USING COMMUNITY ENGAGEMENT TOOLS TO DEVELOP MORE SUCCESSFUL HARM-REDUCTION STRATEGIES AMONG PEOPLE WHO USE INTRAVENOUS DRUGS

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

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by
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May 2018

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ABSTRACT

The current opioid epidemic has had grave financial and mortal costs for our nation, and the numbers continue to climb despite our best efforts. In spite of attempts to limit the prescription of opioids and implementation of harm reduction strategies, it is clear that we are not doing enough for people struggling with drug addiction. There are many voices present in the war on drugs, however one that is noticeably absent from the conversation is that of people who inject drugs. It is clearly time to try something new which requires a fresh approach and a new point of view. Confronting the current crisis using a public health approach addresses the associated moral challenges faced in the past and provides a new lens to view potential challenges and solutions. With this new approach arises the need for a public health ethical framework to make ethically informed, community engaging, evidence based decisions on a societal, public health, and everyday level. In addition to this new public health ethics framework, the engagement of the community of people who inject drugs is no longer negotiable in order to develop more effective harm reduction interventions and policies.

Keywords: urban bioethics, harm reduction, community engagement, public health, people who inject drugs

For my Parents, Jasper and of course, Andy.

ACKNOWLEDGMENTS

This thesis would not have been possible without my passionate, inspiring professors in the Center for Bioethics, Urban Health, and Policy. You may never truly know the impact you have had on me, but I can confidently say that you have made me a better community member, physician and person. To Dr. Jones, I will never be able to convey my gratitude for your continued guidance and support throughout my medical education. You have provided me with a toolkit to tackle any future obstacle, and a desire to continue to learn from and improve my community.

I would also like to acknowledge the Temple University physicians that have served as powerful role models of how to provide patient-centered, holistic care. Lastly, I would like to thank the Northern Philadelphia community for allowing me to learn from you, and for playing a pivotal role in inspiring and shaping my future career as a Family Medicine Physician.

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CHAPTER 1

INTRODUCTION

According to the American Society of Addiction Medicine, in 2015 approximately 591,000 Americans had a substance use disorder involving heroin (Opioid Addiction 2016 Facts & Figures 2016). More concerning is the fact that during that same year there were 12,990 heroin related overdose deaths, and according to the Center for Disease Control (CDC) these numbers continue to trend upward resulting in an average of 174 Americans dying each day from a heroin overdose (Opioid Addiction 2016 Facts & Figures 2016). We are in the midst of a public health crisis and it is time we demand a public health ethics framework to develop more effective, ethically minded interventions.

Addiction statistics are frightening and mean different things to different people. To the CDC and other health organizations they signify an epidemic, to government officials they indicate the need for policy change, to the communities they denote violence and crime, and to the many family members who have loved ones battling addiction they mean that their lives have been changed forever. As a result there are many voices in this modern war on drugs, however the one that is often absent is that of the people who use inject drugs (PWID). Who are they and what are their stories? The mother who overdosed with her baby in her arms; the teen resorting to prostitution just to get her next fix; the young man whose arm has been destroyed by flesh eating bacteria; the man in the hospital who was so desperate he injected through his IV line. They are the individuals who we have so far failed to help, and as a result they are scared, sick, and wary of people outside of their community. How can we overcome these barriers to communication in order to give this community a voice and allow them to direct us to

how we can better help them – these are the questions I hope to shed some light on for healthcare professionals, policy makers, and researchers. Given the magnitude of the opioid epidemic and the amount of destruction it has already left in its path it can at times seem like an impossible problem to tackle, but at the very least we owe it to those who are currently fighting and those who have lost their own wars on heroin to start listening.

CHAPTER 2

THE OPIOID EPIDEMIC

Statistics and Current Interventions

The current opioid epidemic is a national issue as well as one that hits close to home in Philadelphia. Before discussing where we are today, it is important to take a brief journey back to where this all started. Prior to the 1980's opioid analgesics were prescribed quite sparingly with the exception of the terminally ill or cancer patient. This all began to change under the influence of articles written in 1981 and 1986 by Kathleen Foley, a pain management specialist from Memorial Sloan-Kettering Cancer Center in New York City, reporting a low frequency of addictive behaviors in both cancer and non-cancer patients prescribed opioids along with a short letter written in 1980 reporting the rare occurrence of addiction among inpatients treated with opioid medications (Foley 1981, Foley 1986, Foley 1980). This data served as the launchpad for a campaign to address pain as "The Fifth Vital Sign," and the promotion of the long-term use of opioids in chronic non-cancer pain by Dr. Foley and her colleague Dr. Russell Portenoy. In support of their crusade the physicians claimed there was no long-term published data suggesting high addiction rates among patients treated with opioids, despite the fact that this was due to the absence of any such studies. With the support of opioid manufacturers including Purdue Pharma, the team produced a pamphlet and gave many presentations promoting chronic opioid therapy. In the wake of the current opioid epidemic both Dr. Foley and Dr. Portenoy defend their roles by citing the lack of evidence in the 1980's that we have today, and both continue to work in the field of pain management. Many patients and physicians jumped at this supposed safe and effective treatment for chronic pain

management, and large pharmaceutical companies had no qualms about supporting the movement. This breakthrough looked to be a solution for the quarter of a million individuals suffering from chronic pain and as a result a lower quality of life and productivity. There were other physicians that spoke up and highlighted the lack of existing studies, the observed addictive behaviors, the dangers associated with overdose and serious side effects including those on cognitive function (Meldrum 2016). Things took a turn for the worse when Purdue Pharma began heavily pushing their new extended release OxyContin, and both well-intentioned and more financially motivated physicians began prescribing it liberally. Addicts quickly realized how to divert the medication by tampering with the pills or using very high doses, as well as how lucrative the illegal sale of such medications could be. When certain agencies began cracking down on the prescription of such substances, street prices soared and business savvy drug dealers began targeting the sale of their more modestly priced heroin to the often middle-class addicts who were no longer able to support their pill habit. As a result heroin became less off-limits while more dangerous opioids such as Fentanyl came into play, ultimately landing our society with the challenges we are facing today. (Meldrum 2016)

This story contextualizes the data, specifically the fact the 4 out of 5 new heroin users had their first exposure to opioids from prescribed medications (Muhuri, Gfroerer, & Davies 2013), and that despite all of the startling revelations surrounding the addictive qualities of opioids 2016 data from the Drug Enforcement Agency (DEA) indicates healthcare providers continue to prescribe such medication in quantities greater than medically indicated (Maughan, et al. 2016). The duration of treatment and quantity of medication dispensed are important because data shows that the probability of long-term

opioid use increased with each day of use (Shah, Hayes, & Martin 2017). The history of the epidemic and the current failure of physicians to appropriately prescribe these dangerous medications are important examples of how we have failed the community of people who inject drugs from a preventative standpoint. The less expensive and more readily available heroin has led to 300,000 Americans reporting using heroin in the last year, and a 16.3% increase in overdose deaths between 2016-2017 (CDC 2018, HHS 2016). Nationally, the opioid crisis cost an estimated $504 billion, or 2.8% of the gross domestic profit (GDP) in 2015, and resulted in a 20% reduction in the male workforce (Case & Deaton 2017, CEA 2017).

On a local level, data suggests that in Philadelphia between 50,000 and 60,000 people misused a prescription opioid medication in the last year, and a conservative count estimates there are 70,000 heroin users in Philadelphia (HHS 2013). As a result Philadelphia sees 46.8 drug overdose deaths per 100,000 residents per year, 80% of which involve opioids, which is greater than Chicago and New York City combined (Paone, Tuazon, Nolan, & Mantha 2016). The face of the epidemic in Philadelphia is mostly non-Hispanic white males between the ages of 35-54 years old, many of which flock to the Kensington and North Philadelphia neighborhoods of the city (Samkoff & Baker 1982, Philadelphia Department of Public Health 2017). Despite the approximately 14,000 Philadelphians treated within the Community Behavioral Health (CBH) network of opioid treatment programs, residential treatment facilities, halfway houses, Crisis Response Centers, hospitals and case managers it is clearly not enough (Kenney 2017). Philadelphia's war on drugs is just a smaller scale example of what is occurring on a

national level, and magnifies the fact that although efforts are being made to help this community of individuals addicted to opioids it is not enough.

The failure of the medical community to prevent the current opioid epidemic leaves our society in the difficult position of trying to play catch up by reducing current harms and helping those ready to engage in treatment. Harm reduction is a relatively recent international movement rooted in activism and research that shifts the focus from complete abstinence from drug use, to people who use drugs and prevention of harms related to drug use (Harm Reduction International 2018). Nationally, the political climate surrounding the acceptance of harm reduction is beginning to change. This began during the final years of the Obama administration, and more recently has captivated the attention of historically conservative politicians now being faced with rapidly growing fractions of their constituents battling opioid addiction (Nadelmann & LaSalle 2017). Unfortunately, this highlights a common theme surrounding the care for PWID which is that those with the most power and means to help this community often dodge the controversial topic until it has grown to such proportions that it is no longer avoidable. Here I would like to highlight some of the more widely accepted harm reduction practices seen across the country, as well as a few more controversial options some states have begun to explore.

Syringe Exchange Programs are one of the more widely accepted harm reduction interventions and are responsible for a substantial decrease in the transmission of HIV and Hepatitis C from the sharing of used needles. For example, HIV in PWID declined by 70% between 2002 to 2011 due to the increased availability of sterile syringes

(Lancaster, Santana, Madden, & Ritter 2015). Despite the acceptance from many leading governmental, medical, and public health associations there are still 14 states today without this service (Hodel 2015, Directory of syringe exchange programs 2017). It is also concerning that 12 of the states that do employ safe needle exchange facilities only have them available in one or two of their cities, and data suggests that the exchange programs that exist nationally only meet 3% of the estimated need (Directory of syringe exchange programs 2017, Hodel 2015). This illustrates another common thread among the harm reduction conversation that while doing something is better than nothing what we are doing is clearly not enough.

Another rather widely accepted solution is the use of opioid agonist therapy to help individuals addicted to heroin transition to a safer, regulated opioid substitute as a first step towards recovery. Two major issues accompanying this therapy are the associated stigma and the difficulty accessing them. Methadone and Buprenorphine, also known as Suboxone, are widely recognized as the most effective treatment for opioid use disorder (National consensus development panel on effective medical treatment of opiate addiction 1998). A widely accepted misconception is that these substances are just allowing PWID to substitute one drug for another, which has led to a generalized stigmatization of opioid agonist therapies. However, the stigma surrounding Methadone specifically tends to be more severe as patients are required to appear daily at specialized clinics in order to access this highly regulated substance (Rettig & Yarmolinsky 1995, Kleber 2008). Conversely, Buprenorphine is available in the more private setting of a physician's office. There are also significant differences between the populations who receive Methadone compared to Buprenorphine which further feed into the stigmatization

of Methadone. For example, individuals who receive Buprenorphine are more likely to be white, employed and college-educated (Hansen, et al. 2013). In addition to the social barriers associated with opioid agonist therapy there is the issue of access and the multitude of bureaucratic hoops one must jump through to obtain their medication. To start, reportedly only 9% of drug treatment facilities in the United States offer opioid agonist therapy (Substance Abuse and Mental Health Services Administration 2017). Additionally, access to Buprenorphine is limited by insurance coverage and the number of prescriptions any one provider can write (Nadelmann & LaSalle 2017). Meanwhile the heavy government restrictions and inflexible practices of many Methadone clinics make the system a challenging one to navigate even before taking into account the mental and physical state of someone who may be seeking Methadone therapy (Nadelmann & LaSalle 2017). Furthermore, it is not uncommon for someone on opioid agonist therapy to lose access if they are incarcerated. As a result, less than 10% of individuals who are opioid dependent are receiving these therapies (Nosyk, et al. 2015), again highlighting how much room for improvement exists.

According to the CDC our country is currently enduring the "worst drug overdose epidemic in history," so it should come as no surprise that there is a large focus on improving our overdose prevention interventions (Paulozzi 2008). Cracking down on supply reduction and prosecution of both the sale of opioids and accidental drug-induced homicides have proved challenging and there is little evidence of their efficacy in reducing opioid overdoses (Nadelmann & LaSalle 2017). There has been a national effort to improve access to Naloxone, also known as Narcan, an opioid antagonist used to essentially reverse an opioid overdose. There are currently 44 states that allow

pharmacies to distribute Naloxone without a prescription, although the majority of the medication distributed still goes to law enforcement and first responders (Davis & Carr 2017). Furthermore, states are able to use federal funds for purchasing and distribution (Nadelmann & LaSalle 2017). In addition to increasing access to Narcan, 36 states and the District of Columbia have passed Good Samaritan Laws to protect citizens who call for emergency assistance in the event of a drug overdose (Davis, Chang, & Carr 2017). Good Samaritan Laws protect the bystander from arrest or prosecution for drug related crimes including possession of drugs or paraphernalia. While these laws are not perfect and vary by state, the hope is that they will encourage people to seek emergency assistance if they experience or are a witness to a drug overdose (Davis, Chang, & Carr 2017). Promoting wide distribution of Narcan in combination with Good Samaritan Laws puts the power and the responsibility in the hands of both the PWID and the surrounding community.

In addition to these more widely accepted and studied interventions, there are certain regions of the country that have begun to explore more controversial methods of opioid harm reduction. Safe Consumption Site (SCS), also known as safe injection sites or comprehensive user engagement sites (CUES), is one such intervention that several states have demonstrated interest in pursuing. California, Maryland, Massachusetts, and Vermont have introduced bills to establish such sites, and King County of Seattle, Washington in 2017 voted unanimously to establish two pilot sites (Nadelmann & LaSalle 2017). Such facilities aim to minimize disease transmission by providing sterile needles, decrease overdose fatalities by having Narcan and medical staff on site, reduce the burden of public injection on the community, and have resources on site for health

and social services as well as referral to drug treatment programs. SCSs exist in other countries including Canada and Australia, but such models are difficult to replicate in the U.S. due to differences in health insurance and legal systems. The prospect of federal intervention is also a major obstacle to the implementation of such facilities in America.

Another provocative therapy supported by bills out of Maryland and Nevada is known as heroin assisted treatment (HAT). Such programs distribute pharmaceutical-grade heroin in specialized clinics with close monitoring by healthcare professional to individuals who have failed conventional treatments but would like to stop using illicit heroin (Nadelmann & LaSalle 2017). Research trials conducted in Canada, Switzerland, the Netherlands, Germany, Spain and the United Kingdom have demonstrated positive therapeutic outcomes, and suggest the implementation of HAT is "feasible, effective, and safe" as a last resort for people addicted to heroin who cannot be effectively treated with other available interventions (Fischer, et al. 2007). Of course there are political and social barriers facing this active area of research including growing polysubstance use and the fact there is currently only short-term data available; however, the robust results warrant long-term examination of the therapy.

Medical cannabis has also been proposed to have harm reduction benefits for individuals addicted to heroin and other opioid medications. Studies have shown that when marijuana is available as an alternative therapy for pain management there is a reduction in mortality, individuals use lower doses of opioids, and they experience fewer side effects (Abrams, et al. 2011). Recent data has also demonstrated that states with dispensaries experienced 15-35% reduction in substance abuse hospital admissions and

opioid overdose deaths, and that states with medical cannabis laws had an approximately 25% lower mean annual opioid overdose mortality rate compared to states without such laws (Powell, Pacula, & Jacobson 2015, Bachhuber & Saloner 2014). There is still a lack of conclusive data on whether or not cannabis can be used as a therapy to treat opioid addiction but there are ongoing trials (Hurd, et al. 2015).

Finally, both Seattle and Santa Fe have begun piloting Law Enforcement Assisted Diversion (LEAD) Programs that in some ways resemble a Portuguese-style decriminalization of heroin. This is a "pre-booking diversion program" that provides police and prosecutors the discretion to redirect those accused of low-level drug offenses to community based supportive services as an alternative to processing them through the criminal justice system (Drug Policy Alliance 2016). This intervention has been described as one of the least coercive forms of drug enforcement, and initial evaluations have been strongly positive (Nadelmann & LaSalle 2017). Briefly, in 2001 Prime Minister António Guterres, the current United Nations Secretary General, decriminalized the use of all drugs and launched a massive public health campaign to address drug addiction in Portugal. The legislation did not legalize drug use, but made purchasing or possessing small quantities of drugs an administrative offense instead of a criminal one. Those found in violation were required to appear before a multidisciplinary "Dissuasion Commission" who attempted to intervene before an individual's drug use escalated to an addiction, or rarely handed out a fine. During the first year of the policy an increase in drug use was observed, however there was an overall decline in morbidity and mortality due to public health efforts put in place. The decriminalization and public health interventions were accompanied by a societal shift in the way the country approached

drug addiction, from viewing it as a criminal justice issue to a medical challenge, and viewing people suffering from drug addiction disorders as struggling with a chronic illness. By the numbers, in 2018 there are an estimated 25,000 heroin users in Portugal compared to 100,000 when the policy began, and at its peak there was an 85% decrease in overdose deaths (Kristof 2017). If the U.S. saw similar results it would equate to saving 1 life every 10 minutes, or the number of lives currently lost to guns and car accidents combined (Kristof 2017). Although there are vast differences between the U.S. and Portugal that complicate implementing such a policy in our country, this concept poses the question of whether it is possible to "win the war on drugs by ending it" (Kristof 2017).

Ultimately, the U.S. has made leaps and bounds in embracing harm reduction interventions as part of the solution to our current opioid epidemic, however we still have a long way to go. Beyond the unacceptably high number of lives that continue to be lost, our current interventions are not as effective as we had hoped and the epidemic has cost us $504 billion (CEA 2017). Meanwhile, it is estimated that every $1 spent on implementation of evidence based medicine (EBM) interventions can have a benefit of $58, treatment for substance use disorders can save $4 in healthcare costs, and saves $7 in criminal costs (Ettner, et al. 2006). It is time for us as a nation to recalibrate, and as we search for a new direction we must also seek guidance and possibly a new perspective. While we can continue to reference the trials and tribulations of other nations, it may also benefit us to seek out an ethical lens to help navigate this issue that sits at the intersection of public health and bioethics, as well as to listen for the voice of the community of PWID that are targeted and most impacted by our harm reduction interventions.

Voices from People Who Inject Drugs

One would think that for such a crisis we would have paid more attention to this population of people who inject drugs, but we have not. As a society, we have thought to study them and the interventions we decide are best for them, but engagement of this community is almost always an afterthought. Not only is this problematic from an ethical standpoint, but in the context of our national opioid epidemic that continues to rack up a body count and bleed scarce funds one would think we might consult someone on the inside for feedback if not suggestions on how we might better support their community. There is very little research that has been conducted with the primary objective of seeking the perspectives of PWID, and minimal studies that address this as a secondary or tertiary aim. A 2017 study out of Canada conducted by Boucher et. al. focused on investigating how PWID think about harm reduction which provides a unique dataset that may aid the U.S in developing new or improved harm reduction interventions, and offers a model for how future research opportunities could play out in the U.S. (Boucher, et al. 2017). In addition, a recent article published about the perceptions of PWID in Philadelphia on supervised injection facilities, and some informal conversations with individuals in recovery shed some light on the insights of the Philadelphia community of PWID (Harris, et al. 2018).

In their study Boucher and their colleagues sought the perspectives of PWID in a Canadian Urban Center on three main aspects of harm reduction: their personal histories of drug use and daily harm reduction strategies, facilitators and barriers to using harm

reduction strategies, and suggestions for improving supportive services (Boucher, et al. 2017). An interesting revelation was that for many the motivation to adopt harm reduction strategies and what they considered harm reduction strategies went beyond the traditional concerns of the healthcare community. Some of the participants' personal practices included drug moderation, engagement in the community, and using cognitive and behavioral strategies. The practice of moderation encompassed replacing "more problematic substances" with others that had less impact on their overall functionality such as marijuana, alcohol, nicotine and prescription medications. For others moderation meant attempting to follow medication instructions, minimizing drug use that interfered with prescribed treatments, and seeking treatment for mental illness or addiction disorders. Engaging in activities with other individuals who use drugs or other marginalized populations afforded an opportunity to help others while benefiting themselves by sharing their personal stories of drug use and disseminating information regarding services and training opportunities. In addition, the community reported using self-reflection or increased awareness, and distraction techniques such as staying active or sticking to a routine to help them manage their substance use. Participants also reported using more traditional safe drug use practices, focusing on basic self-care, and fail-safes such as not keeping any cash readily available. Overall, participants preferred having opportunities to self-regulate their harm reduction practices. In addition to the unique harm reduction techniques study participants reported, it was also apparent they had multidimensional reasons for using harm reduction strategies including improving their health, mending social relationships, setting goals to return to normal or find balance, and taking pride in their harm reduction efforts. (Boucher, et al. 2017)

This study also inquired about the facilitators and barriers PWID perceived to using harm reduction strategies. Participants reported that having support in both their social and physical environments aided them in pursuing harm reduction techniques. These supports included emotional support from loved ones and trusted providers, stable housing and income, as well as opportunities to better their communities and themselves both physically and mentally. Other facilitators identified by participants included continuity of care with trusted providers in health and social service settings, developing one's self-esteem, and receiving support from people with lived experiences. Some even reported learning the most about harm reduction from their peers. Conversely, participants also identified multiple obstacles to engaging in harm reduction for instance the rigid eligibility criteria and procedures of health and social services, and accurate information regarding existing harm reduction services accessible to the entire community. Social barriers were also identified including negative affect from family and traumatic circumstances, as well as societal stigmatization and discrimination based on factors such as drug use, homelessness, mental illness, and having an infectious disease. Participants reported often avoiding seeking out services or lying and trying to hide their drug use when interacting with healthcare providers due to past interactions where they felt they were treated with condescension and disrespect. One individual recounted an instance during a hospitalization where they could hear a conversation outside of their room between healthcare workers about them, and remembered "feeling like I wasn't worth much anyway" (Boucher, et al. 2017: page 11).The researchers reported that the topic of barriers to accessing harm reduction strategies was strongly emphasized by the participants in their interviews, and they stressed the importance of addressing the "socio-

structural issues" PWID regularly face in order to design the most effective harm reduction techniques (Boucher, et al. 2017).

An important takeaway from Boucher's work is that "one size does not fit all when it comes to harm reduction" (Boucher, et al. 2017: page 15). The authors highlight the fact that the harm reduction strategies used by PWID in their daily life often are not included in the spectrum of interventions endorsed by public health organizations, however we should still consider them as theoretically effective interventions (UNODC 2016). Similarly, although the strategies suggested by those with lived experience may be difficult to evaluate using the scientific method, at the bare minimum they should be acknowledged as potentially useful techniques that could help other members of the community of PWID. In addition, the researchers pointed out that the current harm reduction services tend to focus on public safety and public health goals of reducing morbidity and mortality, as opposed to prioritizing addressing the needs of the community accessing services (Harris & Rhodes 2011). Finally, in their closing statements the group had two broad recommendations for implementing and improving harm reduction strategies moving forward: shifting the focus of opioid replacement therapy programs to a "person-centered care model," and increasing efforts to endorse facilitators such as development of self-esteem and self-efficacy, continuity of care, and offering more opportunities for peer support. All in all, I believe this study is a shining example of the invaluable information that can be gleaned from engaging the community of PWID.

While there are currently no studies similar to Boucher's published in the U.S. there has been a growing interest surrounding engaging both the community of PWID and members of surrounding communities impacted by intravenous drug use as the nation looks to improve and implement new harm reduction interventions. A recent study conducted by a group of researchers from multiple Philadelphia healthcare institutions sought the perspective of PWID on safe injection facilities (SIF) (Harris, et al. 2018). The topic of SIF is quite relevant in the city of Philadelphia since the Mayor's Task Force to Combat the Opioid Epidemic in Philadelphia released a final report in May 2017, including a recommendation to "further explore Comprehensive User Engagement Sites (CUES)," also known as SIF (Kenney 2017). Two strong themes emerged from the small study, the first being that opinions on SIF were strongly dependent on access to stable housing (Harris, et al. 2018). More specifically, individuals with access to stable housing reported that they were unlikely to use a SIF unless they were very sick, opposed to those experiencing housing instability who said they were more likely to use such a facility. The second major theme expressed was a dual imperative between seclusion and public visibility exists for PWID without housing in order to stay safe (Harris, et al. 2018). PWID in public report a constant struggle between seeking seclusion in order to shield the surrounding community and themselves from robbery, assault, or being arrested, and the fear of violence or not being found in the event of an overdose if they were to use in more remote locations. This study is certainly a step in the right direction, and demonstrates the importance of continuing this type of research with the communities of PWID in the United States.

In the spirit of giving a voice to those you hope to help I had the opportunity to exercise my ability to just listen when my medical school invited a group of people in long-term recovery to tell their stories and discuss barriers to care in an informal setting. There was minimal prompting by the facilitator and the participants were able to share their perspectives over the course of an hour. After reflecting on my notes from the event, I identified several common themes across the participants' stories that I would like to add to the conversation surrounding the development of more effective harm reduction strategies. An overwhelming amount of what was said came back to the concepts of respect and support, and barriers to care often involved disconnect in one of these two areas. Language was something that played heavily into an individual feeling respected. The importance of person-first language such as "people who inject drugs" or "person in recovery" was vital to the self-esteem and empowerment one felt. They also expressed the security that came from hearing a service was "recovery friendly," because they had consciously put out that message and they felt they were more likely to be understanding and respectful of their experiences. The group also expressed that they felt respected during nonjudgmental interactions when they felt cared for, listened to, and valued. Conversely, judgmental, derogatory language and being stigmatized by labels such as "drug user" left people feeling disrespected and lowered their feelings of self-worth which often led to avoidance of health and social support services.

The second major theme of the group discussion was support, and it took a variety of forms for the participants. On one hand, it was support they received from others whether it be emotional comfort or the trust and reliability they gained from continuity of care. They expressed how meaningful it was to have a stable presence throughout their

continuum of recovery that they could rely on to advocate for them when they were unable to themselves. There was also the concept of empowerment, and helping them to support themselves. Promoting self-esteem and self-efficacy through education, independence, and giving them a purpose through community initiatives such as peer-counseling and opportunities to share their stories were important in the recovery process. Additionally, regaining self-worth through feeling empowered, and having that worth reaffirmed by others in the form of "love from strangers" and altruism also seemed to have been very influential for the participants. Alternatively, various forms of instability proved challenging barriers to overcome in order to obtain care and recovery. The group discussed the impact of structural instabilities related to housing, food, education and employment that resulted from their inability to rationally prioritize when they were actively under the influence of substances. Emotional instability due to the lack of a reliable support system, or feeling as if they did not belong to a community because they "weren't normal" served as a challenging hurdle to recovery and seeking help. Others mentioned the impact of mental instability related to the grueling nature of battling an addiction disorder or due to a comorbid mental illness. When discussing harm reduction it is easy to focus on the drugs and their associated effects, however this conversation clearly indicates the social determinants people in recovery identify as some of their biggest obstacles to health and recovery.

In the final minutes of the discussion the participants were prompted to identify qualities they sought in a good physician. They identified the importance of a person-centered, holistic approach to patient care that made them feel as if they were being treated as a person and not a disease. This encompassed relationship characteristics such

as respect, acceptance, hope, choice, and safety. They also advised the importance of continuity of care, and finding someone who is invested, listens, and is "good for you," as opposed to someone who is convenient and just there to "give you a pill." I was struck by how simple and obvious some of these standards appeared to me, but the stories I heard reminded me how easily they can be forgotten or lost along the way. When asked for parting comments, one statement truly impacted me. One young woman said "stop talking in rooms, go out and just listen because we are experts on our own stories," and this is exactly what I hope to persuade others to do. For it is not just the right thing or the most practical thing to do in order to develop more effective harm reduction techniques, but, most importantly, it is the ethical thing to do.

CHAPTER 3

A NEW BIOETHICS OF HARM REDUCTION FOR THE OPIOID EPIDEMIC

Developing an ethical framework is no easy task. However, it is an extremely rewarding one in that it helps to guide ethically centered decision making and to protect the rights of all communities that may be affected by the outcomes of such decisions. In the context of harm reduction, the lack of an ethical code potentially enables values and ethics to be taken as self-evident or demoted to second order issues in the dialogues surrounding pragmatic, clinical, and political considerations which in turn can mean missed opportunities (Fry, Treloar, & Maher 2005). Fry et. al. suggest three levels of ethics engagements in harm reduction research including macro, meso, and micro-ethics which I believe can be translated for broader use as an outline for the levels of ethics required for effective, ethical development of harm reduction interventions (Fry, Treloar, & Maher 2005).

Macro-Ethics: Societal Standards and Objectives for Future Policy and Practice

Macro-ethics is the broadest level of ethical engagement, and one that influences all subsequent levels. There are three macro-ethical considerations with massive implications for harm reduction policy and practice that require analysis at a societal level: defining harm reduction, taking a values stance on drug use, and the role of public health in correcting existing injustices. The question of what falls under the umbrella of harm reduction and who has the authority to make that distinction is an important matter. According to The International Harm Reduction Association, harm reduction encompasses “policies, programmes and practices that aim to reduce the harms associated

with the use of psychoactive drugs in people unable or unwilling to stop. The defining features are the focus on the prevention of harm, rather than on the prevention of drug use itself, and the focus on people who continue to use drugs" (Harm Reduction International 2018). The beauty of this definition is that it is relatively ambiguous and subjective. It also puts a clear focus on the community of people who use drugs who will experience the greatest impact from any interventions. It supports the idea that "one size does not fit all" when it comes to harm reduction, and leaves the concept of what constitutes a harm open to debate as well (Boucher, et al. 2017). The focus on the perspective of people who use drugs in the definition also stresses the importance of engaging such communities when discussing harm reduction to ensure we are indeed addressing actual harms identified by the community and therefore working toward the desired outcome. Additionally, this makes room for a variety of interventions to fall under harm reduction such as destigmatization and providing supports like stable housing, education, and employment at the discretion of the community of people who use drugs. As seen in Boucher's study, the PWID's definitions of wellness and harm reduction often differ from that of the public health or medical community's and it is important to be respectful, supportive, and to acknowledge these differences (Boucher, et al. 2017). While uncertainty in these terms does increase the potential to interject moral judgment and has led to some debate over what constitutes harm reduction as opposed to treatment, the risks seem to outweigh the benefits.

The issue of the morality of drug use is one that has previously been embedded in the debate surrounding harm reduction. Some members of the field claim that there should be a value-neutral attitude surrounding harm reduction, while others are of the

opinion that a side must be taken (Callahan & Jennings 2002, Pauly 2008). The concern is that trying to moralize the argument has the potential to portray drug use as "abnormal" and lesser than the "normal" standard of being healthy and drug-free, thereby potentially marginalizing "abnormal" people who use drugs (Keane 2003). The existence of an ideal state of health causes a shift in power that puts an emphasis on medical expertise and distracts from the reality that "health is not the only need or good health the only value" (Callahan & Jennings 2002). This can minimize and take attention away from the social harms the community of PWID also suffer from (Callahan & Jennings 2002, Boucher, et al. 2017). If instead substance use is viewed as a complex, relapsing, and chronic condition it is more suitable to approach harm reduction from a technical, public health perspective rather than a moral one, and therefore no value stance is necessary (Keane 2003, Pauly 2008). This disallows the justification of coercive practices by affording those battling addiction disorders the same rights to autonomy and freedom as anyone else (Keane 2003, Hathaway 2001). Acknowledging the centrality of human rights to harm reduction expands its reach from medical and social supports to challenging the stigmatization of PWID which can lead to more effective policy and reforms (Fry, Treloar, & Maher 2005, Hathaway 2001). Thus, by adopting a public health approach to drug addiction and harm reduction, we are next tasked with the creation of a professional ethics framework, similar to that of medical ethics, to guide decision making.

One area of tension that could benefit from an analysis using a macro-ethics framework is determining what role, if any, that public health plays in correcting existing injustices within the population of PWID. Harm reduction shifts the culture surrounding PWID from one where it is appropriate to allocate resources on the basis of deservedness

to one in which everyone is inherently deserving (Pauly 2008). This shift in culture also encourages taking a closer look at stereotypes associated with this vulnerable population, for example the label of "difficult patient" or "addict," and rather than accepting them at face value, instead delve into the social determinants of health and multiple constraints members of this population may be facing in accessing care. This relationship is captured by the inverse care law which states that those with significant health needs are often those with the least access to care (Pauly 2008). Inequities are by definition products of social processes and commonly the consequences of multiple factors including poverty, homelessness, unemployment, and lack of social support (Pauly 2008). If inequities are identified as barriers to accessing care or social determinants contributing to their current situation in life, the question that arises is whether or not public health initiatives should play a role in correcting them. Many members of the public health field support a philosophy that calls for public health initiatives to promote equitable distribution of resources to ensure a level of "species typical normal functioning" (Rawls 1971, Daniels 1985, Pauly 2008). However, the opposing perspective believes intervention is only morally required under certain conditions. Engelhardt posits that preexisting social inequities that are unfair in which a person or community were wronged by an identifiable source morally require intervention (Engelhardt 1986). Alternatively, inequities that are simply "unfortunate," which he defines as those resulting from "acts of God or circumstance," do not morally require intervention (Engelhardt 1986). So agreement within the public health community comes down to which forces we believe are responsible for the inequities experienced by the community of PWID: man or a higher power. One could argue the specific circumstances surrounding the inequities

facing the community of PWID as a result of an opioid addiction have a clear and identifiable source which includes the pharmaceutical industry, the medical community, and various governing bodies that facilitated the evolution and perpetuation of the opioid epidemic. This is not meant to remove personal autonomy from the illegal use of drugs, but to help justify a requisite of a public health response. Although it may be more difficult to convince Engelhardt that other social determinants of health, such as socioeconomic status, are not due to circumstance, we can instead appeal to the evidence based public health community with data supporting such an intervention on their part. There is a strong link between poor living conditions and poor health outcomes, and the most powerful predictor of health is class (Kass 2001). Therefore, it is appropriate, if not obligatory, for the creation of public health interventions to reduce poverty, substandard housing conditions, and inferior education at least to reduce morbidity and mortality of disease associated with such social determinants, if not because it is the ethical thing to do. Similarly, access to health services is also one of the most important determinants of health in both the obvious ways and in the impact of the nature of interactions between individuals and the healthcare community; thus, programs aimed at facilitating the act of seeking care and improving access to care are justified by the end goal of reducing morbidity and mortality (Pauly 2008). This type of argument is clear evidence for how essential an ethics framework for public health is to more effective harm reduction.

Meso-Ethics: A Public Health Ethics Framework

Traditionally the field of public health is thought to operate at the level of whole populations or societies and can come across as utilitarian or paternalistic, in contrast to

bioethics which is more individualistic and stresses civil liberties and individual autonomy (Callahan & Jennings 2002). While one option is to choose the type of ethical analysis on the basis of the specific problem, it is more practical to develop a style of ethical analysis unique to public health and the challenges commonly encountered in the field. Such ethical frameworks fall at the meso-ethical level of engagement. By nature public health is bestowed with a lot of power from the law and other governing bodies, therefore it requires a code of ethics (Kass 2001). A code of public health ethics is needed to address the social justice functions of the field. The code would help the field recognize the varied moral issues in its work, provide the field with a moral compass to deal with difficult issues current and future, and help public health professionals establish moral credibility by removing the subjectivity of decision making by instead trusting the code to inform proper ethical analysis (Kass 2001, Beauchamp & Childress 1979, Callahan & Jennings 2002). Having a bioethical influence may also help initiate a shift in thinking that starts with a focus on the individual and their rights before diving into questions of the common good (Pauly 2008). Additionally, despite being the noble, ethical method of approaching difficult circumstances, utilization of an ethical framework will lead to more respectful, evidence based interventions that will ultimately be more effective. Despite the many advantages to this analytic tool one must be aware that the ethical option may not coincide with what is politically preferable and be prepared to handle the challenges that may produce. Below is one suggested public health ethical framework as it may apply generally to topics related to harm reduction.

There are five steps one must complete when conducting an analysis using the public health ethical framework (Kass 2001, Kass & Gielen 1998, Gostin & Lazzarini

1997). The first is to identify the goals of a proposed intervention in terms of reduction of morbidity and mortality. For example, the goal of syringe exchange programs are to reduce the morbidity and mortality related to blood borne pathogens passed through sharing used needles. Any other benefits that may result from an intervention are either intermediary or incidental, but not viewed as a primary outcome. In the above example, this might include the feeling of being cared for and social connectedness PWID experienced when they visited support service sites, which in turn facilitated their use of personal harm reduction techniques (Boucher, et al. 2017). Another example is how providing PWID with stable housing helps decrease morbidity and mortality associated with overdoses because they have a safe place to inject and time to test their product for potency, and instills some stability in their life which facilitates their use of harm reduction techniques (Boucher, et al. 2017). In general, individual public health programs are not carried out unless they are part of a larger initiative with the combined initiative of reducing morbidity and mortality.

The second step is to assess a program's effectiveness on its achievement of its stated goals in terms of morbidity and mortality. "It is when our assumptions seem most intuitively obvious that we are at the greatest risk of neglecting to determine to what extent they are supported by real evidence," thus it is this second step which ensures we are making evidence based decisions (Kass 2001). For instance, health education campaigns are very effective at disseminating information and patients can easily comprehend and repeat the material, however they are less successful at inducing changes in behavior which impact morbidity and mortality. The authors of the suggested framework add that a rule of thumb regarding the quality of data required to justify the

implementation of a program: the greater the burden the program poses, the stronger the evidence must be to demonstrate the program will achieve its goals (Kass 2001). Commonly programs are imposed by an outside influence such as a governing body, the medical community or researchers rather than being sought out by citizens, so it is the responsibility of those implementing the program to provide evidence supporting the program's success, and as discussed later, that the benefits of an intervention outweigh its risks.

The next phase in the analytic process is to identify potential burdens or harms of the intervention and explore methods of minimizing them, as well as alternative approaches to address the same issues that may be less burdensome. Burdens to an individual's privacy and confidentiality can potentially put them in danger or at risk for stigmatization, and infringements on liberty and self-determination may be coercive and threaten one's autonomy (Rendtorff & Kemp 2000). It is the risk of justice violations, or unfair distribution of harms and benefits in society, that is prevalent across several types of interventions and must also be monitored. For example, health education campaigns are often viewed as harmless and participation completely voluntary, as you have the option to listen or to not listen. However, some have underlying aspects of paternalism and can suggest that there are ways of being that are universally valued, for example drug-free, which may lead to the stigmatization of those who do not conform to the universal mold or who seem to be the target of the message (Kass 2001). Another area of good intention that risks infringement on justice is public health research. Certain populations may be disproportionately harmed or benefit through a research effort, or if research findings are never translated into policy the risk-benefits ratio becomes

unfavorable because they do not accrue any of the benefits they were promised in the informed consent process (Kass 2001). In most cases one is ethically required to choose the option with fewer risks to "moral claims" as long as there is no significant impact on benefits received as demonstrated by sound data. In the world of harm reduction and drug use, this may take the form of a code of restraint in order to preserve the negative rights of citizens, such as the right to use potentially harmful drugs (Kass 2001, Fry, Treloar, & Maher 2005). The conflict between the noninterference rights of an individual and the needs of the larger community can serve as an added hurdle to developing population-based health strategies that do not ignore the special needs of individuals, but the next tenet of the public health ethical framework serves to examine program injustices more closely (Callahan & Jennings 2002).

As previously alluded to, the fourth checkpoint in the public health ethical analysis is to ensure a program is implemented fairly, and it is closely related to the final step of process which aims to ensure a fair and just balance of benefits and burdens of a program. Here two general principles come into play: the precautionary principle and distributive justice (Callahan & Jennings 2002, Beauchamp & Childress 1979). First, the precautionary principle dictates that the burden of proof that benefits outweigh threats, and that a risk is rationally worth taking, lies with those who initiate the risk (Callahan & Jennings 2002). For example, in harm reduction involving PWID the burden of proof lies with those motivated to remove risk, which could be the government, medical professionals, or PWID themselves; however, this is complicated by the fact that PWID are not always able to advocate for themselves in which instance it falls to their allies

including physicians, support services, politicians and the public health community to fight with them and for them.

The principle of distributive justice refers to fair distribution of the benefits and burdens related to an intervention (Beauchamp & Childress 1979). Unfortunately, it is not uncommon for the burdens of a program to fall overwhelmingly to the individuals with a disease while mostly benefiting others without a disease. Harm reduction initiatives often involve a complex, contradictory relationship between benefits to the wider community but not necessarily to the PWID that they target (Ezard 2001). Only on limited occasions are such injustices validated because of how important the benefits are and no less burdensome way to achieve them exists. If such a check is not in place it may lead to social harms such as stereotyping, or public health harms including a decrease in vigilance by populations who do not fit the popular risk profile portrayed by educational campaigns. Lastly, many of the previous steps help to ensure that a program fairly balances risks and rewards. By effectively recognizing and attempting to minimize the burdens of a program early on it is more likely a program will be implemented in a nondiscriminatory way, especially if it is backed by sound data. A final word of advice from the author suggested dissent in and of itself does not inhibit the implementation of a program, but special attention should be paid to such sentiments if they are raised by a particular subgroup such as an ethnic minority or residents of a particular neighborhood (Kass 2001). In total, these guidelines aim to produce ethically informed, community engaging, evidence based public health initiatives that promote responsible politics (Callahan & Jennings 2002).

Micro-Ethics: Reflexivity and the Ethics of Everyday Interactions

Once a harm reduction intervention has been analyzed through a public health ethical framework it must find a balance with the micro-ethics of everyday practice. Micro-ethical engagement encompasses the difficult situations medical practitioners, counselors, and researchers encounter throughout their daily interactions which are often subtle and unpredictable. This sentiment is expertly captured by a quote from Keane's work in which he states "ethics is what happens in every interaction between every doctor and every patient" (Komesaroff 1995). Examples of such ethically important moments are facing a pregnant patient who admits to active substance use, a client in recovery who has a positive urine drug screen, or enrolling a research subject who is under the influence of a drug. As we have learned from the PWID quoted earlier in the article, ethics are not always apparent in every patient-doctor interaction; however, it is a goal that will become more attainable by providing physicians and other healthcare workers with the proper tools. In contrast to the professional code of ethics proposed for analyzing potential public health interventions, the notion of reflexivity is suggested to examine ethical circumstances encountered in everyday life (Guilleman & Gillam 2004). By being reflexive one acknowledges and is sensitized to the micro-ethical dimensions of research and clinical practice so to be alert and prepared to deal with ethical tensions that arise (Guilleman & Gillam 2004). Those working in the field of harm reduction must become comfortable with self-scrutiny and the practice of constantly taking stock of their role and actions (Guilleman & Gillam 2004). By utilizing the principle of reflexivity practitioners

respectfully acknowledges that “no one size fits all” when it comes to harm reduction, and the importance of a person-centered, collaborative approach.

In summary, an ethically engaged approach to harm reduction requires taking a step back to appreciate the various levels at which we may encounter ethical dilemmas. By preparing on a societal, procedural, and practical level we are better equipped to make consistently ethically informed, evidence-based, community-centered decisions that will serve to produce more effective harm reduction interventions and help us avoid mistakes of the past. Moving forward, I would like to combine the data presented here from the PWID, ethical, and research communities to put forward a set of recommendations to address representatives from each level of ethical engagement such as society and policy makers, public health workers, and medical practitioners.

CHAPTER 4

HOW EMBRACING COMMUNITY ENGAGEMENT WILL LEAD TO MORE SUCCESSFUL HARM-REDUCTION INTERVENTIONS FOR PEOPLE WHO INJECT DRUGS

As a nation we have reached a point where we must be pragmatic and come to terms with the reality that elimination of drug use is not attainable, nor our goal. Instead we may embrace the idea of trying to "win the war on drugs by ending it," and turn our full efforts toward addressing the harms associated with drug use (Kristof 2017). Not only have interventions solely focused on drug effects proven to be ineffective, they insufficiently address the health and social inequities faced by PWID (Pauly 2008). If we do not recalibrate our expectations we are in danger of "political romanticism" - or minimizing the everyday, impactful achievements of harm reduction approaches compared to achieving a drug-free ideal (Keane 2003). A public health approach is what we need to help ensure justice while focusing on minimizing the harms associated with substance use and protecting the community of PWID. In combination with its professional ethics framework, a public health perspective also promotes harm reduction interventions which are ethically informed, evidence based and community engaging that in turn promote more responsible politics surrounding this controversial issue.

Our current efforts are not adequately addressing the crisis at hand, and as a result engagement of the community of PWID in the harm reduction conversation is no longer negotiable. There has been a lot of chatter but not enough listening, which is what we need if we desire continued innovation and improvement of harm reduction interventions. It has been made clear by the limited perspectives of PWID we are privileged to have that

"one size does not fit all" when it comes to harm reduction, and we need to seek out their lived experience in order to guide our efforts (Boucher, et al. 2017). The varied, wide-reaching definitions of harm and harm reduction were also demonstrated, and we could benefit from this unique view point to identify new problems as well as original solutions. We must promote meaningful participation and continued involvement to create more sustainable, relevant interventions (Paterson & Panessa 2008). Most importantly, we must prioritize such initiatives in order to express our gratitude and respect for their willingness to collaborate. Without such perspectives we will continue to look for inspiration in other countries with vastly different social, legal, and healthcare systems from our own and speculate about the needs of the community of PWID in the United States. For example, a recent report from the Mayor of Philadelphia's office recommended the exploration of implementing SIF in our city. The first of many community forums was held and there was a lot of noise but one very noticeably absent voice. The lack of participation from PWID spoke volumes to me, and signified the need to address the inequalities faced by the community, their needs, and the barriers to their participation before we try to institute any controversial interventions.

The concept of the "risk environment framework" comes from Dr. Tim Rhodes, a London Professor of Public Health Sociology whose work focuses on the social relations surrounding access to care. It is presented in several of his writings and it expertly encompasses the areas in which I believe the most energy should be focused in order to improve harm reduction (Rhodes 2002, Rhodes 2009). He states "harm reduction interventions are social interventions, subject to the relativity of risk and to variations in population behavior in different social, cultural, economic, legal, policy and political

environments. The relative success of individual, community and policy interventions are shaped by the risk environments in which they occur" (Rhodes 2002, Rhodes 2009). Rhodes also references how certain issues relate to specific risk environments such as "housing stability (an important part of the physical environment), financial stability (central to the economic environment), criminalization (largely a result of the policy environment), relationship problems and peer pressure (key to the social environment), as well as challenges related to physical or mental health issues" which I believe could constitute the medical environment (Rhodes 2009). Based on the limited data we do have from PWID regarding harm reduction, I believe there are several of these environments that correspond with concerns and desires they voiced that should be addressed while we work toward obtaining a more representative sample.

Stigmatization is a prominent barrier to accessing care and a theme common throughout the PWID, which constitutes part of one's social environment. Adoption of a public health ethics code promotes the treatment of drug use as a complicated, chronic illness which eliminates the need for a moral stance on the subject. Additionally, in the spirit of public health this is a harm that must be reduced in order to decrease the morbidity and mortality associated with avoidance of seeking care or engaging in harm reduction techniques that occur as a result of stigmatization. In addition to perception, an important component of abolishing stigma is the promotion of using positive, nonjudgmental, person-centered language in the conversations surrounding drug use and PWID. Furthermore, the promotion of a broad definition of harm and harm reduction focused on the perspective of PWID like that of The International Harm Reduction

Association is important in empowering their community to request the supports they need.

Addressing the topic of criminalization of drug use is another avenue to battle stigmatization of PWID (Rhodes 2009). Circling back to the public health approach to harm reduction and drug use, the message that addiction is an illness puts into question the ethicality of punitive rather than supportive action against PWID, and aims to protect the centrality of human rights to the harm reduction movement including the right to noninterference (Pauly 2008). The public health ethics framework requires the goals and achievements of an intervention to be expressed in terms of reduced morbidity and mortality. It also necessitates the presentation of supporting evidence in order to justify the risks involved with an intervention. Incarceration has never had this type of data supporting it, thus failing to satisfy the framework on multiple levels which should at least raise the question on whether or not we are operating based on assumptions and norms, and if it is right to continue. In fact, the illegality of drug use produces some of the most obvious harms (Keane 2003). Decriminalization is a topic that would require extensive community engagement and collaboration with various governing bodies, but the possibility of a Portuguese-style movement or further investigation into a more widespread implementation of LEAD Programs are intriguing areas of investigation (Kristof 2017); especially given that fact that the harder we fight the current war on drugs the worse we seem to fare.

In addition to stigmatization, another common theme throughout the interviews with PWID was instability, or vulnerability they experienced in both physical and social

areas of their lives. Aspects of the physical environment such as stable housing and income are things some may consider necessities but are easily deprioritized when one struggles with addiction to a substance. Earlier in the macro-ethics portion of this piece I entertained both the moral and practical argument for the field of public health addressing such inequities in order to help break down barriers to accessing care, broaden the span of harm reduction interventions, and decreasing morbidity and mortality. Providing stable housing is one example of a harm reduction strategy that addresses an inequity while decreasing morbidity and mortality. This is an issue that also appears to be strongly associated with intravenous drug use and its associated harms, and the current magnitude of homelessness represents the many gaps that exist in the social safety net (Turnbull, Muckle, & Masters 2007).

Drug addiction is just one of many variables that perpetuate homelessness including poverty, lack of family or social support, failed government policies, societal isolation, mental illness and lack of resilience (Turnbull, Muckle, & Masters 2007). None of these factors have simple solutions, which often make them politically unfavorable. However, data shows that the homeless community's age adjusted mortality is 2-8 times greater than housed individuals despite suffering from the same illnesses and utilizing a disproportionate amount of the social, judicial and healthcare system (Turnbull, Muckle, & Masters 2007). Some of the more forward thinking interventions addressing homelessness include Housing First and the Prevention Point Shelter in the Kensington neighborhood of Philadelphia (Turnbull, Muckle, & Masters 2007, Whelan 2018). Housing First is an organization that assists individuals and their families in prioritizing finding permanent housing in order to support them in improving their quality of life and

pursuing their personal goals. They appreciate that in order to attend to critical issues in one's life they need to take care of the bare necessities first. They also understand how challenging it is for some to comply with mandated programs aimed at treatment of substance use and mental health disorders, and instead provide services their clients can take advantage of on a voluntary basis. As a result they have found people who participate of their own accord are more likely to invest themselves more heavily and for a sustained period of time. A Philadelphia group with similar insight into the needs of the community of PWID is Prevention Point who created a 40 bed shelter in an abandoned storefront in Kensington in order to house people during the challenging winter (Whelan 2018). By the same token they do not require residents be in recovery or detoxing, nor do they impose other demanding regulations such as curfews. They went above and beyond to meet people where they are, as Kensington is the heart of the opioid epidemic in Philadelphia, and they hoped to eliminate the social isolation PWID can feel when transported to a shelter located far away from their community. They do not allow drug use inside of the facility, however they do store paraphernalia including syringes for residents during their stay. They hope to build trust with the community and eventually facilitate getting people into treatment programs. To date they have taken in 160 members of the community of PWID, and helped 50 into treatment (Whelan 2018). One salient quote from a resident of the shelter requested "give us a cot, give us a room, give us a chance," and I believe this flawlessly captures the spirit of harm reduction -- just trying to give PWID a chance (Whelan 2018).

In addition to physical instability, PWID also reported experiencing instability within their social environment. They cited a lack of support from their families and a

sense of disconnect from community as the source of feelings of low self-worth and self-esteem, and as barriers to accessing harm reduction techniques. It was suggested strongly by both groups interviewed that the feeling of belonging to a community and having an opportunity to give back gave them the feeling of empowerment and a sense of purpose (Boucher, et al. 2017). To begin, it is important to create supportive, caring healthcare environments which employ invested, nonjudgmental employees in an effort to craft a space that is both medically and emotionally healing, and hopefully discourages avoidance. In addition, the community and personal benefits of storytelling and peer interactions were also conveyed as important ways of feeling integrated, and in Boucher's study many individuals stated that the majority of their knowledge surrounding harm reduction techniques came from other members of their community (Boucher, et al. 2017). Facilitating interventions that put PWID in contact with people with lived experience and creating opportunities for them to give back to their community allows them to take ownership of their recovery and have the ability to self-regulate their harm reduction strategies. I believe it is also important to take one step further the idea of a panel member that the harm reduction community "stop talking in rooms, go out and just listen" and put members of the PWID community into the rooms. Engaging them in research and policy initiatives empowers them to help dictate what the future of harm reduction looks like and incorporates them into the larger harm reduction community. This comes with two caveats. First, we must be reflexive in determining what PWID involvement will look like and engage their input so that their roles may adapt to reflect their current abilities and avoid interfering with their healthcare and harm reduction routines (Strike, et al. 2016). This may look like more flexible times and

locations for group meetings, and voluntary attendance so they may attend as many or as few gatherings as they please without diminishing the impact of their contribution. Secondly, if we plan to solicit knowledge from their lived experiences we must follow through and prioritize the needs they express. This may require consideration of theoretically effective interventions they have witnessed the success of in practice but which may be very difficult to study in a randomized controlled trial setting. In turn, using the public health ethical framework to assess programs without scientific data backing their efficacy or evaluating their burdens will aid us in protecting this population and its rights while we allow the research community time to evolve their methods in order to produce an evidential basis.

Finally, Rhodes references challenges PWID may encounter related to their physical or mental health issues which constitute their medical environment (Rhodes 2009). Outside of providing adequate access to quality healthcare, I believe interventions in this arena must also focus on properly training healthcare professionals in order to provide them with the tools they need to reach the gold standard of the presence of ethics in every doctor-patient interaction. Although physicians are generally caring and well intentioned the experiences of PWID have taught us that everyday ethically important moments are often not recognized or properly addressed which lead to feelings of disrespect, condescendence, and avoidance. By educating professionals on ethical challenges they may encounter in daily practice and insight into how to appropriately respond we may allow them to provide trauma informed, recovery friendly care despite the time and systemic constraints they experience. In addition, it is important to promote a patient-centered, holistic approach to caring for this population. Creating a

collaborative relationship validates PWID as experts on their own stories and allows them to contribute knowledge gleaned from their experiences to their care. It also promotes honesty regarding their current position on the continuum of recovery which may serve as an indicator to a physician about how well they are able to advocate for themselves, compared to when extra effort and deeper listening may be required to ascertain what they truly need. Providers can ensure PWID have accurate knowledge regarding harm reduction interventions they may benefit from and share with the greater community including how they can access Narcan, providing awareness of their state's Good Samaritan Laws, and the availability of local support and treatment services. Being able to react so reflexively to a patient requires a level of emotional engagement and trust from both parties which can only be established with continuity of care. Although this emotional investment is vital to the success of a doctor-patient relationship, it does not come without some risks to the physician including the potential for manipulation by a trusted patient. That being said, they must be prepared to take a step back from the situation and appreciate that the patient's actions are not a personal attack but part of the disease process they are suffering from, and have the ability to continue to provide them with the support they need to get through it.

There are additional interventions that can be designed to modify the medical environment at a systemic level. Overall, our healthcare system needs to become more reflexive in order meet patients where they are instead of requiring them to conform in order to receive help. Many PWID referenced the negative impact of rigid structures including protocol related to receiving opioid treatment programs, negative urine drug screen to receive care for mental illness, and requirements of being in recovery or detox

in order to be welcomed into a shelter (Boucher, et al. 2017). The examples of the above housing assistance programs demonstrate that such regulations are not required to ensure success, and should prompt the reevaluation of such standards. In addition, the culture of prescribing opioids for chronic pain management must also be addressed. As mentioned earlier, four out of five people who begin using heroin had their first opioid exposure in the form of prescription medications, and there is evidence of a strong correlation between likelihood of becoming addicted and the length of an opioid prescription (Muhuri, Gfroerer, & Davies 2013). Prescription monitoring has been implemented in most states and physicians are being reprimanded for overprescribing opioid medications which is beneficial for limiting the exposure of the public to opioids in general, however it leaves physicians in a precarious situation because they are still encountering complaints of chronic pain on a daily basis. In order to accommodate this patient population we must expand the scope of chronic pain interventions available and become more open-minded to options including national legalization of medical cannabis, complementary medical practices such as acupuncture, or programs that may only have theoretical or anecdotal evidence. They say when one door closes another opens, but in our current circumstance we are trying to avoid the replacement of prescription opioids with heroin so our better option may be opening a window.

CHAPTER 5

PARTING THOUGHTS

The current opioid epidemic has put an immense amount of pressure on our country. The force is so great that it has begun to unite political parties, yet it is still unable to integrate the community of PWID into mainstream society. We have reached a point where our only options are a new public health perspective and new and improved harm reduction interventions; engagement of the community of PWID is vital in accomplishing all of this. It may have been easy in the past to pretend the welfare of this community does not fall under your jurisdiction, turn off the news, or ignore the homeless you pass on your morning commute, but it will stand no more. We must rally as local communities, and as a nation in order to make sure we give everyone a chance.

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