-episode series on needle exchange that was broadcast on a local TV station. During this same first meeting, "the group chose the name 'Sterile Needle Exchange Coalition'" (Lichty 1990; Peak, 1990).

Results: Syringe exchange program. The first attempt at bringing the bill for the SEP to the Legislature failed. "We thought that we would try to do a very low key bill and just kind of, not exactly, sneak it through, but try not to raise too much, call too much, attention to it" (K. I. 9). Following this initial defeat, the GCA decided to "create a coalition and come at it from a totally different, transparent angle" (K. I. 9).

In the fall of 1989, the bill was revised to include wording so the "State Director of Health would have authority to initiate a needle exchange program" (Peak, 1990, p. 4). The Governor would name the State Director of Health, and the program would be supported and managed by the Department of Health (K. I. 24). In the winter of 1989, a letter written by Dr. Lewin acknowledged the Governor's support of the Department of Health, "making every effort to attempt to decrease the transmission of the HIV virus, through all avenues possible, including education, testing, counseling, drug treatment and needle exchange" (Peak, 1990, p. 8).

By the time the next SEP bill was introduced in Hawai'i State Legislature in January 1990, it was a topic of open discussion (K. I. 3). According to Vogt et al. (1998), "The coalition decided to pursue an initial pilot syringe exchange program and to refrain from seeking state funding for the program in the legislation" (p. 1403). In addition, evaluation criteria were implemented "in an effort to respond to concerns about the impact of the program" (Vogt et al., 1998, p. 1403). Further, an oversight committee was "appointed by the Director of Health to

conduct a thorough and unbiased evaluation of the program" (Lichty, 1990, p.14). Hawai'i's Governor Waihee signed into law a bill authorizing the nation's first state-approved needle exchange program on June 25, 1990 (Adamski, 1997; Lichty, 1990).

In 1990, the SEP officially began in the Rubber Room on 61 N Hotel Street, in downtown Honolulu. "When the law had passed, Peak, an outreach worker with the Life Foundation, and without asking permission from anybody, decided the Life Foundation should be the one to start the SEP" (K. I. 23). There was no further threat of arrest and the SEP now had official support from the HPD. According to K. I. 17, "Law enforcement and public health go together. It's important to remember that, one's a thumb, one's a pinky, but they are still both valuable, when you don't have one, you're missing something." Having HPD involved was incredibly important.

In 1992, according to Vogt et al., (1998), "Anticipating the end of the pilot program, the coalition returned to the legislature and proposed an act that would authorize the Department of Health to establish an ongoing syringe exchange program in Hawai'i" (p. 1403). At the same time, but under a separate bill, the AIDS omnibus bill addressed funding for the SEP (Vogt et al., 1998). The result of these bills was the authorization for the Department of Health to establish an ongoing state supported SEP in Hawai'i (Vogt et al., 1998).

Meanwhile the CHOW Project, headed by Sena Gates, continued to be actively involved with HIV prevention and peer education and still was supported by a grant through the Research Corporation of the University of Hawai'i (K. I. 23; K. I. 24). During her time as Executive Director, Gates applied for and received a National Institute of Drug Addiction grant in 1992 "to do studies on Outreach and Prevention for Injection Drug Users" (K. I. 24). The CDC "funded a lot of the initial HIV prevention. It was sort of an add-on to sexual transmitted disease (STD)

and that is how the Branch was formed. STD and HIV were glommed together and it became a Branch" (K. I. 24). This grant "was the money that really funded the CHOW project initially (K. I. 24).

Once CHOW received the grant to do outreach studies in 1992, outreach workers were sent into the community and found themselves alongside the HIV/STD outreach workers [funded by the Department of Health]. There was "a little bit of tension," and there was a feeling the leader of CHOW [Gates] had the idea CHOW would be the "overall agency" in outreach. K. I. 5 expressed the feeling, "We are out there in the middle of the night and they were in the office during the day." The CHOW outreach workers were just learning how to do outreach work and there was a 'divide' and a 'big learning curve' for all involved (K. I. 5). CHOW was in the process of data collection and the HIV/STD outreach workers were in a position to help them obtain their data (K. I. 5). CHOW would later find funding more difficult to obtain because of the research component and a need to change its focus from research to a SEP would emerge.

Extending the contract for CHOW became more difficult because of the repeated need "to get the Governor's agreement" (K. I. 24). Although CHOW did have a research component to it, it was not a research program (K. I. 24). The consensus was that it would be preferable for CHOW to be its own 501c3 nonprofit organization [which did not occur until 1999] allowing it to not only bid on proposals with the option of pulling money from other sources, but also to gain more independence as an organization (K. I. 24).

When funds became available for the SEP, it was CHOW that was in a position to submit a proposal to the Department of Health and to be able to get the funding for the proposal (K. I. 23; Marten et al., 2005). In 1993, while still under the leadership of Gates, CHOW took over the responsibility of the SEP. K. I. 24 said Gates took CHOW "through the initial startup days

where things were still pretty raggedy." A discussion with a K. I. addressed the move of the [SEP] contract from the Life Foundation, "They just moved it over to CHOW" (K. I. 23). Another K. I. stated, "I think people felt in those days that CHOW kind of stole the SEP from Life Foundation and from Aaron" (K. I. 24). However, "HIV was exploding and it was way more than enough work for the Life Foundation to do" (K. I. 24). The Life Foundation worked with men and women infected with HIV through sexual transmission; while CHOW, "really became the sort of the go to organization for injection drug users" (K. I. 24). CHOW, in 1993, became the lead for the state SEP (Vogt et al., 1998). During Gates' time as Executive Director, up to and including 1998, a total of 527,412 syringes were exchanged.

Suzette Smetka was the next Executive Director of CHOW, from 1999 through to 2009. During Smetka's term, 4,233,432 syringes were exchanged. According to K. I. 24, Smetka took CHOW "through the stage of really making it secure, having proper budgets, proper training, and proper disposal." There was only one more executive director between 2009 and 2012. The current Executive Director, H. Lusk, for the CHOW project took over the position in 2012, and according to K. I. 24, this Executive Director "has a much broader view of public health and different social service agencies." Currently, CHOW remains contracted by the Department of Health for looking "at individuals not in disease silos but according to their behavior being potentially at risk for multiple infections that could include HCV, HBV, HIV, [and] STDs" (K. I. 24).

The chronological framework of the events leading up to the creation, development, and growth of the SEP was presented in this section, helping to answer the first research question. This section further demonstrated how a group of well-linked people, united by a common goal,

can truly make a big difference in a small state, which resulted in Hawai'i having the first state funded SEP.

Positive Perfect Storm

The word “storm” conjures up a feeling similar to a whirlwind, a force that is tumultuous or energetic. K. I. 3 referred to the GCA as a “perfect storm in a positive way.” The term ‘positive perfect storm’ had two main aspects: (1) dynamic personalities at the individual level, having either past or present connections with the SEP, and (2) dynamic personalities that influenced the community.

K. I. were consistent in identifying individuals who were instrumental in forming the SEP as dynamic advocates for the at-risk community. Consistency was identified as a major contributor to the development and sustainment of the SEP. Having a strong, progressive Director of Health (Dr. John Lewin) was also a major asset. Many of the individuals who developed the program are even now involved with it in some fashion; therefore, consistency continues today. The words used by K. I. included:

> . . . a large cadre of very positive, amazing, go-getter kind of people, passionate, excitable, dedicated, aggressive people in positions of power in the Department of Health, what a phenomenal group of people, and without the GCAs there wouldn’t have been a SEP.

Also, K. I. credited the strength of the ongoing program to a well-known researcher, Dr. Don Des Jarlais, whose research highlighted the need for SEP to prevent the spread of HIV/AIDS (Adamski, 1997; Des Jarlais et al., 2009; Des Jarlais et al., 2013; Des Jarlais & Semaan, 2008; Vogt et al., 1998).

Additionally, several K. I. described the current leader of CHOW as "a shining star" and "amazing beyond words." Further, K. I. felt a sense that the CHOW leader treats staff members as indispensable, and she does everything possible to keep them. They (K. I.) emphasized that the leadership of the organization has been very critical to the success of the program, and they indicated that CHOW is something to be proud of. According to the K. I., there is a feeling "of taking responsibility for yourself, your family, and your community, and then you are doing something positive."

In the following section of this chapter, major themes and barriers are identified. Additionally, this section provides an explanation of how the SEP in Hawai'i incorporated the five principles of HR.

Major Themes and Barriers

Out of the discussions with the K. I. (n=22), two major themes emerged: *fear*, and *knowledge is power*. The identified theme, *fear*, included barriers that had the potential to impede the delivery of the SEP. A concern was identified over innocently contracting a blood borne disease; therefore, safety is a barrier and a fear—it is a concern for the outreach worker and also the community.

Theme 1 and barriers: Fear. Fear is a result of personal experiences, real or imagined, and is greatly influenced by an individual's surrounding environment and can be considered a barrier. The HIV virus was scary—"friends were dying"—and it was impossible to distinguish the infected from the healthy since the virus could be contracted in a seemingly innocent way, such as picking up trash and receiving a needle stick from a discarded, used syringe carrying the deadly virus (K. I. discussions). Fear influenced people's feelings about HIV/AIDS, and two

types of fears were culled from the K. I. discussions: (1) fear of the known, and (2) fear of the unknown.

The majority of K. I. identified safety as a concern for not only the outreach workers, but also the community. There was a real fear of contracting HIV though needle stick injuries. One K. I. identified how some members of the community just did not understand how getting someone clean equipment equaled a safer community. Another K. I. identified that when the program first began, there was a feeling that the program needed to keep a low profile.

Other barriers also emerged from the discussions. More than one currently involved K. I. pointed out that stigma is still very real; it is still the biggest barrier within the community, even though the community is now more educated about HIV/AIDS against PWID. K. I. 6 reported recently feeling physically threatened by a member of the community:

> I was just in the courthouse the other day and a lawyer actually approached me and told me that he thought I was one of the biggest enablers he knew, and if I was a man, you know, he would deal with me.

Therefore a major barrier related to stigma, and also a safety concern, was the physical threat made to a current outreach worker. Feeling threatened was not only isolated to K. I. who are *currently involved* with the CHOW project. Rather, K. I. with *past involvement* indicated when they were first starting out with the SEP there was a feeling of publically battling substance abuse treatment programs, to the point the outreach workers felt threatened.

Stigma is clearly identified as a major barrier (K. I. 6; K. I. 9; K. I. 10; K. I. 13; K. I. 15; K. I. 20; K. I. 22; K. I. 24). Identified by K. I. is the problem of finding a permanent site for the CHOW because landlords are unwilling to rent for a variety of reasons including fear, and the stigma associated with the underserved populations that use the services of the CHOW project

(K. I. 1; K. I. 24). Stigma is very real as it affects PWID. According to Diep (2016), "Stigma isolates people, discourages people from coming forward for treatment" (p. 2). However, according to K. I. 10, CHOW currently has "low threshold services," which help make their services easily accessible for the PWID.

Funding cuts to the CHOW program is another identified barrier. As a result of these funding cuts, fewer supplies are available for the vulnerable population of PWID (K. I. 6; K. I. 7; K. I. 8; K. I. 16; K. I. 18; K. I. 20; K. I. 24).

The barrier identified by more than one K. I. was the law regarding *one-for-one* exchange. K. I. stated there were clients that requested syringes but did not have any to exchange, and the current policy is a *one-for-one* exchange—a client may only receive an amount equal to that turned in. The current distribution law needs to change because some clients may not be able to carry syringes on the bus to the exchange, or perhaps a family member has discarded them, or they may be afraid to carry them if they are living on the streets. Without access to clean sterile syringes, a PWID may resort to using a used syringe.

Theme 2: Knowledge is power. One major finding is threaded throughout this study—education is common sense. From the K. I. interviews, two themes were identified that relate to *knowledge is power*: (1) the GCA recognized the need for educating the public when the SEP was in the process of being formed, and (2) individuals that engage in risky behaviors may be encouraged to change their behaviors with education. With education, a person is empowered to make healthier choices.

According to the GCA Interim Report (1988), "The most effective measure for controlling the spread of HIV is felt to be education of the public, especially those individuals at greater risk" (p. 3). In the *Report and Recommendation of the Governors Committee on AIDS*

(1992), 27 policies were identified to provide a blueprint for HIV/AIDS policies in Hawai'i. Of these 27 policies, 10 specifically identified the need for education, and an additional 12 identified the need for education in either their rationale or their goals. Therefore, it is apparent that education plays a colossal role within the GCA's policy recommendations.

One of the K. I. mentioned that the current CHOW leaders are able to reach out and educate the police force and other agencies. Through education, partnerships are created, and there is a sense of a close connection with the Department of Health. Another K. I. described building a relationship with the PWID, thus links with social services could be completed. One K. I. spoke about the planning stages of the SEP and how there were allies in the legislature who were open to learning about SEPs. In addition, there was a widespread belief in the community that PWID did not care about themselves or about their health; however, CHOW leaders are trying to change this impression through education.

Hawai'i's Syringe Exchange Program: Harm Reduction in Action

The last portion of this study includes the deductive directed content analysis of Hawai'i's SEP reports, and also includes discussions with the K. I. of their perceptions of how the SEP in Hawai'i incorporated the five principles of HR: pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals. The findings help answer the second research question: *How has the syringe exchange program in Hawai'i incorporated the principles of harm reduction*?

Content analysis: Principles. Part of this study was a retrospective deductive directed content analysis conducted on Hawai'i's SEP's annual reports from 1995 up to, and including 2015, no annual report was excluded. For the year 2016, the CHOW Operational Manual was

used in place of the 2016 annual report because the report for 2016 was unavailable; therefore, no number of syringes is documented for 2016.

The main strength of using a deductive directed approach to content analysis is that existing theory can be supported and extended. In this second part of the study, the theory of HR was tested against data from Hawai'i's SEP annual reports to identify how the SEP incorporated the five principles of HR. The number of pages for these annual reports ranged from 15 pages in length for one report to 93 pages in another report. Over 1500 pages of reports were analyzed in a qualitative oriented manner; therefore, Mayrings (2000) approach using a methodological controlled content analysis helped "to support (not replace) steps of text interpretation" (p. 6).

The use of categorical coding for each of the five HR principles was conducted: first by providing definitions for each category or principle, and then coding rules were formulated for each category to determine under what circumstances a text passage could be coded (Table F3.1). Examples of the HR principles were extracted from the annual reports based on the coding rules, until data saturation for each year was reached. Each example extracted was used only once. In subsequent reports, if the wording was exactly the same as a previously stated sample it was not extracted and coded, thereby eliminating duplication and biased results.

To address validity, a sample of coding for each category was discussed with a PhD prepared neutral researcher: first, the researcher was provided the definition and coding rules for each principle, and then example texts were provided from the annual reports. The results were compared and no variation was identified. Following this discussion, no additional refinements were required for the development of this study. Once the data was coded, the interpretation focused on frequencies of the principles across the years.

From the 20 years of reports, 284 text passages were identified using the definitions of the five HR principles. Finally, the SEP's annual reports were analyzed and categorized (Mayring, 2000; Roberts, 2010). SPSS Version 23 (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp) was used to calculate frequencies and percentages regarding the use of the five principles of HR from 1995-2016.

The frequency procedure in SPSS was useful in describing the status of the 20 annual reports in this study using a moderate number of categories; the categories were the five HR principles: pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals. The purpose of this section of the study was to identify the percentages and frequencies of the five HR principles from Hawai'i's SEP annual reports. Although there was no specific research question for this type of analysis, the main interest was simply to determine what the percentages and frequencies of the five principles were associated with each annual report.

From 1995-2016, the most common HR principle was priority of immediate goals 35.6% (n=101), followed by balancing costs and benefits 21.5% (n=61), and third was focus on harms 16.5% (n=47). Humanistic values were identified 14.8% (n=42) of the time, and the fifth principle was pragmatism 11.6% (n=33) (Table G4.1; Table H4.2).

The next step was to determine if there was a difference in the percentage of HR principles identified in the text by every five years. This identified the frequency a text met the coding rules to be placed under the category of one of the five HR principles, and also identified the percentage over five years (Table I4.3).

From 1995-1999, the most common HR principle was balancing costs and benefits 31.3% (n=25), followed closely by priority of immediate goals 30.0% (n=24), and third was pragmatism

15.0% (n=12). Focus on harms was identified 12.5% (n=10) of the time, and the fifth principle, humanistic values, 11.3% (n=9).

From 2000-2004, the most common HR principle was priority of immediate goals 33.8% (n=23), humanistic values 20.6% (n=14), and balancing costs and benefits 19.1% (n=13). The two principles, focus on harms and pragmatism, both were identified as ranking 13.2 % (n=9).

From 2005-2009, the most common HR principle was priority of immediate goals 45.2% (n=14); second was focus on harms 29.0% (n=9), and balancing costs and benefits 19.4% (n=6). The two principles, pragmatism and humanistic values, were identified as ranking 3.2 % (n=1).

From 2010-2014, just the same as 1995-1999, the most common HR principle was balancing costs and benefits, 50.0% (n=9); second was priority of immediate goals, 27.8% (n=5); the third principle was focus on harms 16.7% (n=3), and the fourth principle identified was humanistic values, 5.6% (n=1). The principle, pragmatism, was not identified during this period.

From 2015-2016 priority of immediate goals 40.2% (n=35) again ranked first. The second principle identified was humanistic values 19.5% (n=17), and third was focus on harms 18.4% (n=16). The fourth principle identified was pragmatism 12.6% (n=11), and fifth was balancing costs and benefits 9.2% (n=8).

To further visually simplify the comparison of data, a bar chart was used to compare the data and display the results of the frequencies of the five principles over five years (Figure 4.1).

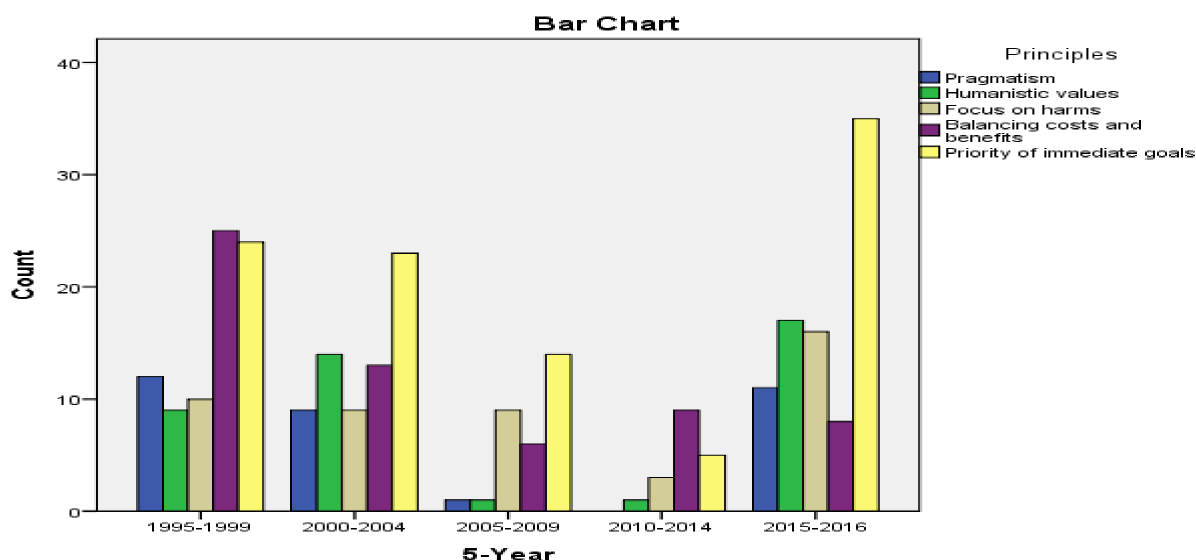


Figure 4.1. Bar chart of common HR principles by five years. The five HR principles summarized by year, and *priority of immediate goals* was consistently the most frequently cited HR principle. These results are similar when compared to the 20 years of data.

Finally, the number of syringes exchanged was compared over the 20 years (Table J4.4) and then compared with the five principles (Table K4.5). Clearly, there has been a significant increase of syringes exchanged from the year CHOW began documenting the number of syringes exchanged in 1995 (n= 75,230) to 2015 (n= 959,237). However, there was no correlation between the five principles and the number of syringes exchanged.

Key informant discussion. The K. I. discussions for this section were conducted with 12 participants who have current connections with the SEP. To learn about the K. I. perceptions on how the SEP has incorporated the five principles of HR in Hawai'i's SEP, three questions from the Key Informant Questionnaire Guide (Appendix E) were used: (1) what HR principles that you know of have been, or are currently, incorporated in Hawai'i's SEP and in what way; (2) what do you feel was the most influential principle of harm reduction and its relationship with

the Hawai'i SEP in the past, and (3) what do you feel is the most influential principle of HR and its relationship with the Hawai'i SEP on the present, or future.

The following definitions for the five principles were provided: (1) Pragmatism: The act of taking a commonsense approach when dealing with the high-frequency rate of risky drug use; (2) Humanistic values: Treatment of individuals as worthy of the same dignity and rights as any other member of society, with respect, and without judgment; (3) Focus on harms: The act of viewing the extent of drug use as less important than its adverse consequences; (4) Balancing costs and benefits: The act of identifying, measuring, and assessing the relative importance of drug-related problems and their associated harm, and (5) Priority of immediate goals: The act of identifying a fact or condition that is more important than another (Appendix E).

K. I. agreed that all five principles have been, or are currently, incorporated in Hawai'i's SEP. K. I. 1 expressed feeling the original principle was costs and benefits; however, under the current Executive Director Lusk, all of the principles are incorporated in the SEP. The consensus among the K. I. was that humanistic value was a predominant principle. One K. I. indicated feeling that "unconditional positive regard" exists, and that "every person is valued and respected" (K. I. 10). K. I. 5 stated, "We don't judge our clients with what they do," and K. I. 19 stated, "They are not bad people; they just do bad shit sometimes." K. I. 1 felt the one core value that has infused over time is humanistic values and that looking at the person using drugs or using needles is not a second class worthless individual, but is treated, shall be treated with the same dignity.

The K. I. agreed that priority of goals was incorporated in the SEP, and basically was looking at what the most urgent need for the PWID community was, and then meeting those needs (K. I. 6; K. I. 8; K. I. 10; K. I. 13; K. I. 14; K. I. 18). K. I. 18 provided the examples of

Naloxone and wound care services for addressing the most urgent needs for some of the PWID. Further, K. I. 18 reported how an PWID had recently been released from prison with a severe infection of the leg, but rather than a priority of treating the infection, this PWID's priority was "getting a clean syringe." Hawai'i's SEP incorporates the principle focus on harms simply by helping to alleviate harm through syringe exchange, and as K. I. 13 summed it up, " It's not about you; it's about them."

When the K. I. were asked the question, "What do you feel was the most influential principle of harm reduction and its relationship with the Hawai'i SEP in the past?" the predominant response was humanistic values. K. I. 13 expressed how just listening to the stories of PWID changed the view of addicts, "They weren't just addict. They became something. They had a story, and your view and your feelings change because now they're not just a face, they're someone you can relate to." K. I. 19 stated, "Everyone's human." Pragmatism was also identified as an influential principle of HR in the past. Words expressed were "it was a common sense approach" (K. I. 8); "it's pragmatic, you know, and that they use our program" (K. I. 14; K. I. 19), and "most important is that they can have actually access to clean syringes" (K. I. 6).

When the K. I. were asked the question, "What do you feel is the most influential principle of HR and its relationship with the Hawai'i SEP on the present, or future?" the predominant response was humanistic values. K. I. 7 indicated the importance of treating "the individuals as worthy human beings; they're not pieces of crap." K. I. 10 expressed the importance of taking those humanistic values into the community and helping others "see that our participants, people who inject drugs could be your neighbor, your auntie, your mother. It could be you." Although costs and benefits was not a predominately identifiable principle, K. I. 10 indicated, "By preventing one HIV infection, we pay for our self."

Summary

This mixed-methods study focused on discussions with K. I., historical events obtained from the literature, and deductive directed content analysis of 20 years of reports on Hawai'i's SEP. A chronological framework of the events leading up to the creation, development, and growth of the SEP in Hawai'i was presented. Barriers were identified that have the potential to impede the delivery of the SEP in Hawai'i. Limitations for this study and recommendations that could strengthen the SEP and further improve public health in Hawai'i will be discussed in Chapter 5.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

The purpose of this study was to analyze the factors leading to the creation, development, and growth of Hawai'i's syringe exchange program (SEP); to identify barriers that impede the delivery of the SEP, and to examine whether the Hawai'i SEP followed, and is following, harm reduction (HR) principles (Appendix E). Using a HR approach with people who inject drugs (PWID) implies using principles, concepts, strategies, interventions, programs, and policies as a way to reduce the serious consequences of risky behavior related to injection drug use (IDU) (Ball, 2007; Harm Reduction Coalition, 2015; Newcombe, 1992; Weatherburn, 2009). An example of using a HR approach in Hawai'i is its SEP. This chapter ties together the findings from the previous chapters and suggests some ways in which health policy in Hawai'i could be set up to improve overall health in Hawai'i, especially for PWID.

The homogenous sample of 22 key informants (K. I.) was recruited through a combination of purposeful and snowball sampling. Initially the K. I. were publicly identified as having direct experience with either the formation of Hawai'i's SEP or being presently involved with the Hawai'i SEP; snowball sampling occurred when the purposeful sample of key informants identified additional K. I. participants. The main results were an identification of factors that led up to the creation, development, and growth of Hawai'i's SEP. Two major themes—*fear*, and *knowledge is power*—were culled from the discussions.

Creation, Development, and Growth of Hawai'i's Syringe Exchange Program

Hawai'i is indeed unique; not only with its atmosphere, isolation, 'melting pot' of cultures, health care programs, but also its political setting of a one-party state (Chambers, 2005; DeGiacomo, 2013; Info Grafik, 2016; Montes, 2015; Neubauer, 1992; Neubauer, 1993; Rucker

& Goldfarb, 2014). K. I. were consistent in reporting what they felt were the factors leading to the creation, development, and growth of the SEP in Hawai'i. They described Hawai'i in the 1980-1990s as having a social setting right for the SEP, influenced by the progressive atmosphere of the state. None of the other 49 states can boast their health care program accomplishments quite like Hawai'i can. It is not surprising then to discover that Hawai'i passed the law to allow abortion as early as 1970, or that it had a television series on sex education, or of its creation of the Prepaid Health Care Act of 1974, or that it was home to the first state funded SEP.

It was interesting to find that K. I. identified Hawai'i as being a predominantly strong, single-party legislative state with the Democratic Party in control; the data in the literature also reflected this (Chambers, 2005; Hickey, 2013; Montes, 2015; Neubauer, 1992; Neubauer, 1993; Rucker & Goldfarb, 2014). According to Rucker & Goldfarb (2014), a "mostly one-party control has made Hawai'i an incubator for progressive policies" (p. 2). However, political factors alone were not the sole driving force, dynamic personalities also helped to shape Hawai'i's future in cutting edge health care programs.

Positive Perfect Storm

Dynamic personalities played a major role in helping to make Hawai'i unique with respect to its healthcare programs. The words used by the K. I. to describe the personalities behind the SEP included "a large cadre of very positive, amazing, go-getter kind of people, passionate, excitable, dedicated, aggressive people in positions of power in the Department of Health, what a phenomenal group of people" (K. I. 3). Moreover, according to K. I. 3, the 1985 AIDS Task Group was a major influence on the Governor's Committee on AIDS (GCA), and without the GCA there would not have been a SEP. It was not surprising when K. I. 3 referred to

the GCA as a “perfect storm in a positive way.” The dynamic personalities behind the SEP help to make Hawai'i unique. Simply put, this study cannot be generalized, nor can it have transferability because no other state has the same history as Hawai'i’s SEPs, and, further, it is not a representative sample of any other SEP in the United States.

Peak was just one dynamic personality whose influence was a driving force behind Hawai'i’s SEP. His partner died of HIV as a result of IDU, and Peak, himself, also had a history of drug use and was HIV positive. Peak was instrumental in setting up and operating an underground needle exchange, and he also helped establish the state funded SEP in Hawai'i. Similarly, Des Jarlais and Semaan (2008) acknowledged, “Many PWIDs have worked as peer educators to educate their peers about the risk of HIV and other threats” (p. 608). Further, Bryne and Albert (2010) also identified peers as playing an important role in the creation of underground needle exchanges and acknowledged, “It was drug users themselves who kick started the HR movement” (p. 110). It was interesting to discover that following the formation of Hawai'i’s SEP, Peak moved to India where he set up another SEP and was the recipient of the 1998 *International Rolleston Award for Harm Reduction* (N. Crofts, personal communication, January 1, 2016).

K. I. identified another dynamic personality as holding the current position of Executive Director, Lusk the current leader of CHOW. They described the current leader as a shining star and amazing beyond words. In addition, they described her leadership of the organization as being very critical to the success of the program.

K. I. identified *consistency* a major factor to the development and sustainment of the SEP. Many of the same people involved in the development of the SEP remain active today—in the political arena, serving on the SEP Board, serving on the oversight committee, or employed

with the Department of Health. Put simply, the large cadre of dynamic personalities played a major role in the factors that led up to the creation, development, and growth of Hawai'i's SEP, and consistency with these same personalities continues to influence the SEP. Hawai'i's SEP could not have materialized without the dynamic personalities that helped plan and develop the setting for the first state-funded SEP. The political and social demographic setting was right for the creation, development, and growth of the progressive policy of a SEP in Hawai'i.

Major Themes and Barriers

Two major themes emerged out of the discussions with the K. I. (n=22). The major themes were consistent among K. I., and the two major themes culled from the informant statements were *fear*, and *knowledge is power*.

Theme 1 and barriers: Fear. It was interesting, but not a surprise, to find the theme *fear* emerged out of the discussions with the K. I. Fear is a result of personal experiences, real or imagined, and is greatly influenced by an individual's surrounding environment. There was a real concern in the 1980-1990s about the increasing numbers of cases of AIDS, and it seemed that there was very little that could be done other than prevention. Fear influenced people's feelings about HIV/AIDS, and two types of fears were gleaned from the K. I. discussions: (1) *fear of the known* and (2) *fear of the unknown.*

Fear of the known. One K. I. reported feeling physically threatened by a member of the community. Another K. I. described how many of the people who used the services of the SEP would get mad at the outreach workers when told, "We can't give free needles; it's one for one exchange." Yet, another K. I. expressed feelings that outreach workers put themselves at risk, "It is [their] hands that are getting bloody." Another expressed the way the people who use CHOW's service live 'brings chaos to us' [outreach workers]. Additional studies that explore

fear for the outreach workers could offer insights on how to avoid burn-out for the workers, and provide education on how to deal with the real fear of safety. Jozaghi, Lampkin, and Andersen (2016) identified that PWID can obtain smoking paraphernalia, such as pipes, in vending machines. Most recently, April 13, 2017, *NBC News* reported that Nevada has become the first state to install syringe vending machines (O'Hara, 2017). As such, future studies should further consider vending machines as a way to distribute syringes, as this might eliminate some unnecessary fear over the current one-for-one syringe exchanges and decrease some of the chaos.

Also identified was the fear of the PWID seeking health care services for wounds resulting from implications from IDU. Similarly, other studies identified wound, or other health problems resulting from non-sterile injecting practices, as a concern for PWID (Bridge, 2010; Des Jarlais et al., 2015; Fraino, 2015; Harris & Young, 2002; Hilton et al., 2001; Islam et al., 2010; Ronan & Herzig, 2015; Strike et al., 2010). A registered nurse (RN) [volunteer] now accompanies the CHOW van twice a week, providing wound care to PWIDs. The RN sees approximately 20 clients per week, and she allows nursing students to accompany her and participate with the wound care needs of this vulnerable population as a way to educate future nurses. The RN reiterates that many of this population inappropriately use the hospital emergency room for services that she and her team can deal with on an outpatient basis (C. Wang, personal communication, February 5, 2017). This suggests additional research is needed to help eliminate unnecessary hospital visits and to gain a better understanding of the health care needs of this population. Further, the ANA (2016) position statement on SEPs and HIV identified the need to have nurses and qualified health care providers involved with SEPs as a way to help combat the consequences of IDU. Perhaps Hawai'i's SEP could follow Baltimore, Maryland's "Wounds on Wheels" and implement a mobile wound care clinic utilizing nurses and

other health care providers in conjunction with the current use of vans to provide HR services (Robinowitz, Smith, Serio-Chapman, Chaulk, & Johnson, 2014).

In the 1980s, there was a conscious discussion about the consequence to innocent victims because the implication was that PWID “deserved what they got, if you will, and they were choosing their path and choosing to put themselves at risk. But their sex partners and their children were not” (K. I. 9). Recently, used needles were found outside a Hawai'i public library, raising a growing safety concern for the children who use the library (Morales, 2015). The threat of a child contracting Hepatitis B (HBV), Hepatitis C (HCV), or HIV is a very real fear for parents. Additional studies also identify the concern of innocent victims (Drash & Blau, 2016; Fowler, 2010). As such, future studies should consider if variables at public locations, such as sharp containers or graphical placards, placed in strategic locations might influence PWID to discard used syringes in a safe manner.

Fear of the unknown. It was not surprising to discover that K. I. found HIV scary and that people they knew were dying. They also expressed concern that it was impossible to distinguish the infected person from the healthy person. Furthermore, the virus could be contracted in a seemingly innocent way, such as picking up trash and receiving a needle stick from a discarded used syringe that carries a deadly virus. K. I. expressed real fear of contracting HIV through needle stick injuries, as there was no way to tell by looking at the syringe if it carried a deadly virus. It was interesting to find that a feeling with some family members, or members of the community, that may have lost somebody or they are injecting, needed someone to blame for the behavior. The outreach workers often carried the brunt of the blame because they were the ones providing syringes for the PWID. This suggests fear of the unknown within the family members or community and therefore a need for education.

When talking about barriers, another K. I. suggested that some people simply “can’t see past their own personal values,” which suggests that stigma is a very real concern. A common concern identified by K. I. is the difficulty Hawai'i’s SEP has finding a permanent site for their site. The common belief for this unwillingness to rent was identified as a result of stigma. Stigma was identified as a driving force, a common concern, and there would be backlash from people who just did not understand. Again, education was suggested as a way to overcome it. Similarly, Pauly, Reist, Belle-Isle and Schactman (2013) found, “HR programs often face opposition and illicit drug use remains highly stigmatized” (p. 285). Additional studies also identified stigma as a very real concern (Anderson, 1991; Erickson et al., 2002; Friedman et al., 2007; Islam et al., 2010; Tempalski et al., 2007). Studies that explore the meaning of stigma in the community could offer insight on how to address the lack of a permanent site for Hawai'i’s SEP.

One K. I. expressed feelings that lack of knowledge created fear in the Honolulu Police Department (HPD). However, in the 1980s, out of this fear, emerged training, education, practical equipment, and different ways of patting people down as a way of keeping the officers’ safe. Additional articles identified fear, and a concern of needle stick injuries, for police. There was a feeling that “if the programs [SEP] reduce officers getting stuck, that’s a good thing” (Vogel, 2013, p. 3). Burris et al. (1996) identified the importance of having “some negotiation with local law enforcement officials” to successfully operate a SEP (p. 1164). Similarly, in another article, a police officer is quoted as saying, “ I may agree or disagree philosophically with NEPs, but if it keeps my officers safe, I may need to put my philosophy aside” (McCampbell & Rubin, 2000, p. 3). Preventing the spread of HIV, HBV, and HCV can be a dilemma for police officers; restrict the access to clean syringes for PWID, or enforce laws for

the possession of drug paraphernalia (The Center for Innovative Public Policies, 2000). It is incredibly important to have the police involved with the SEP. Because of its importance, future studies should consider how to gain a better understanding of the role that HPD plays within Hawai'i's SEP and how it can be further expanded.

Theme 2: Knowledge is power. For this study, the environment of HIV/AIDS resulted in fear that, in turn, stimulated the positive perfect storm, which, in turn, stimulated the need for education. Out of the discussions with the K. I. emerged two formulated meanings related to knowledge is power: (1) the GCA recognized the need for educating the public, and (2) PWID may be stimulated to change their behaviors through education. The GCA Interim Report (1988) asserted, "The most effective measure for controlling the spread of HIV is felt to be education of the public, especially those individuals at greater risk" (p. 3). Similarly, the Report and Recommendation of the Governor's Committee on AIDS (1992) identified 27 policies that would provide a blueprint for HIV/AIDS policies in Hawai'i. Of these 27 policies, 10 specifically identified the need for education, and an additional 12 identified the need to educate in either their rationale or goals. Assuredly, education plays a huge role with the GCA. Many studies described how education is needed to stimulate change (Bunning 1991; Hilton et al., 2001; Marazzo et al., 2014; Midford et al., 2014; Needle, Coyle, Normand, Lambert, & Cesari, 1998).

More than one K. I. discussed a HR course that was offered at the University of Hawai'i at Mānoa School of Public Health in the spring of 1997 and 1998. Currently, there are no courses offered on HR, but certainly courses that would address a HR approach, and its principles and strategies, would benefit the students [future Registered Nurses] by increasing their knowledge base, and also would help to decrease stigma for the PWID who have need of

health care services. Studies that explore the implementation of HR in the curriculum of Hawai'i's nursing schools could offer insights on how to decrease, or eliminate future stigma in the health care setting.

Hawai'i 's Syringe Exchange Program: Harm Reduction in Action

Content analysis: Principles.

Pragmatism. The principle that ranked fifth was pragmatism (11.6%). Pragmatism refers to taking a common sense approach when dealing with risky drug use and sexual behavior. Similarly, K. I. identified pragmatism as an influential principle in Hawai'i's SEP. Words used by K. I. were, "it was a common sense approach; it's pragmatic that they use our program; we are a common sense approach." These findings are consistent with the literature since taking a pragmatic approach is basically common sense; education is an effective measure for controlling the spread of HIV, and PWID should inject drugs with clean needles (CDC, 2010; GCA Interim Report, 1988; O'Hare, 2007).

Humanistic values. The principle of humanistic values (16.5%) ranked fourth. Although this principle ranked fourth in the annual reports, the consensus among the K. I. was that humanistic values was a predominant principle currently followed at Hawai'i's SEP. One K. I. indicated feeling that an "unconditional positive regard" exists, and that "every person is valued and respected," and "we don't judge our clients with what they do." Non-judgmental attitude is another attribute commonly identified with the concept harm reduction (Erickson, 1995; Hilton et al., 2001; Keane, 2003; Lichty, 1990; Marlatt et al., 2012; Newcombe, 1987; Pauly, 2007; *Report and Recommendation of the Governor's Committee on AIDS*, 1992; Tiderington et al., 2013; Virdo, 2012) .

Focus on harms. Focus on harms ranked third (16.5%) as the most frequent principle in the 20 annual reports. Similarly, in the discussion with the K. I., focus on harms was identified as playing a huge part of Hawai'i's SEP. K. I. believed for PWID who are addicted:

> . . . the optimal approach would be to get them to stop using drugs, but sometimes they can or will not, so pragmatically you try to reduce the harm that they are going to be engaged in and that would be giving them sterile needles.

It is well known that IDU can lead to the spread of HIV, HBV, and HCV, therefore it is pragmatic to focus on ways of prevention (Beletsky et al., 2011; Bruneau et al.,1997; Vogel, 2013). Several studies found that focusing on harms was a major component of using a HR approach, and the spread of HIV is a far greater danger to PWID, and the community, than the simply focusing on the drug itself (CDC, 2010; Hilton et al., 2001; Marlatt et al., 2012; Riley et al., 1999).

Balancing costs and benefits. The second most frequent principle was balancing costs and benefits (21.5%). In the 1990s, the cost to Hawai'i's health care system for treating preventable HIV infections ranged between $224 million and $538 million (Adamski, 1997). Similarly, K. I. expressed feeling the original principle was costs and benefits, and that was the only thing that mattered. However, K. I. 16 verbalized concerns about recent financial cutbacks,

> Like any nonprofit we're dealing with funding issues, and this past year we exchanged 960,000 syringes, which is nearly double our contract amount. But they didn't increase the amount of funding and so we've had to like weigh the cost-benefits of the other supplies that we make available.

The cost attributed to the care of a person inflicted with a blood borne disease far outweighs the cost of taking a harm reduction approach (Fowler, 2010; Guinnes et al., 2010; Peak, 1990; Vogt

et al., 1998). As such, future studies could be on the variables that are eliminated, replaced, or made available, while comparing and contrasting to other SEPs in an effort to proactively determine alternative ways to deal with the threat of cutbacks.

Priority of immediate goals. The statistical tables' summaries for each of the five HR principles are helpful in showing that although each HR principle is different, they all have particular attributes that link them together to form the theory of HR. Regardless of the individual principle, defining factors are important to make up a HR approach, and the findings revealed priority of immediate goals (35.6%) as the most frequent HR principle identified in the 20 years of reports.

Similarly, the K. I. agreed that priority of goals was incorporated in Hawai'i's SEP, and it simply meant looking at what was the most urgent need for the PWID community and then meeting those needs. Current examples of addressing the most urgent needs for some PWID include providing Naloxone and wound care services. An example provided by a K. I. was how an PWID, recently released from prison with a severe infection of the leg, priority was getting a clean syringe rather than having a priority of treating the infection; whereas, for the K. I., the priority was treating the wound.

Other studies were found that identify priority of goals as an important principle to effectively work with PWID (Beirness et al., 2008; Erickson et al., 2002; Harm Reduction Coalition, n.d.; Pauly, 2007; Riley et al., 1999; WHO, 2009). The priority goal is geared toward moving from the more serious consequences of risky behavior to the less harmful ones (Canadian Center on Substance Abuse, 1996; Denning, 2000; Duncan, Nicholson, Clifford, Hawkins, & Petosa, 1994; Foley, 1997; GCA, 1989; GCA, 1992; Marlatt et al., 2012; Newcombe, 1987, Newcombe, 1992; Tiderington et al., 2012; Drucker & Hantman, 1995). The

PWID may choose to continue drug use, however, focusing on priority of goals can prevent some of the negative consequences.

This section also included the analysis of the collection of annual reports from 1995 up to and including 2015; in addition, excerpts from the K. I.'s perceptions on the use of a HR approach were included under each of the five principles identified in the annual reports. This collection of reports was physically obtained, each report read, and then converted to a PDF file for uploading ability, and then Mayring's Qualitative software solution was chosen to help work through the many text passages of the reports.

The most common HR principle identified in the 20 years of reports was priority of immediate goals 35.6% (n=101), followed by balancing costs and benefits 21.5% (n=61), focus on harms 16.5% (n=47), humanistic values 14.8% (n=42), and pragmatism 11.6% (n=33). The literature consistently suggested using a HR approach is guided by the five principles: pragmatism, humanistic values, focus on harm, balancing costs and benefits, and priority of immediate goals (Ashton & Seymour, 2010; Beirness et al., 2008; Centers for Disease Control and Prevention [CDC], 2010; Denning, 2000; Erickson, 1995; Foley, 1997; Fowler, 2010; Governor's Committee on AIDS: Interim Report 1988; Guinnes et al., 2010; Hilton et al., 2001; Inciardi, 2009; Keane, 2003; Lichty, 1990; Marlatt et al., 2012; Newcombe, 1987; O'Hare, 2007; O'Rourke et al., 2015; Pauly, 2007; Peak, 1990; Riley et al., 1999; Tiderington et al., 2013; Virdo, 2012; Vogt et al.,1998; WHO, 2009).

The HR principle priority of immediate goals 35.6% (n=101) was identified as the most frequently used guiding principle in the 20 annual reports. WHO (2009) suggested that "priority setting is an essential, if often overlooked function of national research systems" (p. 1). The content analysis of the annual reports clearly identified priority of goals as playing an important

part in the functioning of Hawai'i's SEP, and, simply put, is an immediate reduction in harm for not only the drug user, but also the community. According to the Hawai'i State profile (2015), in 2013, Hawai'i ranked 38th in the number of HIV cases diagnosed; whereas, the National Center for HIV/AIDS (2013) ranked Hawai'i 40th. This is in sharp contrast to 1990, when Hawai'i ranked eighth among the 50 states (Lichty, 1990). Perhaps the priority of immediate goals, threaded throughout the annual reports, helped contribute to this rank decrease in Hawai'i.

The overall results of the CHOW annual reports (1995-2015) demonstrate that the principles of a HR were used long before a HR approach was included in CHOW's mission statement. CHOW implemented a HR approach in their mission statement in 2012 (CHOW 2012-2015 Strategic Plan, 2012), and the mission statement remains in effect today. "The CHOW project is dedicated to serving individuals, families, and communities adversely affected by drug use, especially people who inject drugs, through participant-centered harm reduction approach" (CHOW Project 2015 Evaluation Report, 2015, p. 3). Following the inclusion of HR in their mission statement, the CHOW annual reports showed a significant increase in the use of HR principles (Appendix I, Table 14.3).

Key informant discussion. There was a consensus by the K. I. that all five principles were, or are currently, incorporated in Hawai'i's SEP. It was interesting to find the consensus among the K. I.s of humanistic values as the predominant principle. One K. I. indicated feeling that an "unconditional positive regard exists" and that "every person is valued and respected."

When the K. I. were asked the question, "What do you feel was the most influential principle of harm reduction and its relationship with the Hawai'i SEP in the past," the predominant response was humanistic values. Although not as common, pragmatism was also identified as an influential principle of Hawai'i's SEP in the past. Examples of words expressed

by the K. I. were “it was a common sense approach,” and “most important is that they can have access to clean syringes.”

When the K. I. were asked the question, “What do you feel is the most influential principle of HR and its relationship with the Hawai'i SEP on the present, or future?” once again the predominant response was humanistic values. Examples provided by the K. I. of humanistic values included “treating the individuals as worthy human beings,” and “they’re not pieces of crap.” Although costs and benefits was not a predominately identified principle used in Hawai'i’s SEP, examples of costs and benefits included “by preventing one HIV infection we pay for our self.”

The barriers identified stigma, no permanent site, fear/safety, one-for-one exchange, and funding cuts as having the potential to impede the delivery of the SEP in Hawai'i. It was not surprising that stigma was identified as a barrier, nor that a permanent site location for the SEP remains an issue. Other studies also identified stigma as a barrier (Anderson, 1991; Erickson et al., 2002; Friedman et al., 2007; Islam et al., 2010; Pauly et al., 2013; Tempalski et al., 2007). Fear/ safety was not as clearly identified in the literature; however, there are many studies that identify peers as outreach workers. Perhaps more use of peers within the current SEP, as well as political allies in the legislature, would help to eliminate this barrier (Jain, Krishnan, Ramesh, Sabarwa, & Dhingra, 2014; North Carolina HR Coalition, n.d.).

Limitations

This study had many limitations. The number of K. I. who were members of Hawai'i’s GCA, current and past board members, or involved with the CHOW project, was relatively small with only 22 participants; however, this number was still sufficient to identify major themes. In addition, the memories of K. I. able to participate could have been imprecise; therefore, some of

the discussions may not accurately reflect the creation of Hawai'i's SEP. However, a search and comparison of the literature confirmed dates, and also verified contextual factors that helped influence the formation of the SEP.

The interview questionnaire was constructed according to the definitions of HR principles identified in the literature. However, the participants may have had alternative definitions for HR that the questionnaire did not allow for. Additionally, the guided questionnaire may have prevented the K. I. from responding differently. For example, with the question, "How do you feel about providing clean syringes or other harm reduction services to drug users?" although there were many positive responses from the K. I., there were some responses that expressed mixed emotions. The positive responses included, "totally supportive, absolutely invaluable service, should be available on the free street corner, very positive for it, it's imperative, a no brainer." However, a few responses suggested mixed emotions on feelings about providing clean syringes or other harm reduction services to drug users:

> Sometimes I feel like am I making it easier for people to inject—I hope I don't get in trouble for this—I have mixed emotions; we are almost fostering codependency by meeting them [PWID] where they're at [home delivery]; there is no accountability on their [PWID] end; such a loaded question—you're going to use my name, damn it—I have strongly mixed feelings, it's a really difficult thing not to take personal.

Perhaps the responses that included, "I hope I don't get in trouble for this," and "you're going to use my name, damn it" suggest a response that was geared towards what the participant may have thought the researcher was looking for, or perhaps a fear of what someone who reads their responses may think. Studies that explore the outreach workers' feelings allowing for an

anonymous response could generate different insights about how workers actually feel about providing clean syringes or other harm reduction services to PWID.

Another limitation with this study was the deductive directed content analysis of the 20 years of reports. Mayring's Qualitative software solution was used to help work through the many text passages (n= 284), and "strict content-analytical rules for the whole process and for the specific steps of analysis" was followed (Mayring, 2014, p. 10). Although a deliberate effort was made to analyze the data in an unbiased manner, it is possible that another researcher could code a report differently. However, to avoid this, a PhD prepared researcher was given a sample of text along with the definitions of the principles and no variations were found.

Although there were some limitations, there were also several strengths to this study. When looking at the K. I.'s perceptions about the factors leading to the creation, development, and growth of the SEP, their responses were compared to what was found in the literature, lending credibility to their perceptions. All K. I. were receptive to meeting and participating in the study and provided additional names of potential participants. Finally, many of the participants expressed how incredibly important this dissertation is as a way to document how a perfect positive storm was instrumental in changing how Hawai'i dealt with such a deadly disease.

Recommendations and Implications for Nursing Research, Practice, and Policy

This study captured the perceptions of the factors leading to the creation, development, and growth of the SEP in Hawai'i, addressing Research Question 1: *What were the factors that led to the creation, development, and growth of the syringe exchange program in Hawai'i*? Until there is a cure for the deadly blood borne viruses, prevention remains the primary focus, such as with the HR approach to SEP (Harm Reduction Coalition, n.d.).

Research Question 3: *What barriers currently impede the delivery of the syringe exchange program in Hawai'i, and what recommendations could strengthen the syringe exchange program and further improve public health in Hawai'i?* The following recommendations for consideration include the areas involving *stigma* attached to PWID and SEPs, *lack of a permanent site* for the current SEP, addressing *fear and safety* for not only the civic community, but also the community of PWID, dealing with the policy of *one-to-one syringe exchange*, and the impact of *funding cuts* for the current SEP. In addition, the results of this study identified implications offered for future research, clinical practice, and suggestions for policy changes that could further improve public health in Hawai'i.

Research. This study centered on the perceptions of the factors leading to the creation of the SEP, and focused on a HR approach SEP and the five HR principles; pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of goals.

Given the paucity of research that has been conducted investigating why Hawai'i's SEP seems to have been so acceptable and successful compared to other states such as Indiana, the factors leading to the creation, development, and growth of Hawai'i's SEP can be seen as original and significant enough to contribute to knowledge.

Finally, an important finding is how the SEP in Hawai'i incorporated the five principles of HR: pragmatism, humanistic values, focus on harm, balancing costs and benefits, and priority of immediate goals. Future studies, exploring the use of a HR approach comparing Hawai'i's SEP to other SEPs, may further define the impact of using HR strategies with the vulnerable community population of PWID.

Practice. People who inject drugs tend to exhibit a high number of emergency room visits for injection related wounds (Robinowitz et al., 2014). Interesting, but not an unexpected

finding, was the *fear* of the community of PWID for seeking health care services for wounds resulting from implications from IDU, such as wound or other health problems resulting from non-sterile injecting practices. To promote physical health among PWID, health care providers and nurses should consider following Baltimore, Maryland's, Wounds on Wheels, thereby implementing a mobile wound care clinic in collaboration with the current use of vans to provide HR services (Robinowitz et al., 2014). In addition to the community of PWID, *fear and safety* is a concern for the outreach workers. Two suggestions to promote physical and mental health among the outreach workers include monthly educational services inviting guest speakers with expertise in psychology and human behavior, and continued emotional support and counseling. Perhaps medical students that are currently in their mental health residency could be approached and asked to volunteer their services. Ideally, but perhaps financially unrealistically, would be outreach workers working in pairs rather than working individually.

Policy. The cost attributed to the care of a person inflicted with HIV far outweighs the cost of taking the HR approach of a SEP. Therefore, research needs to support the comparison and contrast to other SEPs in an effort to proactively determine alternative ways to deal with the threat of future *financial cut backs*. Perhaps vending machines as a way to distribute syringes might eliminate some unnecessary constraints over the current *one-for-one syringe* exchange. It is essential for health care practitioners and nurses to focus on harms related to IDU and its consequences to not only the civic community, but also to the community of PWID. In doing so, the community of PWID will be empowered to make healthy choices, and the threat to the community, and potential innocent victims, will be addressed. Further, the protection of the civic community and community of PWID is important; therefore, sharps' containers placed in strategic locations might influence PWID to discard used syringes in a safe manner.

A major finding that seemed to be threaded throughout this study was education. The power of education and using HR strategies, such as a SEP, among the civic community and community of PWID is important and could help decrease *stigma.* Furthermore, studies that explore the meaning of *stigma* in the community could offer insights on how to address the lack of a permanent site for Hawai'i's SEP. Moreover, educational programs for the civic community could include schools, schools of nursing, and churches, which may help to decrease *stigma*. Through education, church leaders may become actively involved in helping to decrease the *stigma* within their own congregations. Finally, it is incredibly important to have the police involved with the current SEP. Because of its importance, future studies should be considered to gain a better understanding of how the role HPD can be further expanded through education.

Positive Perfect Storm

Another major finding threaded throughout this study that led to the creation, development, and growth of Hawai'i's SEP was the presence of so many dynamic personalities. Without these personalities, the SEP in Hawai'i would not have been so successful—Hawai'i is truly a unique state.

APPENDIX A

IRB APPROVAL

UNIVERSITY of HAWAI'I®
MANOA

Office of Research Compliance
Human Studies Program

April 7, 2016

TO: Penny Morrison
John Casken, Ph.D.
Principal Investigators
Nursing

FROM: Denise A. Lin-DeShetler, MPH, MA
Director

SUBJECT: CHS #23841 - "Hawaii's Syringe Exchange: Harm Reduction in Action"

This letter is your record of the Human Studies Program approval of this study as exempt.

On April 7, 2016, the University of Hawai'i (UH) Human Studies Program approved this study as exempt from federal regulations pertaining to the protection of human research participants. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.101 (b) (Category 2).

Exempt studies are subject to the ethical principles articulated in The Belmont Report, found at http://www.hawaii.edu/irb/html/manual/appendices/A/belmont.html

Exempt studies do not require regular continuing review by the Human Studies Program. However, if you propose to modify your study, you must receive approval from the Human Studies Program prior to implementing any changes. You can submit your proposed changes via email at uhirb@hawaii.edu. (The subject line should read: Exempt Study Modification.) The Human Studies Program may review the exempt status at that time and request an application for approval as non-exempt research.

In order to protect the confidentiality of research participants, we encourage you to destroy private information which can be linked to the identities of individuals as soon as it is reasonable to do so. Signed consent forms, as applicable to your study, should be maintained for at least the duration of your project.

This approval does not expire. However, please notify the Human Studies Program when your study is complete. Upon notification, we will close our files pertaining to your study.

If you have any questions relating to the protection of human research participants, please contact the Human Studies Program at 956-5007 or uhirb@hawaii.edu. We wish you success in carrying out your research project.

1960 East-West Road
Biomedical Sciences Building B104
Honolulu, Hawai'i 96822
Telephone: (808) 956-5007
Fax: (808) 956-8683
An Equal Opportunity/Affirmative Action Institution

APPENDIX B

CONSENT TO ACCESS CHOW REPORTS

Community Health Outreach Work

677 Ala Moana Blvd., Suite 226
Honolulu, HI 96813
Phone (808) 853-3292 • Fax (808) 853-3274

March 13, 2013

Penny Morrison, MS, BSN, RN
UHM School of Nursing and Dental Hygiene
2528 McCarthy Mall, Webster #406
Honolulu, HI 96816

Dear Ms. Morrison,

Thank you for your interest in working with us to evaluate the effectiveness of syringe exchange in Hawaii. This letter will serve as an agreement between you and CHOW. You may have access to CHOW's daily log database and syringe exchange evaluation database and all related data for your research. All of this data has been collected utilizing unique identifiers and you will not have access to any data which may identify an individual participant of our program. In return, you agree to maintain integrity of the data and agree to not share specific information about the data with others without explicit CHOW permission. The use of this data is only for your use in your PhD dissertation, and may not be used for any other purpose.

Sincerely,

Heather Lusk
Executive Director

APPENDIX C

RECRUITING SCRIPT

Hawai'i's Syringe Exchange: Harm Reduction in Action?

My name is Penny Morrison and I am a graduate student at the University of Hawai'i at Mānoa in the Department of Nursing. To earn my Doctor in Philosophy in Nursing degree I plan to analyze the factors leading to the development and growth of Hawai'i 's Syringe Exchange Program and I am inviting you to participate because you were either part of Hawai'i's Governor's Committee on AIDS in the late 1980s and early 1990s, or an individual currently involved with the Syringe Exchange Program in Hawai'i.

If you participate in this project, I will meet with you for an interview at a location and place convenient to you. The interview will last approximately 60 minutes. The interview will consist of semi structured questions. Interview questions will include questions such as, "What is your past or present connection with Hawai'i 's Syringe Exchange Program?" "What factors do you feel facilitated the delivery of a Syringe Exchange Program in Hawai'i ?"

If you have any questions or would like to participate in the research, I can be reached at 808-392-8011, or by email at pennym@Hawai'i.edu.

APPENDIX D

CONSENT AGREEMENT TO PARTICIPATE IN HAWAI'I'S SYRINGE EXCHANGE

My name is Penny Morrison and I am a graduate student at the University of Hawaiʻi at Mānoa in the Department of Nursing. To earn my Doctor in Philosophy in Nursing degree I plan to analyze the factors leading to the development and growth of Hawaiʻi 's Syringe Exchange Program. This study will explain the relationship between Hawaiʻi 's Syringe Exchange Program and Harm Reduction's five principles; pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals. *Definitions for the five principles are: 1)* ***Pragmatism****- the act of taking a commonsense approach when dealing with the high- frequency rate of risky drug use. 2)* ***Humanistic values****- treatment of individuals as worthy of the same dignity and rights as any other member of society, with respect, and without judgment. 3)* ***Focus on harms****- the act of viewing the extent of drug use as less important than its adverse consequences. 4)* ***Balancing costs and benefits****- the act of identifying, measuring, and assessing the relative importance of drug-related problems and their associated harm. 5)* ***Priority of immediate goals****-the act of identifying a fact or condition that is more important than another.*

I am asking you to participate because you were either part of Hawaiʻi's Governor's Committee on AIDS in the late 1980s and early 1990s, or an individual currently involved with the Syringe Exchange Program in Hawaiʻi.

Activities and Time Commitment: If you participate in this project, I will meet with you for an interview at a location and place convenient to you. The interview will last approximately 60 minutes. The interview will consist of semi structured questions. Interview questions will include questions such as, "What is your past or present connection with Hawaiʻi 's Syringe Exchange Program?" "What factors do you feel facilitated the delivery of a Syringe Exchange Program in Hawaiʻi ?" Only you and I will be present during the interview. I will audio-record the interview. After the interview, the audio recording will be stored in the University of Hawaiʻi 'Scholar Space', which is an open-access set of services used to preserve research in digital format. Users will be permitted to use, in unpublished works, short excerpts from the audio recording without obtaining permission as long as proper credit is given to the interviewee (you), interviewer (me), and the University of Hawaiʻi 'Scholar Space'. I would like to store the audio files of my interview with you in the University of Hawaiʻi 'Scholar Space' and the purposes of storing the file are to:

a) Maintain a "living" audible file of the interview as they sounded, and

b) Permit students, faculty, researchers, and the public to listen to the interview.

Voluntary Participation: Your participation in this project is completely voluntary. You may withdraw from participation at any time, until the completion of this project which is expected on/or before 03/21/2017. During the interview, you can choose to not answer any question(s) at any time for any reason. If you disapprove of, wish to change, add to, delete, or otherwise change the transcripts or the audio file of the interview, you may do so at any time up to the completion of this project. If you decide that the transcripts and/or audio files should not be archived, we will end the project and there will be no penalty or loss to you.

Benefits and Risks: There is no direct benefit to you for participating in this interview. There is no compensatory incentive to participate. Your participation will contribute to the historical record Hawaiʻi's Syringe Exchange: Harm Reduction in Action? I want to create an authentic record and make available it to scholars and the general public as a reliable historical document. To do that, it is important that your actual name appear as the interviewee on the transcript. In addition, the transcripts and audio files of the interview will include your name and personal recollections. If you choose, pseudonyms (fake names) may be used in place of your name; however your voice may still be recognizable. Thus one potential risk to you is a loss of privacy. Another risk is that some topics you discuss during the interview might bring back painful or unpleasant memories. You may become stressed or uncomfortable answering any of the interview questions or discussing topics with me during the interview. If at any time, you feel stressed, or uncomfortable you can skip the question or take a break. You can also stop the interview, or you can withdraw from the project altogether.

Privacy and Confidentiality: In order to accurately document this historic event, it is important that your name appear as the interviewee on this transcript. If you choose, pseudonyms (fake names) may be used in place of your name; however your voice may still be recognizable. You retain the right to change, delete, or add information in the transcripts and audio files.

I will keep all information in a safe place. Only my University of Hawaiʻi advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records include the University of Hawaiʻi Human Studies Program. The audio transcripts will be stored in the University of Hawaiʻi 'Scholar Space' and may be permanently stored there until data are moved to a discipline specific data repository. When I report the results of my research project, I will use your name with your consent. I will not use any personal identifying information that can identify you, unless you provide permission. Your name may appear as the interviewee and the information you provide may be used in this dissertation, or you may choose to respond anonymously. If you choose to respond anonymously I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

Questions: If you have any questions about this study, please call or email me at 808-392-8011 or via email to pennym@Hawaiʻi .edu You may also contact my advisor, Dr. John Casken, at 808-956-5750, or via email to casken@Hawaiʻi .edu .

If you have questions about your rights as a research participant, you may contact the UH Human Studies Program at 808.956.5007 or uhirb@Hawaiʻi .edu .

If you agree to participate in this project, please sign and date this signature page.

Signature(s) for Consent

I give my permission to participate in the research project entitled, *Hawaiʻi's Syringe Exchange: Harm Reduction in Action?*

I certify that I have read and that I understand the information in this consent form, that I have been given satisfactory answers to my questions concerning the project, and that I have been told that I am free to withdraw my consent and to discontinue participation in the project at any time without negative consequences to me. I understand that if I am injured in the course of this research, I may be responsible for the costs of treating my injuries.

I herewith give my consent to participate in this project with the understanding that such consent does not waive any of my legal rights". Please initial next to either "yes" or "No" to the following:

______Yes ______No I consent to be audio-recorded and for the audio to be transcribed and uploaded to Hawaiʻi 'Scholar Space' for the interview portion of this research

______Yes ______No I allow the investigator to use my name to be used in any publication of this research (if you check 'No', pseudonyms (fake names) will be used in place of your name)

Name of Participant (print) ____.

Participant's Signature ____.

Signature of the Person Obtaining Consent: ____________________________.
Date: ____________________.

A copy of this Consent Form will be provided to you (interviewee)

APPENDIX E
QUESTIONNAIRE GUIDE
University of Hawai'i at Mānoa

TITLE**: Hawai'i's Syringe Exchange: Harm Reduction in Action?**
Name: __________ Date: _________

1. What is your past or present connection with Hawai'i 's Syringe Exchange Program?
2. What factors do you feel facilitated the creation of a Syringe Exchange Program in Hawai'i ?
3. Describe how you saw the socio cultural and political environment at the time of the formation of the Syringe Exchange Program
4. Describe the socio cultural and political environment that you see affects the operation of the current Syringe Exchange Program
5. What changes do you feel have occurred since the formation of the Syringe Exchange Program that has impacted the operation of the program in Hawai'i ? (either negatively or positively)
6. What harm reduction principles that you know of have been, or are currently incorporated in Hawai'i 's Syringe Exchange Program and in what way? (pragmatism, humanistic values, focus on harms, balancing costs and benefits, and priority of immediate goals)
7. How do you feel about providing clean syringes or other harm reduction services to the drug users?
8. What do you feel was the most influential principle (**pragmatism, humanistic values, focus on harms, balancing costs and benefits,** and **priority of immediate goals**) of harm reduction and its relationship with the Hawai'i Syringe Exchange Program **in the past**? *Definitions for the five principles are: 1) **Pragmatism**- the act of taking a commonsense approach when dealing with the high- frequency rate of risky drug use. 2) **Humanistic values**- treatment of individuals as worthy of the same dignity and rights as any other member of society, with respect, and without judgment. 3) **Focus on harms**- the act of viewing the extent of drug use as less important than its adverse consequences. 4) **Balancing costs and benefits**- the act of identifying, measuring, and assessing the relative importance of drug-related problems and their associated harm. 5) **Priority of immediate goals**-the act of identifying a fact or condition that is more important than another.*
9. What do you feel is the most influential principle (**pragmatism, humanistic values, focus on harms, balancing costs and benefits,** and **priority of immediate goals**) of harm reduction and its relationship with the Hawai'i Syringe Exchange Program on the **present, or future**? *Definitions for the five principles are: 1) **Pragmatism**- the act of taking a commonsense approach when dealing with the high- frequency rate of risky drug use. 2) **Humanistic values**- treatment of individuals as worthy of the same dignity and rights as any other member of society, with respect, and without judgment. 3) **Focus on harms**- the act of viewing the extent of drug use as less important than its adverse consequences. 4) **Balancing costs and benefits**- the act of identifying, measuring, and assessing the relative importance of drug-related problems and their associated harm. 5) **Priority of immediate goals**-the act of identifying a fact or condition that is more important than another.*

APPENDIX F—TABLE F3.1

Table F3.1: Coding Rules

Table F 3.1

Coding Rules

Category of HR Principles (CHRP)	Definitions	Coding rules
CHRP 1. Pragmatism The act of taking a commonsense approach when dealing with the high-frequency rate of risky drug use; addressing those who cannot or will not stop Injection drug use	"..the most effective measure for controlling the spread of HIV is felt to be education of the public, especially those individuals at greater risk" (GCA Interim Report, 1988, p. 3)"Knowledge itself is power" (Bacon, 1597) "persons who inject drugs should use a new, sterile needle and syringe for each injection" (CDC, 2010, p. 1). "if the danger was infected equipment, clean equipment had to be made available" (O'Hare, 2007, p.142).	The aspect of the definition of pragmatism must be identifiable
CHRP2. Humanistic values Treatment of individuals as worthy of the same dignity and rights as any other member of society, with respect, and without judgment	"obstacles to the provision of adequate care include…prejudice against the risk groups…injection drug users" (GCA, 1992, P.62). " those who are homeless and using drugs are highly vulnerable to inequities in health and access to health care as a result of structural injustices" (Pauly, 2007, p. 5). "people will make more health positive choices if they have access to adequate support, empowerment, and education" (Marlatt, Larimer & Witkiewitz, 2012, p. 6)."either public health is for everyone or its only for people whose behavior we approve of" (Purchase, in Litchy, 1990, p.15).	The aspect of the definition of humanistic values must be identifiable
CHRP 3. Focus on harms The act of viewing the extent of drug use as less important than its adverse consequences	"…the spread of HIV is a greater danger to individual and public health than drug misuse and that measures to reduce drug use must not compromise efforts to reduce the spread of HIV" (Riley 1998 in Hilton, 2001, p.359). "consider harm at; 1) individual level-> HIV contraction from shared needles, necrotizing skin infections; 2) community->unsafe drug use environment posing risks to the affected individual; 3) societal level -> economic loss (Marlatt, Larimer & Witkiewitz, 2012, p. 8)"…purpose is to prevent the spread of blood-borne pathogens and help reduce the incidence of infection and other harm associated with the use of damaged, non-sterile or shared syringes" (CDC, 2010, P.).	The aspect of the definition of focusing on harms must be identifiable
CHRP 4. Balancing costs and benefits The act of identifying, measuring, and assessing the relative importance of drug-related problems and their associated harms	"HR materials need to be based on scientific knowledge, meaning that their content needs to be constantly reassessed" (Newcombe, 1987, p. 1). "..if we could save one infant or two adults, the program would have paid for itself" (Peak, 1990, p 7.)."..costs an average city about $160,000 to run an NEP…one syringe infected AIDS patient will require upwards of $120,000 per year in public health expenditures" (syringe exchange in the united states:1995 Update , HIV Capsule Report, in Fact sheet, 2006, page 1). "…lifetime cost of treating just one person with HIV in U.S. is between $400,000 and $600,000, while a new sterile syringe costs less than $1.." (in Fowler, 2010, p. 2). "the annual budget for the integrated community outreach/syringe exchange project currently $625,000…estimated that combined programs would need to prevent 5 or more HIV infections per year in Hawai'i " Vogt, 1998, p. 1404).	The aspect of the definition of 'benefits and costs' must be recognizable
CHRP 5. Priority of immediate goals The act of identifying a fact or condition that is more important than another	"…implementing a program to provide opportunities for IV drug users to exchange sterile needles anonymously and at no cost" (GCA, 1989, p.30) "effects of drug use must be addressed to stop the spread of HIV" (GCA, 1992, p. 30)."clients may not readily state abstinence as a goal, for example, but maybe more likely to state that obtaining a job or financial assistance is important to them" (Marlatt, Larimer & Witkiewitz, 2012, p. 302)"Starting where the patient is. This means accepting them with whatever goals and level of motivation for change that they come with" (Marlatt, Larimer & Witkieiwitz, 2012, p39) "…meet/accepting clients where they are at" (Denning, 2000; Marlatt, 1998; O'Rourke, 2015)."..working with crack user, one of the problems is that they don't eat enough...so I say why don't you make sure you have one meal a day….do a little bit that's comfortable, then build on it later" (conversation with Springer in Foley, 1997, p. 2).	The aspect of the definition of goal prioritization must be identifiable

Note: Coding agenda adapted from Mayring (2000)

APPENDIX G—TABLE G4.1

Table G4.1: Common HR Principles over 20 Years

Table G 4.1

Common HR Principles over 20 Years

			Principles					
			Pragmatism	Humanistic values	Focus on harms	Balancing costs and benefits	Priority of immediate goals	Total
Year	1995	Count	2	1	3	4	5	15
		% within Year	13.3%	6.7%	20.0%	26.7%	33.3%	100.0%
	1996	Count	2	0	1	4	4	11
		% within Year	18.2%	0.0%	9.1%	36.4%	36.4%	100.0%
	1997	Count	2	3	3	7	5	20
		% within Year	10.0%	15.0%	15.0%	35.0%	25.0%	100.0%
	1998	Count	6	5	2	4	7	24
		% within Year	25.0%	20.8%	8.3%	16.7%	29.2%	100.0%
	1999	Count	0	0	1	6	3	10
		% within Year	0.0%	0.0%	10.0%	60.0%	30.0%	100.0%
	2000	Count	1	1	1	6	4	13
		% within Year	7.7%	7.7%	7.7%	46.2%	30.8%	100.0%
	2001	Count	3	3	3	3	6	18
		% within Year	16.7%	16.7%	16.7%	16.7%	33.3%	100.0%
	2002	Count	0	3	0	2	2	7
		% within Year	0.0%	42.9%	0.0%	28.6%	28.6%	100.0%
	2003	Count	2	2	1	2	6	13
		% within Year	15.4%	15.4%	7.7%	15.4%	46.2%	100.0%
	2004	Count	3	5	4	0	5	17
		% within Year	17.6%	29.4%	23.5%	0.0%	29.4%	100.0%
	2005	Count	1	0	3	2	3	9
		% within Year	11.1%	0.0%	33.3%	22.2%	33.3%	100.0%
	2006	Count	0	0	2	2	4	8
		% within Year	0.0%	0.0%	25.0%	25.0%	50.0%	100.0%
	2007	Count	0	0	1	0	3	4

		% within Year	0.0%	0.0%	25.0%	0.0%	75.0%	100.0%
	2008	Count	0	1	2	0	3	6
		% within Year	0.0%	16.7%	33.3%	0.0%	50.0%	100.0%
	2009	Count	0	0	1	2	1	4
		% within Year	0.0%	0.0%	25.0%	50.0%	25.0%	100.0%
	2010	Count	0	0	0	2	1	3
		% within Year	0.0%	0.0%	0.0%	66.7%	33.3%	100.0%
	2011-2012	Count	0	0	0	2	1	3
		% within Year	0.0%	0.0%	0.0%	66.7%	33.3%	100.0%
	2013	Count	0	1	1	3	3	8
		% within Year	0.0%	12.5%	12.5%	37.5%	37.5%	100.0%
	2014	Count	0	0	2	2	0	4
		% within Year	0.0%	0.0%	50.0%	50.0%	0.0%	100.0%
	2015	Count	3	2	7	3	8	23
		% within Year	13.0%	8.7%	30.4%	13.0%	34.8%	100.0%
	2016	Count	8	15	9	5	27	64
		% within Year	12.5%	23.4%	14.1%	7.8%	42.2%	100.0%
Total		Count	33	42	47	61	101	284
		% within Year	11.6%	14.8%	16.5%	21.5%	35.6%	100.0%

APPENDIX H—TABLE H4.2

Table H4.2: Overall Percentages of the Five Principles: 1995-2016

Table H 4.2

Overall Percentages of the Five Principles: 1995-2016

Principles

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pragmatism	33	11.6	11.6	11.6
	Humanistic values	42	14.8	14.8	26.4
	Focus on harms	47	16.5	16.5	43.0
	Balancing costs and benefits	61	21.5	21.5	64.4
	Priority of immediate goals	101	35.6	35.6	100.0
	Total	284	100.0	100.0	

APPENDIX I—TABLE I4.3

Table I4.3: Common HR Principles by Every Five Years

Table I4.3

Common HR Principles by Every Five Years

5-Year * Principles Crosstabulation

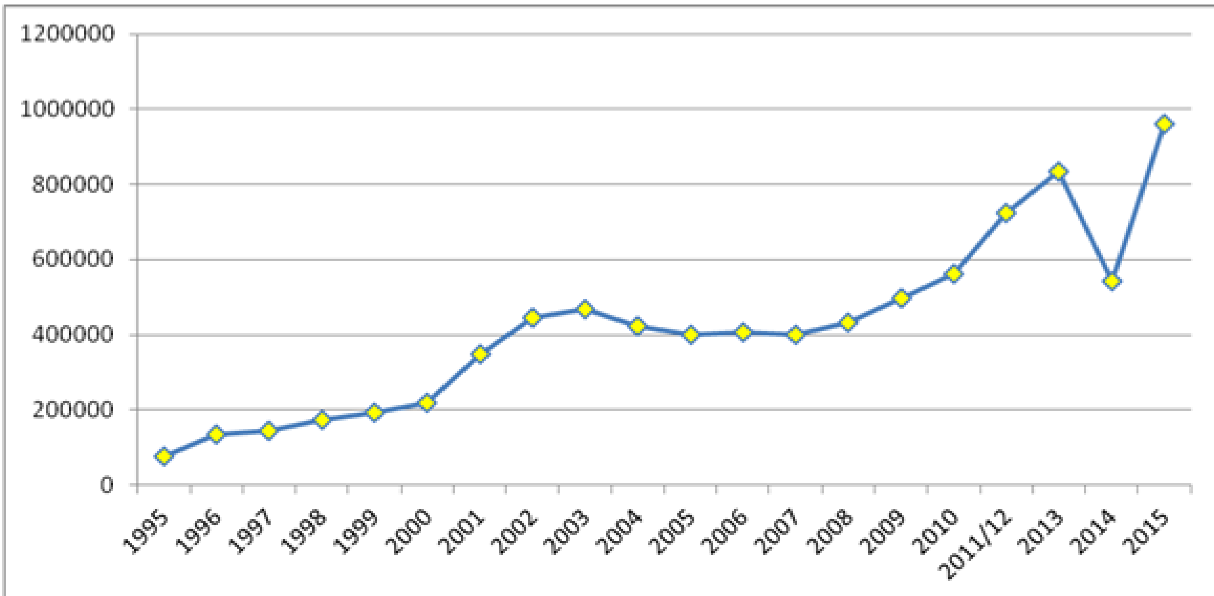
			Principles					
			Pragmatism	Humanistic values	Focus on harms	Balancing costs and benefits	Priority of immediate goals	Total
5-Year	1995-1999	Count	12	9	10	25	24	80
		% within 5-Year	15.0%	11.3%	12.5%	31.3%	30.0%	100.0%
	2000-2004	Count	9	14	9	13	23	68
		% within 5-Year	13.2%	20.6%	13.2%	19.1%	33.8%	100.0%
	2005-2009	Count	1	1	9	6	14	31
		% within 5-Year	3.2%	3.2%	29.0%	19.4%	45.2%	100.0%
	2010-2014	Count	0	1	3	9	5	18
		% within 5-Year	0.0%	5.6%	16.7%	50.0%	27.8%	100.0%
	2015-2016	Count	11	17	16	8	35	87
		% within 5-Year	12.6%	19.5%	18.4%	9.2%	40.2%	100.0%
Total		Count	33	42	47	61	101	284
		% within 5-Year	11.6%	14.8%	16.5%	21.5%	35.6%	100.0%

APPENDIX J—TABLE J4.4

Table J4.4: Number of Syringes Exchanged Per Year: 1995-2015

Table J4.4

Number of Syringes Exchanged Per Year: 1995-2015



APPENDIX K—TABLE K4.5

Table K4.5: Five HR Principles and Number of Syringes Exchanged

Appendix K4.5

Five HR Principles and Number of Syringes Exchanged

Year	Pragmatism n (%)	Humanistic values n (%)	Focus on harms n (%)	Balancing costs and benefits n (%)	Priority of immediate goals n (%)	Number of syringes exchanged
1995	2 (13.3%)	1 (6.7%)	3 (20.0%)	4 (26.7%)	5 (33.3%)	75,230
1996	2 (18.2%)	0 (0.0%)	1 (9.1%)	4 (36.4%)	4 (36.4%)	133,958
1997	2 (10.0%)	3 (15.0%)	3 (15.0%)	7 (35.0%)	5 (25.0%)	143,715
1998	6 (25.0%)	5 (20.8%)	2 (8.3%)	4 (16.7%)	7 (29.2%)	174,509
1999	0 (0.0%)	0 (0.0%)	1 (10.0%)	6 (60.0%)	3 (30.0%)	193,350
2000	1 (7.7%)	1 (7.7%)	1 (7.7%)	6 (46.2%)	4 (30.8%)	219,218
2001	3 (16.7%)	3 (16.7%)	3 (16.7%)	3 (16.7%)	6 (33.3%)	347,793
2002	0 (0.0%)	3 (42.9%)	0 (0.0%)	2 (28.6%)	2 (28.6%)	444,183
2003	2 (15.4%)	2 (15.4%)	1 (7.7%)	2 (15.4%)	6 (46.2%)	468,379
2004	3 (17.6%)	5 (29.4%)	4 (23.5%)	0 (0.0%)	5 (29.4%)	424,116
2005	1 (11.1%)	0 (0.0%)	3 (33.3%)	2 (22.2%)	3 (33.3%)	399,907
2006	0 (0.0%)	0 (0.0%)	2 (25.0%)	2 (25.0%)	4 (50.0%)	408,014
2007	0 (0.0%)	0 (0.0%)	1 (25.0%)	0 (0.0%)	3 (75.0%)	398,863
2008	0 (0.0%)	1 (16.7%)	2 (33.3%)	0 (0.0%)	3 (50.0%)	432,852
2009	0 (0.0%)	0 (0.0%)	1 (25.0%)	2 (50.0%)	1 (25.0%)	496,757
2010	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (66.7%)	1 (33.3%)	563,332
2011-2012	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (66.7%)	1 (33.3%)	723,600
2013	0 (0.0%)	1 (12.5%)	1 (12.5%)	3 (37.5%)	3 (37.5%)	833,677
2014	0 (0.0%)	0 (0.0%)	2 (50.0%)	2 (50.0%)	0 (0.0%)	542,700
2015	3 (13.0%)	2 (8.7%)	7 (30.4%)	3 (13.0%)	8 (34.8%)	959,237
2016	8 (12.5%)	15 (23.4%)	9 (14.1%)	5 (7.8%)	27 (42.2%)	

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