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April 4, 2019

# Community Stigma and Opioid Use Disorder in Southern West Virginia

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## Community Stigma and Opioid Use Disorder in Southern West Virginia

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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
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#### Abstract

# Community Stigma and Opioid Use Disorder in Southern West Virginia By Karina Collins

This thesis explores the different types of stigma experienced during the opioid epidemic, using the town of Pineville, West Virginia as a case study. An exploration of stigma as a common experience during public health epidemics led to the discovery of two new stigmas that had not been previously observed: stigma against treatment and physicians. These different stigmas emerged out of the unique genesis of this epidemic. Unlike epidemics of the past, the opioid epidemic rose to prominence as physicians over prescribed opioids to patients suffering from post-surgical or chronic pain, as opposed to infection from a pathogen in other epidemics. The treatment of this disease also has multiple recovery options, both having variable outcomes depending on the individual and the context which leads to conflicting ideas regarding treatment implementation within one's community. Through participant observation and analysis of a community survey, I was able to identify the stigma against treatment within the community of Pineville and the opposition in these viewpoints. An anthropological perspective allowed me discern the differences in beliefs and opinions held by individuals of the community and those of the imposing party (in the case of treating epidemics, this would be public health officials).

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## **Introduction**

Sitting in a plastic folding chair at the entrance of Goodsons' Supermarket, a small family run grocery store in Pineville, West Virginia, I stare out into the parking lot as I wait for people to pass. Across the half empty parking lot, I see a Dairy Queen, one of the few restaurants located in Pineville. From there, I allow my eyes to wander to the mountainous backdrop looming on all sides. The tree-covered hillsides are a prominent feature of this small town located in the south of the Wild and Wonderful state of West Virginia.

Suddenly I see someone getting out of a car and head towards the Goodsons' entrance. "Hello," I cheerfully acknowledge the two women as they walk across the lot in my direction. "Would you be interested in taking a survey for a chance to win a \$50 Visa gift card?" After having attempted multiple lines to draw in participants for my survey, I found that incentivizing people with the gift card on the front end provided the best results in regard to willingness to participate. The middle-aged lady who accompanied an older woman paused in front of my table as she scanned over the objects that littered it. "What's the survey about?" "Community stigma and the opioid epidemic in Pineville." Her response was an unenthusiastic "Why not" as she told the other woman who accompanied her that she would meet her inside. As she filled out the survey there were occasional scoffs or snickers while she responded to the questions. When she got to the question asking about her thoughts on Medication Assisted Treatments (MAT), such as suboxone, she offered her opinion aloud—"suboxone is just another drug." In my mind, yes, it was another drug, but it was a drug that has been shown to help many people who have opioid use disorder to alleviate their withdrawal symptoms and make headway on recovery from their addiction. This woman mentioned that her brother was recovering from opioid use disorder with suboxone and that it had done nothing but harm him. He now spends all his money on suboxone

and has made little progress in his recovery. There are ways to manipulate suboxone and use it to elicit a high similar to that of opioids rather than just numbing the symptoms of withdrawal, as is the drug's intended use. It was at this point I realized why the solution to this drug problem was not to simply throw more drugs at it, especially in a manner that was currently being implemented. I had heard of the controversy and stigma associated with MAT but had never understood why until I heard this woman explaining the case of her brother.

In 2016 alone, across the nation there have been 14,487 prescription opioid deaths, 15,469 heroin deaths, and 19,413 synthetic opioid deaths (National Safety Council 2018). These numbers exclude those who are still living with opioid use disorder (OUD), or are in recovery, and the family and friends dealing with the aftermath. This epidemic affects numerous people, with 45% of respondents in a nationally representative survey knowing someone who has misused a prescription painkiller, 39% knowing someone who had been addicted to prescription painkillers, and 16% knowing someone who had died of a prescription painkiller overdose (DIJulio et al. 2015). My purpose in this study is to examine the timeline of the opioid epidemic to see how it has become the problem that it is and how this prescription drug has managed to take such a stronghold in communities across the nation, especially in regards to the stigma associated with this epidemic. To achieve that end, I will consider the commonalities and differences between the opioid crisis faced today, and the HIV/AIDS epidemic that plagued our nation over two decades ago.

Stigmatization was a prominent factor exhibited during the HIV/AIDS epidemic. People diagnosed with HIV were automatically outcast from society, being seen as having a "homosexual disease". This label facilitated the spread of HIV to other populations. It remained unchecked due to a large number of people believing that they could not contract the disease

given that they did not engage in homosexual activity. With the bridging of this knowledge gap, researchers began to make significant headway on the treatment and reduction of HIV cases across the nation. But what does one do when people seem to understand the scope of the problem but continue to place blame on the person with opioid use disorder (OUD)? By analyzing the history of and community response to the HIV/AIDS epidemic that began in the 1980s, we can learn about the role stigma plays in perpetuating such widespread epidemics. Although the two diseases are different in their physiologic basis and their pathways to being affected and treatment, the stigma surrounding the diseases produce similar outcomes regarding response and barriers.

The history of these epidemics is key to understanding why people react negatively and derogatorily to these diseases. Because of the origin of HIV/AIDS in homosexual populations, the spread of the disease increased the stigma associated with that group. Communities blamed gay men for introducing this fatal new disease to numerous other populations such as children, hemophiliacs, and people who had blood transfusions. Over time, researchers found that there were multiple modes of contracting this disease from bodily fluids such as blood, breast milk, and semen, leading to a great reduction in the stigma of this disease. Similarly, people suffering from opioid use disorder are doubly stigmatized—for their disease and their desire to seek medication assisted treatment (MAT).

A comparison of these two significant epidemics in the United provides a basis to understand why these stigmas persist and how they impact people who are suffering from these different ailments. Stigma has long been a barrier to receiving treatment, being socialized into society, and leading as normal of a life as one can under the given circumstances. Although some stigma associated with HIV/AIDS remains, it no longer is designated as as the gay disease,

thereby allowing a more well-rounded and accurate description of the disease. Although much differs between these two epidemics, there is much to learn from the community reactions to the HIV epidemic and apply in dealing with the opioid epidemic moving forward.

To understand a baseline of community stigma in West Virginia and the community reactions to this epidemic, I spent two days in Pineville, a small town in Southern West Virginia that has been greatly affected by the far-reaching epidemic. By distributing a stigma survey I gathered a baseline of the community reactions and thoughts regarding this epidemic. Many respondents either know someone or are related to a person who used opioids. This factor of personal relationships will provide a point of comparison regarding how individuals react to someone with opioid use disorder. Even amid progress, there is still stigma regarding aspects of treatment and prevention alongside the destigmatization of the disorder and individuals afflicted by it. The community meetings initiated in Wyoming County provided a look at the various perspectives held in the community regarding treatment, prevention, and those affected by opioid use disorder. The meetings provided a look into the communities varied perspectives and why they have such differing ideas regarding how to treat this epidemic. The stigma experienced within this community is just a snapshot of the issue as a whole. Many people who stigmatize the problem do not understand the extent to which this epidemic is a problem, so by providing an ethnographic snapshot of the community reactions I hope to make this epidemic a more accessible and realistic issue in the eyes of those who find themselves dissociated from it.

In this paper, I will introduce the opioid epidemic and all that it entails followed by briefly describing HIV epidemic in America to provide a context for which I can frame my research. The idea of stigma is then introduced as the focus of this paper. An analysis of stigma during the HIV and opioid epidemic will represent the issues of stigma in modern public health

epidemics and the issues that ensue in their wake. This sets the stage for the work done in the Pineville as a small case study of the opioid epidemic in the epicenter of opioid use disorder cases and overdoses. Within the case study of Pineville, West Virginia, some common themes are observed across the survey and community meetings. Religion, medication assisted treatments, and the syringe exchange programs were all sources of stigma found in the small population that was sample and/ or observed. The ideas held within the community at times were contrary to the ideas and experiences held by outsiders, particularly in regards to suboxone and other medication assisted treatments. The survey, community meeting, and Partners in Hope Consortium all provided a brief look into a community that is dealing with an epidemic that over 91% of survey respondents believe to be a serious problem.

## **Background**

# **Defining the Problem: The Opioid Epidemic**

An introduction to this epidemic will provide an overview of the scope of the opioid problem being dealt with across the nation. While the opioid epidemic has a pervasive presence in the world of public health and medicine, those within the field of anthropology may be scratching the surface with the knowledge that is seen within the field's literature. As I began my search of the works pertaining to the opioid epidemic in anthropology, it was not surprising the extreme lack of research. While many of the public health papers are conducted with an additional anthropological lens, most of the works dealt with statistics and numbers while the individual stories and cases were left to the newspapers and documentarians. I hope to introduce this epidemic as humanistic issue stemming from greater social issues as opposed to an untamable contagion that has been seen in health epidemics of the past.

## What are Opioids?

Opioids are a class of drugs that are utilized as pain relievers for both chronic (e.g., following cancer treatments) and acute pain (e.g., post-surgery recovery). Opioids include the illegal drug heroin, synthetic opioids such as fentanyl, and pain relievers available legally by prescription, such as oxycodone (OxyContin®), hydrocodone (Vicodin®), codeine, morphine, and many others (U.S. Department of Health and Human Services 2018c).

Many people receive an opioid prescription for anything ranging from pain post-wisdom tooth extraction to pain due to cancer. At the peak of prescribing opioids in 2012, the rate of opioid scripts was 81.3 per 100 persons, more recently decreasing to 58.5 people per 100 persons (Centers for Disease Control 2017b). The high rate of prescribing opioids contributed greatly to the addiction rates seen in the United States. In October of 2017, President Trump declared the opioid crisis a national public health emergency following the dramatic increase in overdose rates of affected persons during previous years. In 2016 and 2017, an estimated 11.4 million people had at some point misused prescription opioids, 2.1 million people had an opioid use disorder, 42,249 people died from an opioid overdose, and 17,087 of those deaths were attributed to an overdose on commonly prescribed opioid (U.S. Department of Health and Human Services 2018b). The continued prescribing by physicians, although at lower rates, means that these statistics are expected to continue climbing.

Opioids have been found to successfully manage pain when taken in shorter durations and in smaller doses. These drugs, however, are highly addictive (National Institutes of Health 2011). Because a large number of the patients being prescribed opioids were for chronic illnesses such as cancer, the timeline of usage tended to exceed the safe limits. Addiction stems from the effects of opioids on the brain. Receptor cells associated with pain and pleasure found in the

brain, spinal cord, and other organs are the sites to which opioids bind. The opioids block pain signals from being released throughout the body, and instead initiate the release of dopamine. Long term opioid use can lead to a tolerance, which is how many people develop the addiction that is plaguing the country (NIDA 2018b).

According the American Psychiatric Association (APA), "addiction is a complex condition, a brain disease that is manifested by compulsive substance use despite harmful consequence" (Parekh 2017). Additionally, the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-5) (2013) refers to OUD as a condition in which "opioids produce high levels of positive reinforcement, increasing the odds that people will continue using them despite negative resulting consequences. Opioid use disorder is a chronic lifelong disorder, with serious potential consequences including disability, relapses, and death" (Saxon et al. 2018). According to the Substance Abuse and Mental Health Services Administration (SAMHSA), successful treatment options are available for OUD such as Naltrexone (oral/injection), Buprenorphine, Buprenorphine-naloxone, and methadone (SAMHSA 2015). Treatment costs ranging from \$6,550 to just over \$14,000 (NIDA 2018a) create obstacles for those with OUD who are unable to afford treatment.

# The Opioid Epidemic

My first introduction to the opioid epidemic was six years ago in my high school health class. At the time, I did not realize that the case I observed was soon to become one of many similar situations. The film told the stories of individuals and their struggles with drug addiction, and one pertained to a middle-aged woman who had found herself on the streets looking for a constant supply of opioids. She had spoken of her life before addiction, with a family, a husband

and children. But she went to the hospital for a procedure and was prescribed pain medication. Following her discharge, she continued to seek relief from the medications she had been prescribed but was unable to do so through prescriptions. As in many cases, families do not know how to deal with the addiction their family members are enduring and occasionally withdraw the familial support that is so important to the user during this time. The story I recall is not unique, as it resembles many similar stories of countless others.

Opioid use and addiction are not novel. Since the 18<sup>th</sup> and 19<sup>th</sup> centuries, physicians' high rates of prescribing opioids, along with recreational use of opium among the elite, led to large numbers of opioid addicted, middle class individuals (Courtwright 2009). Yet, only recently have such high numbers of overdose deaths associated with these drugs emerged. With the recent elevated rates of opioid prescribing, it is no wonder that prescription opioids find themselves among the second most commonly abused illicit drug in the United States. Just over 11 million people had misused prescription opioids in 2017, with Hydrocodone accounting for 6.3 million of those cases and Oxycodone another 3.7 million. Although the statistics are alarmingly high, the numbers are on the decline from the 12.5 million recorded misused prescriptions in 2015 (McCance-Katz 2017). Declining statistics like these make the reduction of the opioid epidemic seem promising. Nonetheless an increase in the prevalence of Heroin Use Disorder seems to correspond to the reduction in opioid use disorder from 2015 to 2017.

A recent history of the opioid epidemic includes greedy pharmaceutical companies and doctors, and the institution of pill mills, which set a strong foundation for the physician facilitated addiction that was the basis of this epidemic. The greed by these people created a market for high grade prescription pain medication and the epidemic ensued. Purdue Pharma was to blame as the producer of OxyContin and other opioids incentivizing physicians to prescribe

these pain relievers. Twenty-two states have since sued the company for encouraging the use of highly addictive medications and developing an epidemic of drug addiction across the United States (Kelman 2018).

In 2017, the Centers for Disease Control and Prevention (CDC), in coordination with the U.S Department of Health and Human Services (HHS), published their Morbidity and Mortality Weekly Report (MMWR) on a 35-hour nonfatal opioid overdose outbreak in Cabell County, predominantly within the border of Huntington, West Virginia. In a span of 35 hours in 2016, this area saw 20 reported overdose cases by the first responders and EMS who were called to the scene (Massey et al. 2017). By this time, the epidemic was in full swing and emergency response teams were prepared with stocks of naloxone, an overdose reversal drug. The emergency response team had dealt with cases similar to these with such frequency that when they recorded initial suspected cause of overdose they overwhelming logged Heroin as the culprit. Of those who received an emergency department toxicology, opioids were found in all but two patients, proving that, while not necessarily heroin, and opioid was involved.

One of the most profound aspects of opioid addiction is how non-selective it is. As seen in the case above, half of the 45% of the overdoses were female, and the age distribution was varied as well: 18-25 (15%), 26-35 (50%), 36-45 (15%), and 46-60 (20%) (Massey et al. 2017). Before I started researching the epidemic, I thought that poverty would have been a significant risk factor to using opioids, but West Virginia has the highest rates of drug overdose deaths in the nation and only four counties in the top 100 most impoverished in the nation. Georgia on the other hand comes in at 38<sup>th</sup> nationwide in drug overdose deaths but has ten counties in the top 50 poorest in the nation (United States Census Bureau 2017b; Hedegaard et al. 2018). The

stereotypical image of drug users as homeless or in poverty, and "having the same story" does not characterize the opioid epidemic.

Even though high rates of opioid use disorder can be found across the nation, data from the CDC show that the counties having the highest prescribing rates of opioids tended to contain smaller cities or larger towns with a high percentage of white residents, high number of dentists and primary care physicians per capita, large numbers of uninsured and unemployed, and high numbers of residents who have diabetes, arthritis, or some sort of disability (Centers for Disease Control 2017b). The high rates of dentists and physicians corresponds to the overprescribing that characterized the onset of this epidemic. A common procedure following wisdom tooth extraction is for dentists to prescribe opioids to predominantly adolescent patients who become more susceptible to addiction following the surgery (Schroeder et al. 2018). Another study found that physicians were at times prescribing different dosages of opioid pain relievers to patients who had received the same surgical procedure, and frequently led to overprescribing (Hill et al. 2017). These differing prescriptions meant that the dosages were arbitrarily prescribed for each patient and excess pills taken on the basis of differing pain thresholds. Even as doctors in some capacity decrease their opioid prescriptions, owing to the new prescribing guidelines set forth by the CDC (Dowell et al. 2016), the rates of substance use disorder remain, owing to the shift toward an increase in cases of heroin use disorder, perpetuating the epidemic down an alternate route.

#### The Correlation of HIV to OUD

The opioid epidemic is reaching its height, transitioning to an illicit drug issue with fentanyl and heroin. The HIV epidemic, on the other hand, has seen a steady decline in new cases since the introduction of antiretroviral drugs. Yet, it has not disappeared. With the rise in the opioid epidemic, new correlations between HIV and OUD may be worrisome for the future of eliminating HIV. For the first time since 1990, the incidence rates of HIV among injection drug users has increased. The increase in HIV among injection drug users is said to be attributed to the opioid epidemic (Dawson and Kates 2018). While the two epidemics are severe issues on their own, their current overlap is reason for worry. A study of HIV and its history is important to this paper considering a possible resurgence of HIV among populations who are also affected by OUD.

# The HIV Epidemic in America

The HIV epidemic, while a contagious disease spread via various bodily fluids, is a lifestyle disease with social implications beyond merely being host to a deadly virus. The stigmatized identity of carriers as the walking dead follows them, living a life of societal exile until their death sentence as an HIV positive person is fulfilled. The identity of a person carrying a deadly disease is a horrible stigma to carry on its own, but a significant portion of the infected population were dually stigmatized for their identity as a homosexual. Religion and greater society are seen to advocate this additional identity as the reason for the suffering and infection seen plaguing the country. The social implications are seen in the stigmatized identities administered to those who were found to be HIV positive during the height of this epidemic. As another recent public health epidemic that is partially a lifestyle disease, depending on the mode of transmission, it provides the best point of comparison to the opioid epidemic.

A common saying is that we as society must learn about our history and the mistakes that were made so that we do not repeat those mistakes. Over the course of the HIV/AIDS epidemic,

there were many barriers to decreasing the incidence rates and discovering a treatment because of the actions of either an individual or a group. This history provides society with lessons of a slow response and stigmatized reaction that have been seen to change with the opioid epidemic.

The first time HIV came to public attention in the United States was in 1981 when the CDC published a Morbidity and Mortality Weekly Report on Pneumocystis carinii pneumonia in Los Angeles. P. carinii normally does not present itself in people who are not immunocompromised, which is why the cases perplexed physicians at the three different hospitals where the cases were analyzed. All five of the men were active homosexuals, which led researchers to assume that there was "an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and *Pneumocystis* pneumonia in this population" (Centers for Disease Control 1981). Upon the circulation of this report, more cases were reported in cities such as New York and San Francisco. Following these cases, the CDC launched an investigation into developing a case definition. There was a need to act fast as the number of cases continued to rise and the mortality rate was seen to increase accordingly with around half of the cases dying between 1981 and 2000 (Francis 2012). However, due to the Reagan administration declaring this newfound disease to be extremely dangerous and transmissible, the CDC was unable to effectively respond in the ways that were seen in recent years with Ebola and Zika. According to Dr. Donald Francis of the Public Health Service and the CDC, the Reagan administration did not provide sufficient funding and placed restrictions on research and rejected the national AIDS prevention plan that had been drafted by the CDC. This lack of support from the government prevented a strong initial attack against this virus. Similarly, a lack of local governmental support can be seen in West Virginia with the closing of the syringe exchange program in Charleston (Katz 2018). Without a strong effort from the

government, epidemics such as these can take hold in a way that could have been remedied with greater government action.

In 1983, the Four-Hs—homosexuals, hemophiliacs, heroin and other IV drug users, Haitians—were formally introduced in a *Morbidity and Mortality Weekly Report* from the CDC as representing the highest number of HIV cases (U.S. Department of Health and Human Services 2018a). This formal indication is likely the start of the stigmatization of those who identify with any of these groups faced. In the same year, the CDC formally declared the sources of transmission: sexual activity and by sharing blood and blood products (Francis 2012). Even with the identification of transmission, the discovery of the cause was slow in coming. That same year, two French scientists, Françoise Barré-Sinoussi and Luc Montagnier, discovered the human immunodeficiency virus (HIV). This finding helped doctors and the CDC to identify those infected with the HIV to reduce the spread of this deadly virus to a greater portion of the population (Abbott and Brumfiel 2008).

With a way to diagnose the HIV virus, the next step was to develop a treatment for this lethal virus. Significant funding had been allotted to research on treatment and possible cures for the HIV virus, including \$10 million to the National Institutes of Health (NIH) in 1982 and \$12 million from Congress to the Health and Human Services (HHS) in 1983 (U.S. Department of Health and Human Services 2018a). In response to the rising number of cases and no impending treatment options, President Clinton created the Office of National AIDS Policy (ONAP), a part of the White House Domestic Policy Council whose mission statement includes "coordinating the continuing efforts of the government to reduce the number of HIV infections across the United States. The Office emphasizes prevention through wide-ranging education initiatives and

helps to coordinate the care and treatment of citizens with HIV/AIDS" (*The White House*: President Barack Obama n.d.; U.S Department of Health and Human Services 2018a).

It was not until 1996 that the country saw its first decline in incidence cases of HIV, and in 1997 a substantial decline in the number of AIDS deaths. This decline followed in the wake of the large numbers of advocacy programs and funding for research that resulted in the discovery of antiretroviral drugs and establishing HAART (highly active antiretroviral therapy) as the new standard of treatment for HIV (U.S. Department of Health and Human Services 2018a). With this new treatment, an HIV diagnosis was no longer a death sentence and many people were able to recover and return to their normal lives by staying on a daily medication regimen.

Today, most people with HIV can expect to live long lives by adhering to their antiretroviral treatment. The life expectancy following the diagnosis of HIV in 1996 was 39 years old, but in 2011 there was a significant increase in the life expectancy to 70 years of age (Mascolini 2016). This promising increase in life expectancy is accompanied by a significant decrease in the incidence rate of HIV (Centers for Disease Control 2016). The new cases of HIV that are occurring are still predominantly seen in men participating in same-sex sexual practices, but there is a shift towards minority groups that had not previously been noted. Similar to many negative health outcomes, minorities are disproportionately affected. Gay and bisexual men as a minority group represent 68% of those newly affected by the HIV virus in 2015 and have always disproportionately been affected (Centers for Disease Control 2018a). Following all groups of men who have sex with men, African American heterosexual women are the next most affected group, followed by African American heterosexual men, white and Hispanic heterosexual women, and then injection drug users (Centers for Disease Control 2016). The most recent statistics show African Americans being disproportionately affected with new cases of HIV in

2017, with those partaking in male-to-male sexual contact representing around 10,000 new cases in comparison to 7,000 new cases in white males engaging in male-to-male sexual contact. Following all males partaking in homosexual contact, African American women engaging in heterosexual contact are the next largest contributing group (Centers for Disease Control 2018a). The stigma afflicting these minority groups is likely the reason for the shift in health outcomes to disproportionately affect those minority groups, and the shift continues to grow to encompass larger numbers of minority ethnic groups along with those who identify as homosexual. The stigmatization of and discrimination against minority groups in their daily lives has led to the disproportionate health effects regarding HIV within these groups. This is a trend that has not yet been seen regarding the opioid epidemic, however as the epidemic progresses, a shift in demographics most affected by opioid use disorder may be seen.

## Stigma

Stigma has been seen in all major public health epidemics: influenza, the black plague, HIV, Ebola, and opioids. While the means of stigma differ, the results are the same-- those affected by the epidemic become ostracized from society as their disease becomes their identifying label. They are no longer the mother, neighbor, doctor, or friend, they become the addict and the homosexual with HIV. An analysis of all the past epidemics would find many comparisons, but also numerous differences, therefore I decided to focus on the two most recent epidemics that heavily afflicted the United States. The HIV epidemic that took hold in the 80s will provide a point of comparison for the opioid epidemic. There can be found numerous similarities and differences regarding the two epidemics, one such difference being the modes of transmission. One epidemic is not contagious at all while the other is exchanged via certain

bodily fluids such as blood, semen, vaginal fluid, and breast milk. The way the people are stigmatized differs for each public health outbreak, so using the HIV epidemic, I intend on exploring the commonalities in stigma across the two public health epidemics that afflicted the United States and determine those that are uniquely affiliated with the opioid.

# What is Stigma?

In terms of health, stigmatizing a group has many negative outcomes, such as creating barriers to receiving treatment, exclusion from society, and harmful self-perceptions. Numerous studies have been conducted on stigma and health, especially in relation to mental health, an outwardly observable change in health. In his book *Stigma: Notes on the Management of the Spoiled Identity*, Goffman (1963, 3) defined stigma as an attribute that "reduce[s] in our mind [the person] from a whole and usual person to a tainted, discounted one." When people stray from the cultural norm, others tend to identify them as "different," and the group to which they belong becomes stigmatized once the difference has been labeled as either a failing, shortcoming, or handicap. This leads to fear of disclosing one's disease status (Brown and Closser 2016). Mental health is not physically observable, but there is an outward change in a person's demeanor that can be observed if not treated. This is a dilemma with the opioid epidemic as the disclosure of a person's addiction can lead to discrimination in finding housing and a job, as was observed in the survey responses.

Stigma can also be seen as the point at which stereotyping and discrimination tend to meet. Stereotyping is the action by which people assign a general definition or description to an entire group. For example (and elaborated in the "Stigma and HIV" section), people stigmatized four groups ("Four-Hs") as carriers of HIV: homosexuals, hemophiliacs, heroin users, and

Haitians (Farmer 1993). Not everyone in these groups had HIV, but because the rates of transmission were exceedingly higher within each compared to the overall population, many people with an affiliation to one of the Four-H's were stigmatized and suffered discrimination. Three main types of stigma may be experienced by an individual: enacted stigma, perceived stigma, and self-stigma (Luoma 2007). Enacted stigma is active discrimination by an outside group, leading to the ostracization of the person being stigmatized. Perceived stigma is what a person, who is part of a stigmatized group, believes that outsiders think about him or her because of the stigmatized association. And finally, self-stigma is the way people perceive themselves because of their identity with a stigmatized group and their struggle with detaching their personal identities from their stigmatized identity. All three of these can be exhibited by people who have opioid use disorder, as they have been seen in other injection drug users (Latkin 2010; Sattler et al. 2017).

A major issue is this inability to dissociate an individual from their stigmatized identity. Associating a person with his or her disease lessens the status of the person and does so in a dehumanizing way. As such, the disease becomes a person's master status because the attributes of the illness override the other attributes of a person (Lucas and Phelan, 2012). For example, when a person becomes labeled an addict, they are being defined by their addiction first and foremost. This same stigmatization has occurred throughout the history of humanity. In the Bible, people who have leprosy were called lepers, defining their identity with their disease. Similar to HIV, people avoided contact with those who had leprosy, and continue to do so, because they are unaware of the mode of transmission. Leprosy, formally known as Hansen's Disease, cannot be contracted unless a person is in prolonged contact with a person having leprosy for many months according to the CDC (CDC 2017b). Similar to HIV, people were

taught to avoid contact with those who have HIV, never share drinks or food because there is a risk of contracting the disease. While these beliefs are untrue, they continue to be perpetuated within groups because those who have the diseases are social outcasts.

## Stigma and the HIV Epidemic

One of the ways in which stigma is perpetuated is through language. The way in which people describe another person and his or her association with AIDS subconsciously affects how they think about the person and the disease. Goals of the second National AIDS Forum in Denver in 1983 included empowering people with AIDS (PWA) and aiming to have them treated with dignity by all. To achieve such goals, organizers emphasized the key principle of changing the manner in which people talk about people who have been afflicted with AIDS. Rather than talk about those who have AIDS as victims of AIDS or referencing them as patients, they generally promoted the phrase "People with AIDS" to eliminate the weakness and complacency associated with the other two terms (The Denver Principles 1983). Doing so allows people to regain their identity as a person instead of being defined by the disease. The one-page Denver Principles identifies the rights of people with AIDS and sets forth recommendations for them, and for all people who support those who have AIDS. Such principles emerged not long after the declaration of AIDS as an epidemic in the United States.

When the HIV epidemic first began in the 1980's, men having sex with men were at a disproportionately higher risk of contracting the virus than the general population. Before the virus had been found, the disease was coined GRID (gay related immunodeficiency disease) (Altman 1982). This group of people were already stigmatized by society for their lifestyle choices, and when blamed as the carriers of a life-threatening disease they were further

ostracized (Cadwell 1991). As the death toll rose, those cast out from society because of their diagnosis or sexual orientation begged the question, who is going to help us? Is there a cure? Are those with the means to help doing so? Their stigmatized identities led them to become their own advocates, creating the activist group known as ACT UP (AIDS Coalition to Unleash Power) in 1987 (ACT UP n.d.). At the time there were no known treatments for AIDS, and those responsible for developing a cure were seen by infected person's as working without urgency. Additionally, the most useful form of prevention, aside from abstinence, was being condemned by the catholic church.

Condoms are an effective form of birth control used throughout the United States, but they are also an effective prevention method against transferring STDs, aside from abstinence. However, the church strictly forbade the use of condoms, thinking that it promoted sexual promiscuity redefined sex as an act of pleasure rather than love. This strictly went against the church doctrine of monogamy and restricting sex to marriage. One Cardinal even suggested that condom use may be contributing to the spread of HIV (Benagiano et al. 2011). This pressure from the church to avoid condom use contributed to the societal rift between homosexuals/persons with AIDS and those of the catholic church. In the documentary "Stop the Church" (1991), the Catholic church seemed to have a great deal of clout in New York City at the time of this epidemic. Due to the blatant disapproval by the Cardinal John O'Connor, members of ACT focused one of their larger protests against his church home, St. Patrick's Cathedral. By the time antiretroviral treatment had been discovered, ACT UP partook in numerous protests. This group not only had to advocate for their rights but had to fight stigma the whole time they did so.

This past winter I enrolled in a global health course at Rollins School of Public Health about the connection between HIV and religion. Prior to this class, my understanding of the

HIV/AIDS epidemic was limited to the articles I read for this paper. This class provided me with real stories and people's experiences with the viral disease from around the world. One story from class mentioned two young girls who were hemophiliacs and had become infected with HIV during a blood transfusion. This was during the height of the HIV epidemic, so word traveled fast of the young girls' infections. The family who regularly attended church were informed that their children were no longer allowed to attend Sunday School for risk of transferring their infection to the other children. The parents refused to return to that church in the future, even though they were devout Christians (January 9, 2019). Although in the United States today it seems absurd to think that HIV could be transmitted via saliva, one student in my HIV and religion class admitted that her first experience regarding HIV was being taught not to share cups for the possibility of becoming infected with HIV. The beginning of Paul Farmer's Book AIDS and Accusation mentions a young woman living in New York who is fired from her job merely because of her Haitian identity and the suspicion of her carrying AIDS. Although she tested negative for the virus, there was no convincing her boss to reinstate her job (Farmer 2006). Stories such as these were not uncommon. Stigma leads to fear of entire groups based on their association with the stigmatized identity. In no time, the stigmatized identity of HIV spreads to created stigmatized groups who suffer discrimination in daily aspects of their lives.

# Stigma and the Opioid Epidemic

As mentioned previously, there are three different types of stigma (enacted, perceived and self) seen enacted throughout the opioid epidemic. The following sections discuss ways studies of addiction and mental health exemplify these stigmas. The self-stigma and community stigma can be seen throughout the HIV epidemic, while the physician stigma is unique to the

opioid epidemic. The focus of this analysis is on community stigma as it was the topic of the survey conducted in Pineville (to be discussed in greater detail later in the paper) as well as a prominent source of stigma seen with HIV. It is important to note that community stigma does not exist in isolation and can lead to these two other types of stigma present in the opioid epidemic. The basis of this section is to create an understanding that there are repercussions in the form of alternate stigmatization as a result of community stigma, be it in the form of an individual's internalization of these negative thoughts and actions or the stigmatization against physicians who are treating those who have OUD. An additional form of community stigma can be seen from physicians who treat patients for OUD with MAT. These stigmas then create barriers to treatment both from the individual seeking treatment and the community.

## Community-Based Stigma

Community-based stigma is the category of stigma which will be focused on throughout this paper. People seem to be knowledgeable about the epidemic and who is being affected by opioid use disorder. A nationally representative web-based survey involving 1,071 respondents to tap into the perceptions of Americans regarding the demographics of "who" is being affected by this epidemic. About 76% of respondents believe that all socioeconomic statuses are affected equally, with the second most popular response being middle class at 15%. Approximately 80% of study participants thought all races were equally affected, with the next majority being white/Caucasian with 17.7% reported, and 79.6% believed that rates were equal across all areas of residence (rural, urban, suburban). The true statistics show that white, non-Hispanics are disproportionately contributing to the rising number of deaths. African Americans, however, have the most rapidly rising rates of overdose deaths (Saloner et al. 2018). Additionally, those of

lower socioeconomic status are at a greater risk of developing OUD due to the high opioid prescribing rates for people insured by Medicaid (NIDA 2017). Saloner considers the role that other stigmatized identities and social determinants play a role in increasing risk during the opioid crisis. While initially higher rates were seen among the white middle class, the rates among marginalized minorities, such as African Americans, are catching up quickly and exceeding the incidence rates among whites. A positive correlation exists between groups who are part of one or more stigmatized group and the increased rate of opioid addiction. These misconceptions may lay the basis for additional stigmatization from the community.

Community members use of particular linguistic labels for people with opioid use disorder further stigmatizes those identities. Numerous studies talk about the added stigma created by labeling someone as an addict or a person with opioid use disorder. Goodyear, Haass-Koffler, and Chavanne (2018) examined the role of such labels. They provided study participants with short vignettes of an imaginary case of individuals with OUD. People in these cases who were painted as having an addiction were viewed more negatively than those described as having attained a disorder as a result of physician negligence or overprescribing. The latter were also seen as being less responsible for their disorder than those who became afflicted with opioid use disorder through their own doing. Thus, like the shift in the HIV epidemic to language that allowed for identities beyond the disease, use of less pejorative labels and attributions beyond individual voluntary actions contributes to reducing negativity associated with OUD. Yet, given that researchers who have produced significant works on the opioid epidemic continue to use the terms "addiction", "suffers from", "addict", etc. in their work, the impact of language alterations will be slow to emerge. Similarly, researchers suggest that community members avoid using are the terms "misuse" and "abuse" (Buchman et al. 2017). These terms imply a moral transgression and perpetuates the stigma of a person with opioid use disorder as a "bad" person, with qualities such as deceptiveness and irresponsibility.

In the *Anti-Stigma Toolkit* produced by Mim Landry (2012), change in language constitutes a primary means to reduce stigma. Similar to the guidelines set out in the Denver Principles (1983), the goal is to reduce the use of the phrases "victim of" addiction, "suffers from" addiction, and "addicted to" within opioid use disorder vocabulary. As these phrases perpetuate the public's negative views about addiction and opioid use disorder, their removal attenuates the barriers disallowing people to receive the aid required for recovery (Landry 2012).

Addiction in and of itself is a complex disorder that the public tends to not thoroughly understand. An online national survey found that people in the U.S. tend to view addiction with a more negative perspective than people who have a mental illness, a group that is highly stigmatized as well (Barry, McGinty, Pescolido, and Goldman 2014). One question asked if a person believed that employers should be allowed to deny employment to a person with a known drug addiction or mental illness, with 64% and 25% respectively agreeing with this statement. Not only does this significant difference in responses towards drug addiction and mental illness highlight the stigma towards drug addiction, but also the lack of knowledge regarding the medical diagnosis of addiction.

# Internalized Stigma

Internalized stigma is the way a person believes other people are thinking about and judging them. Regarding the opioid epidemic, these are the stigmatizing thoughts people with OUD hold about themselves. The anthropological literature on the opioid epidemic is sparse, especially pertaining to stigma, and what little can be found is related to injection drug use as a

whole. Most of the stigma studies focus on general injection drug users rather than narrowing its focus to the opioid epidemic. Such work tends to address internalized and perceived stigma. One study conducted by Carl Latkin analyzed the effects of community stigma on mental health of drug users in India (Latkin et al. 2010). Of the 1,135 male injection drug users, 851 of them stated that they had injected in the last month. The researchers asked questions using a stigma scale (Luoma et al. 2010) based on eight questions such as: "how much do you feel fear family will reject you because you use drugs," "how much do you feel that you need to hide your drug use," and "how much do you think other people are uncomfortable being around you because you because you use drugs." These were ranked on a scale of 1 to 4 using the responses of "not at all," "just a little," "somewhat," to "very much" and responses were aggregated over the eight items. Latkin et al. found a strong correlation between perceived stigma and the participation in high risk injection drug use behaviors.

A study was conducted on the results of this internalized stigma in people suffering from addiction and a feedback loop was found resulting in greater substance abuse (Matthews et al. 2017). When a person is stigmatized by the community, they tend to internalize these negative opinions and find themselves continuing to consume the addictive substance in order to forget or avoid the shame of addiction that they feel. This then perpetuates the issue in a behavior loop which leads to the community once again stigmatizing these individuals with addiction. The effects of internalized stigma tend to correlate to negative views held by a person's community or that of a greater part of society. With HIV, it is difficult even today for people to adhere to strict anti-retroviral therapy (ART) because of the fear of stigmatization from their community. Research on urban youth with HIV in Chicago found that many participants skipped doses out of fear that their friends and family might discover their HIV status (Rao et al. 2007).

## Physician Stigma

Stigma associated with the opioid epidemic extends beyond the users to the prescribing healthcare providers. This stigma extends both from the physician to the patient and from the community to the physician, the first being another form of community stigma. Mendoza, Rivera-Cabrero, and Hansen (2016) looked at a group of physicians who were being monitored to determine if they were abiding by suitable opioid prescribing measures. A result of monitoring physicians during this study was a shift in blame for opioid addiction to the physicians rather than the person with the addiction to opioids. As researchers find a biological source for the addiction, prescribers are more often seen as responsible for initiating the addiction while those with OUD are cast as "victims" by society. This viewpoint adds another issue to stigma by diminishing the strength and value of a person with OUD, seen similarly with the HIV/AIDS epidemic. However, while society shifts their image of a person with OUD from an addict to a victim, physicians who were administering Buprenorphine treatment (a form of MAT) maintained their stigmatized views of patients with OUD. The physicians overseeing Buprenorphine treatment claimed that none of the patients being treated fit the stereotype of a "user." They're "not criminals, they're teachers, nurses, policemen, CEOs" (Mendoza et al. 2016, 472). This statement reveals how the opioid epidemic is pervasive and nonselective, afflicting many people who continue to go about their everyday lives.

The stereotype of someone addicted to drugs is painted by the opinions of physicians.

They must be criminals, nonconformists, deviants. These stereotypes carry into the opinions held about a person once their status of addiction is discovered. Of those interviewed, 75% of Physicians held negative perceptions towards those who those seeking treatment and 88% claimed that they or a colleague suspected that their patients were sharing or selling their drugs

as they would come in with claims of their dogs eating their medication or dropping them down the sink (Mendoza et al. 2016). With large numbers of physicians remaining distrustful of patients, it is no wonder that the prevalence of people with OUD receiving treatment is so low (NIDA 2018c). With the controversy surrounding prescribing physicians and those administering alternative drug treatments that are seen by many as "just another drug", it is not surprising that there is an aura of stigma surrounding all levels of MAT. The outside community do no trust the physicians, as they are the source of the problem yet are given the power to treat OUD patients with a varied form of opioids. And, physicians do not trust patients due to their misuse and abuse of the alternate opioid treatment. This is seen later in the community meetings as a possible reason for the community stigma against MAT.

## Comparison of Stigma of the HIV and Opioid Epidemics

One of the most prominent similarities between the two groups is based on holding those affected responsible for their own condition. Both diseases can be seen as lifestyle diseases, resulting from a choice by the individual. As homosexuality was already stigmatized, people further ostracized them by blaming them for their own illness. The same can be said for those with OUD, as drug use is highly stigmatized. While both diseases have origins outside of the stereotype –blood transfusion for HIV and overprescribing by physicians—blaming the victim continues. By holding the "victim" accountable, the uninfected create a barrier between themselves and the disease. The idea of "it won't happen to me" because the individual abstains from the socially unacceptable behaviors of homosexual acts and drug use is one factor that allowed for these diseases to develop into an epidemic. The opioid epidemic did slightly differ from the HIV epidemic in this respect. Due to the nonselective nature of OUD, quicker action

was taken by the CDC and other initiatives to reduce rates of opioid prescribing by physicians and reduced the stigma of OUD.

Encompassing that more specific stigma is the idea of community stigma as a whole. The stigma of blame and of immoral behavior can be found in both cases. The community stigmatized them for their behaviors and it can be detrimental to their cases. Internal stigma is found almost anywhere community stigma is enacted. When a person is ostracized from their community, told that they are sick because they messed up, they internalize these thoughts and begin to blame themselves. When a person experiences continuous discrimination they are more likely to internalize this stigma and anticipate further social stigma from others in the future (Quinn et al. 2015).

Language as a form of stigmatization that was targeted in both groups. The Denver Principles and the Anti-Stigma Toolkit mentioned removing the words "victim" and "suffering" from the vocabulary referring to persons with HIV or OUD. These terms create a weakened identity for the individual and leads to feelings of helplessness. While researchers during both epidemics realized that changing the language surrounded these diseases was essential for changing the way society looked at those effected by the opioid epidemic. Changing the way an entire nation is talking about the epidemic, however, is no small task and takes time. During my research I found the much of the literature surrounding both epidemics still used terms such as "victim of" and "addict" throughout.

One factor that affected the HIV epidemic, opioid epidemic, and most epidemics throughout history is their adaptive abilities. In the HIV epidemic, although the original source identified by the CDC was the homosexual cohort of men having sex with men, it was eventually found to have been transferred to hemophiliacs, Haitians, and IV drug users. Similarly, the

opioid epidemic had shifted from primarily a prescription drug problem to a heroin and fentanyl problem. Although the epidemics shift, the stigma that is exhibited remains the same throughout the course of the epidemic if not properly addressed and can continue to provide barriers to treatment by assuming that the problems remain the same over the course of the epidemic.

Stigma has presented itself in new ways within the opioid epidemic as well. Stigma against physicians as providers of the drug that led to the opioid epidemic can be seen across the nation as was exemplified by the study by Mendoza and her colleagues (2016). Previously, doctors were seen as the saviors in epidemics, providing miracle drugs with HIV or treating a highly infectious disease while risking their own lives with Ebola. The opioid epidemic, however, is different as a source of the outbreak is overprescribing by physicians themselves. This had led to difficulties with trust regarding drug therapy with MAT, another new source of stigma in the opioid epidemic. While my supervisor at my internship had mentioned that MAT was a point of contention within the opioid epidemic, I did not realize how true it was until I found myself in a meeting listening to discussions about whether funding should be allocated to MAT in Pineville. While a search will turn up numerous articles surrounding MAT and the misconceptions surrounding it, why it works, and people's personal successes, there was little to nothing in the form of MAT community stigma-based research. The brief time I spent in Pineville showed me that this stigma against MAT is pervasive, even among those who wish to help minimize the effects of the opioid epidemic.

# **Research Question**

Generally, as the foregoing suggests, there is little anthropological research conducted on stigma towards the whole opioid epidemic. The stigma surrounding this epidemic is especially

worrisome because it extends to perceptions regarding treatment for opioid use disorder. Here I provide a case study from the heart of the epidemic in West Virginia, the state with the highest rates of OUD and opioid overdose deaths in the nation. I hope to discover what the community reactions to the opioid epidemic in Pineville are and in what ways they invoke stigma. By comparing the stigmatized responses to HIV/AIDS epidemic, I aim to reveal the role of stigma in the face of varied public health epidemics in the United States and the extent of progress (or lack of it) in community reactions. The differences in community reactions can be explained by many factors, and through the analysis of Pineville, some of these differences are likely to be exemplified.

### Case Study: West Virginia and the Community of Pineville

My home state of West Virginia tends to be significantly underrepresented and misrepresented in most scenarios. At Emory University, a school of 8,000 undergraduates, I have only met one other person from West Virginia and heard of two others. Most people I introduce myself to tell me that I am the first person from West Virginia they have ever met. However, in the opioid epidemic, West Virginia is overrepresented, representing the largest rates of overdose in the nation. The state is receiving funding from institutions and the government to combat this epidemic, but with a lack of infrastructure, it will be difficult to institute new programming from the ground up in communities where the epidemic has already deeply extended its roots. As I began to research the opioid epidemic, I found that stigma was a prominent factor in the opioid epidemic, and the community of Pineville was not immune. West Virginia has been stigmatized as being an uneducated state and its people characterized as rednecks, coal miners, and speaking with heavy southern accents. My soccer coach my freshman year of college was from the

neighboring state of Maryland and had turned many of the stigmatized qualities of West Virginians into jokes—of incest, missing teeth, and raccoon skin hats.

With stigmatization emanating from outside of the state in many ways, I was intrigued by how stigma permeated the epidemic from within the state's own borders. The second night I stayed in Wyoming County I lodged at the Twin Falls State Resort Park. This was the closest lodging to the town of Pineville and had come recommended by a co-investigator on the project. I as walked up to the front counter, a young man, who coincidentally matched some of the stigmatized identifiers of West Virginia—heavy accent and missing teeth—greeted me with a smile. Physical identifiers aside, West Virginians are some of the friendliest people one will meet; they are proud of their state and always welcome visitors with open arms and a smile. "So what brings you to Twin Falls?" the receptionist gleefully asked me from behind the counter. I mentioned the research project I was working on in Pineville on the opioid epidemic. He chimed in eagerly, mentioning that I had come to the right place to research this public health emergency. He suggested that I watch the documentary Oxyana since I was going to be doing research in Wyoming County. I was confused by the name so he clarified that Oxyana was a nickname given to the neighboring town of Oceana. Pineville had also seen itself worthy of an opioid related nickname and was labeled Pillville. At the mention of these nicknames I knew that the stigma surrounding the epidemic was pervasive and it is this reason that I chose to focus on stigma and the opioid epidemic.

West Virginia currently has the highest rates of opioid overdose deaths in the nation with 57.8 drug overdose deaths per 100,000 people in 2017 (Centers for Disease Control 2018b). West Virginia has been the focus of many initiatives relating to the opioid epidemic such as a StigmaFree WV campaign and the Johns Hopkins COUNTS! study, as well as the subject of

documentaries such as *Heroin(e)*, *Oxyana*, and *Recovery Boys* due to the high prevalence of OUD within the state. The pervasiveness of this epidemic became apparent to me as I began my research for my internship. My supervisor informed me that I would be working in the small town of Pineville, helping with data collection for a research project being pursued at the West Virginia University School of Public Health about the opioid epidemic. From that moment forward, I noticed numerous news articles and Facebook posts regarding the high incidence of opioid overdose deaths across the country. Regardless of whether the articles were becoming more abundant or I was simply more aware of them, they were everywhere.

As part of my internship, I was responsible for creating a community stigma survey that would be administered in Pineville to determine the stigma towards people with OUD present within the community. The Wednesday prior to my visit in Pineville I had no idea what I was getting myself into, let alone that I was even going to be traveling the three hours to the southern part of the state. Prior to leaving the office that day, one of the lead investigators informed me that we would be leaving after work tomorrow to travel to Pineville to finally administer the survey that we had spent all summer creating. He mentioned that I should pack for three days because I may be staying an extra day to continue collecting surveys. I went home that night and threw the only professional clothes I had brought home with me in a bag, unsure of what I was going to be doing when I got there. The next day we put the final touches on the survey, printed an optimistic 75 copies, and then started the three-hour journey to the southern part of the state.

When I finally arrived in Pineville Friday, August 10th, I did not find it difficult to navigate the two main roads that ran parallel through the town. The first stop of the day was the Wyoming County Health Department. I accompanied the Primary-Investigator and Co-Investigator as they spoke with the four employees to discuss their research project and the needs

of the community regarding the opioid epidemic. Though the county health department was small, it was responsible for supplying all of Wyoming County with their health needs. I was intrigued to hear about the mobile syringe exchange program that had been implemented by the health department. This program was created to provide people with OUD a means of obtaining clean needles to reduce the risk of infections such as HIV that are common when sharing and reusing dirty needles. These syringe exchange programs (SEPs) are important to reducing the rates of HIV among those with OUD, however, among the 220 counties seen as having the greatest risk for HIV outbreak, only 8% of those counties have SEPs (Dawson and Kates 2018). I will discuss this program in more detail later.

During the meeting at the health department, the survey we had created was brought up and we discussed our plan to hand out surveys in front of a local grocery or convenience store. In a matter of minutes, the head of the health department had the manager of a local grocery store on the phone to request permission for us to administer surveys in front of his establishment. He happily obliged. Following this meeting at the health department, we sat in on the Partners in Hope Consortium, a group that consisted of community members working towards reducing the effects of the opioid epidemic within Pineville and the surrounding areas. At the conclusion of the meeting, my supervisor and I made our way to the local grocery store where I was to distribute surveys.

As I administered surveys later that day, it surprised me that some people asked what a syringe exchange was, leading me to wonder how many respondents did not realize that there was a program implemented within their own community. The syringe exchange was an endeavor headed by health department in the hopes to reduce the rates of diseases spread between IV drug users and eliminate the eventual spread outside of this population. The mobile

syringe exchange was operated out of a generic Ford van that was specifically outfitted for the purpose of the harm reduction program. There were four chairs and two small tables for the nurses to examine patients and count needles before providing them with their take home bag which includes a 1:1 exchange on needles, cotton balls, cooker, tourniquet, a bottle for used needles and alcohol wipes. The idea of providing IV drug users with all the tools they need to cook down the drugs and then inject them was more than I had expected from a needle exchange. However, this program embodies the idea of a harm reduction program more than just a needle exchange. The term harm reduction encompasses programs that aim to reduce the negative effects of IV drug use (Harm Reduction Coalition n.d.). The mobile harm reduction program was run by the three nurses who also work at the health clinic. The program successfully provided aid via the syringe exchange aspect of their harm reduction program in two other towns on Fridays.

Even with the efforts to reign in the opioid epidemic, stigma is not absent. Evidence of the stigma comes from two sources: observations and a community survey. Before further describing the town of Pineville, I outline my two data sources.

#### **Observations**

I observed a community meeting in Wyoming County that intended to rally support within the town of Pineville, and throughout the county, to repair the consequences of the opioid epidemic within their families and communities. I also attended a Partners in Hope Consortium meeting, an initiative that sprung from the initial community meeting. This consortium included many local organizations dedicated to providing counseling and therapy for those dealing with OUD. Government officials at the meeting discussed grants and financing for the consortium's efforts. As a hotspot for the opioid epidemic, much funding has been funneled into southern

West Virginia, specifically Wyoming County. According to an overdose mapping tool that has been established by the National Opinion Research Center (NORC) at the University of Chicago, Wyoming County has the one of highest overdose rates in the state of West Virginia with 127.7 per 100,000 people dying from a drug overdose, second only to McDowell where the rate was 134.2 people per 100,000 (NORC 2017). The high prevalence of OUD and overdose deaths in the county provided an opportune environment to study the effects of the opioid epidemic.

#### Survey

#### **Overview**

The 39-question survey (Apendix 1) was created to determine baseline stigma analysis for a research project in Pineville, West Virginia. The survey was to be re-administered at the conclusion of the WVU research study to determine if the results of the study and initiatives had produced any results in decreasing the stigmatized views from the community. The survey asks questions pertaining to individuals' thoughts regarding persons with OUD as well as what they believe to be the opinions of the rest of their community. In my analyses, I focus on whether people who have either interacted with or have relationships with people who having OUD have less stigmatized views of those people. This survey was designated as not requiring IRB review by the Emory Institutional Review Board.

## Respondents

The respondents participated on a voluntary basis, their participation was requested as they entered the local grocery store, Goodsons', but many people declined. Of the 34 responses obtained, 8 (24%) were male and 23 (68%) were female, while 3 failed to respond to this demographic question. The race of distribution of the respondents was 100% white. All

respondents were citizens of Pineville or the surrounding area. Two participants did not fill out the final page of demographic information.

#### Survey Construction

The surveys were created by collecting and adapting questions from previous stigma surveys. Questions 2-7 were derived from Barry (2014) that compared the public stigma of drug addiction to the public stigma of mental illness. Another survey that collected self-reports of perceived stigma towards substance users was the source of questions 13-20 (Luoma 2010). This survey was adapted to collect community opinions rather than individuals' perceived stigma from the community regarding their addiction. Questions 21, 23-25, and 28 were adapted from a self-stigma survey that studied people with OUD who were seeking opioid detoxification treatment (Bozinoff 2018). Latkin's (2010) study on drug use stigma and HIV injection risks among drug users in Chennai, India, provided the basis for questions 29-33. The question regarding community support for the syringe exchange program was pulled directly from a survey conducted on public opinions surrounding safe consumption sites and syringe exchanges (McGinty 2018). Thus, many questions on the survey come from previously validated surveys, therby reducing measurement issues. The remaining questions stem from a class survey administered by Dr. Erin Winstanley in one of her classes at West Virginia University. The syringe exchange question was accompanied by a free response question to determine the reason for support or opposition to this program. A second free response was placed at the end of the survey for any additional thoughts or opinions regarding the survey. Although I referenced a change in language from an addict to a person with OUD, the term addiction was used throughout the survey to appeal to the lay understanding of the epidemic.

#### **Procedures**

As previously noted, the surveys were distributed in front of a locally owned supermarket. The survey was conducted under the auspices of Public Health at West Virginia University (WVU), thus the table set up in front of the supermarket was draped with a WVU tablecloth and poster. The survey's association with WVU may have encouraged greater participation than if I had attempted to collect data without such connection. A bowl of candy, clipboards with surveys, and a gift bag for completed surveys sat on a table. One of the key investigators on the WVU study joined me for the first hour of soliciting respondents to participate in the study.

Surveys were collected for a total of five hours—two and a half hours on Friday afternoon (3:30 pm-6:00 pm) and two and a half hours on Saturday morning (9:30 am-12:00 pm). The survey was administered at the table and participants were incentivized by entering a drawing to win a \$50 visa gift card. As an afterthought, I scribbled on a piece of notebook paper the phrase, "Chance to win a \$50 Visa card." The first day, 16 surveys were completed out of around 60 or 70 people who passed by. On the second day, I tallied all those who passed by without taking the survey and counted 53 within 2 hours. When I distributed the survey, it was hard for me to keep track of those who continued to walk past.

As people walked towards the grocery store, I greeted them with a hello and a "would you like to participate in a survey?" Over time I expanded on my greeting to include the topic of the survey, hoping to spark greater interest in the survey, but the result was quite the opposite. My introduction identifying the topic as the opioid epidemic greatly deterred numerous passersby. Some people had heard of the survey because of their connection to the Partners in Hope Consortium or were greatly concerned about the opioid epidemic, creating a slightly biased

sample. To attract a wider range of people I opened with, "Would you like to take a survey for a chance to win a \$50 Visa gift card?" The results did not noticeably increase.

Those who chose to participate the survey were given a clip board with the survey so that they could fill it out themselves. I read the survey to one woman, transcribing her responses directly to the survey. To maintain anonymity, respondents folded their surveys in half and placed them in a gift bag on the table. No identifying information was obtained from the survey. Following the completion of the survey, respondents wrote their name, email, and/or phone number on a notecard to be submitted for a drawing for the \$50 Visa gift card. To protect the identities of the participants, the notecards were placed in a cardboard ballot box.

#### **Pineville**

The whole of my summer internship had culminated in a trip to Pineville, the town I heard much about but had yet to visit. Located in southern West Virginia, this small town is nestled among the Appalachian Mountains, surrounded by trees, and sitting on 0.80 square miles of land (United States Census Bureau 2012). The town has many empty storefronts that at some point in the towns history were likely to have housed thriving businesses. Today, the population has been on a steady decline since the 90s and in the 2017 Census the population was estimated to be 599 (United States Census Bureau 2017a). With an isolated population, it takes little for a public health epidemic to take hold, especially when the health infrastructure to combat such epidemics is lacking. I arrived in Pineville off a windy two-lane mountain road, with blind turns that made me grateful for the lack of traffic. To one side of me there was a steep mountain ledge where the rock had been cut to make way for the road. The other side boasted a steep drop-off into the forest below. The trees shot up, and due to the fog that blanketed the valley, I was unable

to see the tops of most of the trees on my early morning drive. As I neared Pineville, the buildings I saw in the greatest numbers were churches. The religiosity of the region was reflected in the two meetings I observed as well as the survey results. Of the respondents, 24% said they attended a religious service on a weekly basis, and an additional 38% said they attended religious services more than once a week. Religion plays an important role in the lives of many West Virginians and is a factor that I observed as limiting access to treatments because recovery can be achieved with God alone.

Many issues that facilitate the continuing stigma surrounding the opioid epidemic, but the one I encountered was religion. Similar to the HIV/AIDS epidemic, religion created a barrier for those affected by the epidemic even though chronology of infection distinguishes the two. Religion created a barrier to prevention efforts on the front end of HIV infection, whereas religious barriers for the opioid epidemic follow the onset of OUD with treatment. With HIV, the only treatment options were antiretroviral drugs, whereas OUD is an addiction treatable with other drugs such as methadone and suboxone (which also carry potential for abuse) or by quitting cold turkey. The answer, however, is not that simple. The success rates for those who merely quit using opioids are quite low in comparison to those effectively using OUD treatments. There are numerous successful cases of people overcoming their addictions, but the unsuccessful cases continue to produce prominent numbers.

Many people in West Virginia struggle with poverty as well. Poverty is a factor that exacerbates the effects of the opioid epidemic, and according to the United States Census data for 2017, West Virginia has the lowest median income within the United States (\$43,496), and one of the highest rates of unemployment and poverty in the nation. Accompanying these statistics, West Virginia is among the states having the highest percentage of families with an

income of less than \$10,000 a year (Suneson 2018). With such low incomes, the ability to seek treatment may be difficult because of costs, lack of time, and lack of transportation. Within the United States, 88% of the population own cars, but within the state of West Virginia, only about 40% of the population own a vehicle (Poushter 2015; Statista 2016; World Population Review 2018). Transportation was a major issue brought up at both the community meeting and Partners in Hope Consortium. There was a mention of no treatment options in Pineville, and those who seek treatment require a ride to travel the three hours to Parkersburg. Once a week treatment is not enough to suffice, but that is all may people are able to swing with the limited resources in the area.

Transportation was also a major issue brought up at the Partners in Hope Consortium.

Treatment and recovery are not available within the smaller community of Pineville, and many other towns in Wyoming County, therefore without transportation people are unable to seek treatment and get jobs (especially jobs with enough benefits and salary that people are able to pay for treatment). The solution to the transportation problem is not as simple as providing public transportation because, as one attendee mentioned, people are unable to pay for it (August 10, 2019). Another comment highlighted the mere fact that large transportation vans cannot navigate the narrow winding roads in the geographic area, therefore smaller vans would be the only solution. The transportation problem is a barrier to removing oneself from the stigma of being lazy and not worth the time of resources. Respondents to the survey were split regarding whether people with OUD should have access to medically assisted treatment (MAT), with 46.9% thinking that people with OUD should not have access to MAT while the remaining 53.1% believed that they should have access. In contrast, positive responses to deservingness of

people with OUD represented 87.5% of responses, and only 12.5% who believed that they were not worth any time or resources.

This difference in responses shows that of the sample surveyed, it is not necessarily the people with OUD who are stigmatized, but rather it is the various treatment options. This community, unlike those during the HIV epidemic, are not stigmatizing the person or the disease, but the way they receive treatment. Nonetheless, stigmatization of the person who chooses to seek the stigmatized treatment options then emerges (which in the community of Pineville was MAT, specifically suboxone).

A critical consequence of the economic conditions is the lack of support for public health infrastructure, such as needle exchange programs. Exemplifying this issue is the shutdown of the needle exchange program in Charleston, West Virginia. According to an article by the New York Times, the program, which was run out of the Kanawha-Charleston Health Department, was met with initial support from the community (Katz 2018). After opening its doors to the community, a large influx of community members took advantage of the program. At its busiest, upwards of 400 people passed through the doors on a given day. The unexpected success of the program seemed to have overwhelmed the program's capacity, leading to the mismanagement exhibited near the end of the program. Needles were found strewn on the grounds of the building housing the harm reduction program. Community members grew displeased with the masses of people flooding the area with dirty needles. My internship supervisor had mentioned that the location directly across from the newly built civic center led to great controversy.

A program whose purpose was to help reduce the spread of infectious disease was becoming a greater risk for infection as dirty needles collected in public spaces surrounding the health department. A story of a young girl being stuck by a needle in a McDonald's bathroom

contributed to the program's downfall. The program was shut down due to mismanagement, but the stigmatization of drug users led to great community disdain for the program as the users infringed on public space frequented by families and young children.

As the program lost support from the community it was left an easy target for dismantling by the government. The mayor himself, who was in recovery for alcoholism, did not tolerate the mismanagement of the syringe exchange. When leaders of a community withdraw their support for a program, the community typically follows suit, as was seen with this program (Katz 2018). When the largest city in the state is unable to maintain the infrastructure to uphold these programs, it is discouraging for the smaller towns in West Virginia who do not have the same financial and social support for public health programs. When it seems as though the capital city does not support efforts against a nationwide epidemic it easy for those with OUD to lose hope. With the government pulling the harm reduction program, community members who opposed the program feel validated in their distrust and shunning. When there is a lack of government support, communities initiate grassroots efforts to fix their problems. Such community-based efforts were relevant in the community of Pineville as they convened to discuss actions towards reducing the effects of the epidemic in their town.

## Results

# **Community Meetings in West Virginia**

As a part of my internship at the West Virginia University School of Public Health this past summer, I was asked to take notes for the two meetings, Community Meeting and Partners in Hope Consortium, to determine any similarities in the strategies proposed by the groups and those involved with the research grant, all with the goal of assessing the needs of the community of Pineville. Once I began researching for my thesis I found that the community meetings

provided additional insight into the thoughts of the community. The meetings allowed observation of community opinions on the opioid epidemic in a manner different from those solicited via the survey.

## Community Meeting—Wyoming County, March 15, 2018

Over the summer I watched footage from the first community meeting in Wyoming County—the county in which Pineville resides— pertaining to discussions of the status of the opioid epidemic within their community and action plan to target it. This meeting was open to the public and a wide variety of citizens attended, including researchers from West Virginia University; community members; persons working in recovery and treatment centers; government representatives; and youth from the organization Students Against Destructive Decisions (SADD). This diverse audience shared similar interests and motivations for attending the community meeting—they wanted to help rebuild their community and work together to remedy the effects of the opioid epidemic. One suggested means to do so was to provide people who have OUD with aftercare—a term coined to denote all aspects of recovery and remission. The four major factors of aftercare that had been discussed were transportation, housing, finding a job, and long-term remission. All these aspirations are key to providing a stable livelihood for those in recovery. These components, however, cost money.

Representatives for Senator Joe Manchin and Congressman Jenkins were present at the initial community meeting to show support from Washington D.C. for West Virginia. While the government has funding and is providing verbal support, the lack of support surrounding the Charleston syringe exchange program demonstrates how promises and execution may not always align. As opposed to the initial efforts against the HIV epidemic as was mentioned by Dr. Donald

Francis, the government is taking initiative to reduce the effects of the epidemic, with West Virginia representatives taking a stand for the state bearing the greatest burden.

Meeting attendees acknowledged that kids are greatly affected by this epidemic, predominantly by having a parent who is affected by OUD being absent from their life. One man mentioned that numerous children are currently being raised by their grandparents because their parents are unable to do so, because they are incapacitated or imprisoned. Children are highly impressionable and when drugs are introduced into their lives at an early age it can be detrimental. A statistic stated by Dr. Judith Feinburg was that in eight counties in West Virginia—McDowell, Mercer, Wyoming, Mingo, Raleigh, Logan, Boone and Kanawha— there are high rates of babies born with withdrawal. While children are being affected, they were also mentioned as a way of stopping this problem from progressing into the future. Educating and caring for children who have been affected or at risk, is a promising prevention method suggested by the community of Wyoming County.

A quote by Johann Hari that was brought up during the meeting epitomizes why community stigma can be so detrimental to this epidemic: "the opposite of addiction is not sobriety; the opposite of addiction is connection." When a person falls into addiction, they tend lose the familial support they need to reach recovery. As mentioned in the paper by Steve Matthews (2017), people return to their addiction when they feel that their community is against them and stigmatizing them. This support and outreach from community members were key first steps to reducing the reliance on a person's addiction and potential for relapse.

# Partners in Hope Consortium—Pineville, August 10, 2018

During my weekend in Pineville, I was lucky enough to sit in on a Partners in Hope

Consortium, a direct result of the community meeting I had previously observed. This meeting
consisted of a number of organizations that were treating people with OUD, primarily with
therapy. Twenty-three representatives, along with the young daughter of one attendee, were
present from organizations such as Sound Mind, Southern Highlands (a MAT clinic), Wyoming

County Health Department, Mountain Heart Community Services, Americorps, and various
government agencies. The meeting commenced with introductions of everyone sitting around the
U-shaped table configuration in the center of the room. They discussed the steps forward within
the community regarding the opioid epidemic and how to allocate funds across different phases
of OUD. They started by outlining the priorities for funding. The group agreed that saving lives
is the number one priority. By this they meant that there should be a focus on harm reduction
programs. Harm reduction programs that encompass the syringe exchange focus on reducing the
negative effects associated with drug use (Harm Reduction Coalition n.d.).

The second priority was treatment. None of the treatment programs represented at the meeting were based in Pineville, but they do offer spaces for those from the all over the local geographic region. Sound Mind's representative chimed in that all of those who were staying at the center had been clean since they arrived. Precision testing is regularly used to ensure that those at the center are not using. The testing checks for everything, because those working at Sound Mind have seen that people with OUD will just replace the opioids with another substance not originally included in the check.

Similar to the initial meeting, children were brought up once again. One attendee mentioned that they helped as a school counselor two days a week and they would have kids

come into the office crying because their parents had died of a drug overdose, their parents were in jail, or their parents left them a couple months before and they had not seen them since. The effects on children are felt throughout the town. The mention of children being raised by their grandparents was mentioned as well, an issue that seems to be more common than I had realized.

The remaining priorities were 3) transportation, 4) aftercare, 5) outreach, 6) prevention, and 7) evaluation. These themes were carried over from the first meeting as priorities of the consortium. Aftercare was discussed at length as this encompassed treatment and recovery options, including MAT.

This was the moment that I observed the new stigma against treatment that had not previously been observed in public health epidemics. There were contrasting opinions and experiencing regarding suboxone in the community of Pineville and these differences provided difficulties in coming to a consensus about the implementation of MAT into the program's priorities. There was question of the harmful effects of bringing more suboxone into the community. One initial issue with the current suboxone distribution in Pineville is that the medications are provided on a monthly basis rather than weekly. An attendee stated that there are people who will sell half a strip of suboxone in order to make money and in turn do not adhere to the recommended doses and use of the medication, leading to unsuccessful recovery with the use of this medication. The woman who offered up the story about her brother during survey distribution also mentioned that he just sells his suboxone and has yet to reach recovery even though he is partaking in this recommended treatment option.

Another issue brought up was people using other drugs or abusing the prescription of suboxone. An addicted person will do anything to get the accustomed high experienced from their opioid dependence. One person suggested that suboxone does not work. People will just use

other drugs while in recovery. While this was an issue that people acknowledged among those in recovery with suboxone, attendees failed to acknowledge that suboxone is not the reason people are seeking out other drugs. People who are going cold turkey are just as likely, if not more so, to seek out alternative drugs to alleviate the pains of withdrawal.

The infrequency of physician visits, however, does compromise the quality of the program. While the number of unsuccessful suboxone cases outweighed the number of success stories that were offered up at the meeting, the researchers from West Virginia University tried to counter, noting the success at the program in Morgantown, West Virginia. The program in Morgntown requires patients to be tested regularly and followed for an extended period of time before entrusting them with larger prescriptions. Both sides appeared steadfast in their views of MAT. A researcher from West Virginia University suggested that suboxone was not the only drug that could be utilized as part of a MAT program, methadone has been used in other programs across the country and produced successful results. At the mention of methadone as an alternative to suboxone in Pineville, one attendee stated that it is a "disaster, is a proven disaster."

A gentleman present at the meeting was not fond of the idea of bringing MAT into the community. Offering himself as an example, he stated that he had been sober for 10 years because of strong will, social support, and God. While this is an inspirational success story, not all cases resemble this one. Someone mentioned that helping a person with OUD into recovery requires treating the person not the disease. Every person handles withdrawal differently and therefore requires different forms of treatment and one person's route to recovery may look very different than another's. However, the idea of social support was drawn from his statement and integrated into the priorities.

The outreach aspect focused on building community with people who have OUD. Community outreach, however, requires community involvement, something that had been lacking since the original community meeting. An open invitation had been provided to the whole community to partake in the consortium but they have been having difficulties getting people to show up. Without community involvement, programs are limited in the outreach they can provide, and it was also mentioned that funding does not flow unless the community becomes invested.

### **Themes from Survey and Meetings**

While there was much overlap in discussion at both the community meeting and the Partners in Hope Consortium, much of it regarded the positive efforts the community planned to enact to combat the effects of the opioid epidemic within their community. Once the survey was analyzed, however, themes of stigma seen in the meetings were teased out. While the meetings primarily lay the background for the positive initiatives taking effect within the community, there was surprisingly a great point of contention found among even those who wish to help those with OUD.

## Stigma Against Medication Assisted Treatment (MAT)

Prior to completing the surveys, one of the co-investigator on the project urged me to include a question regarding the community's thoughts on medication assisted treatments, particularly suboxone, the most commonly used treatment in Pineville, and even West Virginia as a whole. Prior to my research on the opioid epidemic, I thought that was an unnecessary question to ask. I assumed that the reason people were not utilizing suboxone was merely

because they did not have access, not that they did not want to. This topic ended up being more controversial than I had imagined. It became immediately apparent during the Partners in Hope Consortium meeting.

A significant portion of respondents believed that addiction, referencing opioid use disorder, is a treatable illness (84.4%), but there seemed to be disagreement on the means of treatment that work best. Question twelve on the survey asked whether that person "believe[d] that drug-assisted treatments (such as suboxone) can help someone who is addicted to opioids recover." The responses to this question are split, just as the co-investigator had predicted—42.4% believing that suboxone would not help and 57.6% believing that it would help. As "just another drug," suboxone is itself an opioid, made of buprenorphine and naloxone, and therefore does have addictive qualities found in other opioids.

During the Partners in Hope Consortium, there was a large debate on the form of treatment and aftercare that would be promoted within the community. As mentioned earlier, the issue of transportation negatively plays into administering suboxone on a regular basis. In Pineville, it is difficult to regularly see a doctor to pick up prescriptions of suboxone, doctors prescribe one month supplies for patients. One meeting attendee mentioned that people with suboxone prescriptions will sell half of a strip of the pills, thereby failing to adhere to their medication, which inhibits the effectiveness of the suboxone treatment. According to my mother, a nurse on a Dual Diagnosis Unit (a unit where patients are diagnosed with a mental illness, such as depression, and substance use) at the psychiatric hospital in Morgantown, people with monthly prescriptions have higher rates of addiction relapse.

In Pineville, monthly prescriptions of suboxone are most frequently prescribed as it is difficult for people with OUD to drive long distances to receive their medication due to the

transportation issue that was previously mentioned. Morgantown has significantly more resources to help provide treatment to those who have OUD. As a university town, Morgantown is equipped with two hospitals. One hospital is sponsored by West Virginia University as a teaching hospital and houses the unit that works with people who have OUD. Methadone, another OUD treatment, is rarely used here, but rather suboxone treatment with weekly therapy sessions. My mother also indicated that the highest success rates are seen in patients who attend weekly therapy sessions concurrently with their medication (February 16, 2019). This confirms the statement made by Hari that "connection" challenges addiction. When people have someone to talk with and gain support from without fear of judgment, they are more likely to have a successful recovery.

Stigma remains an issue even for those who aim to help those suffering from OUD.

Sometimes one's own experiences play into the stigma that is seen within this community. At the meeting, a local pastor who was in remission for his drug addiction said that he overcame his addiction with God alone. Another respondent noted in their survey that they had successfully recovered without suboxone—"I am proof! Without Suboxone!" This respondent also mentioned in the comments that "With God ANYTHING is possible." While there were no significant religious overtones seen throughout my weekend in Pineville, religion would frequently surface as an explanation for their success or motivation. This religious aspect was usually found in connection with the absence of MAT.

These stories are inspirational but not one-size-fits-all. Addiction is an individualized disease that affects people differently, meaning that various recovery options will also have different effects. Numerous people at the hospital in Morgantown are recovering with the aid of medication and others in Pineville are abusing those same sorts of medication. One lady who

works in a recovery center mentioned that a patient had disclosed to her that they had taken their suboxone prescription, dissolved it with water and meth and shot it up their rectum. Such stories reinforce community members' distrust of suboxone as a method of treatment. These differing experiences lead to stigmatization of an entire treatment options, which then limits the access people with OUD have in certain communities. Two other attendees rebutted these negative claims about suboxone, one saying that suboxone is not a treatment, but a means of harm reduction, while the other stated that suboxone makes a person with OUD a fully functioning human being in spirit, body and soul. They acknowledged that one must treat the person and that every person is different.

The Partners in Hope Consortium meeting discussed the allocation of funding for treatment options. With such a stark contrast in the opinions regarding suboxone as a viable treatment option, some people may be unable to receive the individualized treatments that they require. As I administered the survey, one respondent talked with me about the fact that she is in recovery only because of suboxone. While she mentioned that she had to travel all the way to Charleston once a month to receive her suboxone prescription, she regarded suboxone as the reason for her recovery (August 11, 2018). While stigma may be perpetuated because of a single success story or an individual disaster, it is important to look at the whole picture when individuals impart opinions onto a larger group.

# Stigma Against Needle Exchange Programs

Communities are implementing syringe exchange programs are being implemented across the United States as a means of decreasing the transmission of diseases such as HIV and Hepatitis C. These infections spread when people who are already infected share needles. The

reuse of dirty needles increases the rates of transmission, and this often occurs when people do not have the means to invest in new needles, especially when they are being used frequently. Therefore, the implementation of these needle exchange programs has successfully led to the decrease of such diseases. Stigma, however, towards and lack of support for these programs makes it difficult to maintain such programs as mentioned previously with the Charleston syringe exchange shutdown. Regardless of the positive effects being made in the community, there will be conflict of interests due to the stigmatization of these programs. While some reasons for not supporting the Charleston exchange are valid (including the incident young girl was stuck with a needle in the restroom of a McDonalds) (Monahan 2018), other reasons simply reflect beliefs about facilitating the continued use of IV drugs. Such beliefs fail to acknowledge the main reason for these exchange programs: as a preventative measure for infectious diseases, not a treatment for opioid users. Statistically, the distribution of responses to the survey regarding the support or opposition for the implementation of a syringe exchange program was evenly dispersed. Of the responses, 31.2% opposed, 34.4% were neutral, and 34.4% supported the syringe exchange program. The mixed opinions were echoed in some of the free responses on the survey.

Positive Opinions Regarding Syringe Exchange

The survey included a question about the support for a syringe exchange program followed by a free response where respondents could elaborate why or why not they support the program. Of those who supported the syringe exchange programs, they did so because they knew that it reduced the risk of contracting other diseases common with intravenous (IV) drug use, the intended purpose of the syringe exchange/ harm reduction program. Verbatim responses include:

"Avoids disease such as HIV so helps the community as a greater good"

"disease prevention"

"Decrease the spread of disease"

"It is something that they need to keep people from getting a disease from using old ones"

Mixed Opinions Regarding Syringe Exchange

There were also respondents who acknowledge the benefit of disease prevention but additionally think the exchange program does just support users in their addiction by providing them with the means to continue using.

"It may fight infections and disease but only encourages users."

"Would stop spread of disease but would enable addicts to use more."

Negative Opinions Regarding Syringe Exchange

Numerous people blatantly discouraged the establishment of syringe exchange programs within their community because they believe that distributing clean needles merely encourages users to continue using. The fact that people who utilize the syringe exchanges are receiving all the tools needed to inject does lend credence to the idea that it is enabling users to continue with their IV drug use.

"It is enabling"

"Allows users to have easier access"

"Needle exchange is dangerous, they shouldn't be used like that anyhow!"

One of the respondents was unsure of what a syringe exchange was, so I explained to him that it is a program providing clean needles to people who are using IV drugs so that they do not contract HIV or Hepatitis C. His response was overwhelmingly positive. He stated that although he had never heard of such a thing and was unaware that there was a program within his own

town, he acknowledged that if it would help decrease the transmission of infection, he was supportive of the program. This made me question how many people are unaware of the intended purpose and positive outcomes that have followed the implementation of these syringe exchange programs. If the programs already in place were to be removed, there would likely be a sharp increase in the cases of infectious diseases among people with OUD. Syringe exchanges are part of the overarching harm reduction programs with the intended goal of reducing the negative health outcomes associated with IV drug use. If a program is unable to stop a person from using IV drugs, the next best thing is to make sure that they are doing so as safely as possible.

During the Partners in Hope Consortium, a comment was made that mimics this idea. A consortium attendee mentioned that the support of a syringe exchange does not mean that they condone IV drug use. The biggest reason for support was the fact that once the disease is in the IV population, it moves beyond that group to others. Given the nature of transmission through sexual contact, there is an increased risk for the disease to spread to those who do not use IV drugs. This is a point that many people do not consider. In the Partners in Hope Consortium meeting, someone mentioned that the syringe exchange is not just to protect users from contracting HIV but also to prevent the spread to the rest of the community. Given its nature as a sexually transmitted disease, if HIV finds a stronghold with the population of IV drug users it is not likely to remain within this population long. The support of a syringe exchange does not in any way meant that IV drug use is an act that should be accepted within the community, but that there are implications outside of the community of IV drug users. Another attendee threw out the statistic that those who utilize the syringe exchanges are five times more likely to enter recovery. While they did not elaborate on the reasoning behind this statistic, it is possible that this is due to the connections and support found from those who work with the syringe exchange program.

### Anthropology, Public Health, and the Opioid Epidemic

The dynamics of the meetings and responses that local Pineville residents provided to the surveys reveal an aspect of the opioid epidemic that has hardly been explored: the divide between what public health workers believe is necessary to address in the epidemic and what residents grappling with the epidemic see as important. The meanings that different parties attach to the epidemic, especially the ways that it might be contained, reflect their own groups' concerns and prior experiences, sometimes creating a divide between the groups.

Public health as a discipline operates on the assumption that it has all the answers. There is a slight arrogance regarding the implementation of blanket programing into communities and the assumption that the program data represents how treatment programs will work regardless of context. While many programs are effective, they are not always a one-size-fits-all solution. For example, in July 2014 a bulletin was sent out to the public that described a plan for providing Medicaid beneficiaries with access to the MAT that they need in their recovery (Mann et al. 2014). When a notice is produced for the public on behalf of big names in public health such as the CDC, the SAMHSA, the NIH (National Institute on Drug Abuse, National Institute on Alcohol Abuse and Alcoholism), and the Center for Medicaid and CHIP Services, it is often assumed that this is the best means for treating the issue at hand. Organizations in public health then attempt to implement programs such as MAT without analyzing the community beforehand and whether the program is likely to be successful in that community. A visit to Pineville and an analysis of the previous suboxone distribution would show that merely increasing access to the treatment would not solve the problem. An anthropological approach, unlike the routine public health strategy, recognizes that individual communities have different cultures and lived experiences, and even within the same community there are significant differences. Such

differences clearly emerged in the community meeting where residents challenged the experts' emphasis on the importance of MAT programs and how they are implemented.

The role of anthropology in this research project is understanding why people feel the way they do about the implementation of MAT programs and what this means for public health as it tries to reduce the epidemic's effects. Opposition to suboxone in Pineville traces to the negative feelings associated with unsuccessful local cases and the geographic isolation that perpetuates the issue. As a small town nestled in the mountains of West Virginia, it is difficult to implement successful MAT programs when access to physicians for suboxone prescriptions is limited to once a month and receiving therapy requires admitting oneself to a treatment center or commuting weekly to hospitals that offer therapy with MAT. Therefore, residents only understand the MAT programs in the context of Pineville. There are successful programs found in Morgantown where physicians are able to monitor patients as they come for weekly treatment and therapy, but that program has greater resources and access being in a university town.

Therefore, public health officials must acknowledge that some people within the community will adamantly resist new MAT programs because their community is not well suited for it. The research project at WVU understood the importance of learning the needs and desires of the community owing to attendance at early community meetings and through discussions with community members and the health department. Nonetheless, they proposed the implementation of a MAT clinic in the community as a proposed first step to address the epidemic. Such a proposal revealed how public health, as with most disciplines, has its biases despite its best efforts to research the programs and treatment options that work best and then attempt to implement them within a community. Difficulty lies in the disconnect between public health "best practices" and the beliefs of locals. Public health officials may fail to realize that the

infrastructure, experiences, and desires of each community differ. While the anthropological insight generated by my project is preliminary and would benefit from extended follow up, it still provides reason for pause. Identifying the conflicting ideals held by those in the field of public health and those with lived experiences regarding the epidemic is beneficial to understanding why the suboxone programs are not always beneficial and why those in the community feel they are not worth the investment of resources. The case of Pineville and the opioid epidemic is just one example of how an anthropological approach would benefit public health endeavors.

### **Analysis of Survey Data**

Prior to data analysis, I suspected that community members who had a personal experience or relationship with a person having opioid use disorder were less likely to exhibit stigmatizing attitudes. Given stigma's roots of fear and lack of knowledge, it would make sense that those who have less direct interaction with persons who have OUD would exhibit greater stigma. Using SPSS, frequencies and comparison of means were utilized to determine whether those who have any degree of contact with those with OUD differed in terms of stigmatizing opioid users from those who have had no such contact.

# **Development of Measures**

To prepare the data for analyses, I examined whether the 34 respondents seemed to have taken the survey seriously. One respondent marked "4" for nearly all the questions, signaling lack of attention to the substance of each question. Some of the survey items represented positive evaluations of opioid users whereas other negative evaluations. Thus, a repeated response of "4" suggested that the respondent failed to thoughtfully address each question, which would

introduce inaccuracy in the analysis. Therefore, the quantitative analysis is based on 33 respondents.

The survey questions regarding one's interactions with people who are addicted to opioids were used as a basis for the independent variable. I combined two "yes/no" questions pertaining to the respondents' relationships with the opioid users: "I have a family member who is addicted to opioids" (question 9) and "Do you know someone who is addicted to opioids?" (question 10). The new variable, Personal Experience, was coded 0 (does not know someone who is addicted to opioids), 0.5 (either knows someone outside of the family OR has a family member who is addicted to opioids), and 1 (knows someone both within and outside of their family who is addicted to opioids). Most respondents (19 or about 58%) had no direct relation to a person who is addicted to opioids; ten people (about 30 %) knew either a relative or someone outside of their family; and four people (about 12 %) knew someone both within their family and as a companion. When combining the two groups who know someone, the groups are more evenly represented.

The survey contained 30 questions regarding stigmatized viewpoints. I focus on questions 13-33 for analysis because they all utilized the same 4-point scale, where one indicated that they strongly disagreed with the statement and 4 being that they strongly agreed with the statement. Using principal component factor analyses, I created three categories of stigma. The questions that clustered for the first category were questions 13-16 and 20 (for example "Most people would willingly accept some who is addicted to opioids as a close friend" and "Most people would hire someone who has been treated for substance use to take care of their children."), all pertaining to the optimistic opinions of most people in interacting with a person who had OUD, such as whether they believe that most people would be friends with someone who has OUD or

allow them to take care of their children. The second group included questions 22, 26-29, and 31 (for example: People who are addicted to opioids are morally weak" and "Most people are afraid of individuals who are addicted to opioids"), all of which pertained to the stigmatized views held by the individuals, such as whether they would avoid individuals in their community who have OUD or no longer be friends with a person diagnosed with OUD. The third consisted of three questions—21,23, and 30 (for example: "People who are addicted to opioids are unable to care for themselves" and "People who are addicted to opioids are not worth the investment of time and resources.") —which regard to the worth and value of individuals who have OUD. Of these three groups, only group three was significantly related to an individual's relationship with a person who has OUD.

## **Empirical Patterns**

I used one-way analysis of variance to examine if respondents' relationships with opioid users affected the nature of the stigma that they expressed to those with OUD. I expected those with more contact with opioid users to: 1) hold more optimistic opinions of interacting with a person with OUD, 2) be less likely to avoid such individuals, and 3) be more likely to see them of worth and value. Respondents' relationship with opioid users failed to affect their optimistic opinions or their avoidance behaviors. A significant relationship (p=0.015) emerged only with regard to their worth and value. The pattern of means, however, indicated opposite of what I would have expected. Those who have greater personal relationships were more likely to hold stigmatizing views towards people with OUD (M=2.67) than those who had fewer personal relationships and interactions with people who have OUD (M=1.87). Those with at least one interaction with a person who has OUD, be it a familial relationship or other, had a mean that fell

directly in between the other two groups (M=2.03). Even though the pattern of results showed the significant impact of relationships, the actual scale measures suggest that the majority of respondents held views that tended to be more positive.

Although lack of significant statistical relationships involving the stigma scales may stem from the small sample size, I nonetheless ran separate one-way analysis of variance using personal experience with opioid users and each of the 20 questions pertaining to stigma. In order to determine if the lack of significance was a product of respondent interpretation of questions, I created a new personal experience variable replacing question 10 with responses to "I have met someone who is addicted to opioids" (question 8). The question order on the survey led to some confusion regarding how to properly respond to the personal experience questions. By addressing this possible confusion, I reran the one-way analysis with the new variable. The responses were redistributed for the codes 0, 0.5, and 1 (n=19, n=8, n=6 respectively). After this change, three survey responses were found with significant correlation to the variable of personal experience.

Similar to the results involving the scale of worth and value of opioid users, respondents who have more experience are more likely to find people who have OUD to be morally weak (p=0.024). However, those with greater personal experience seem to have increased optimism regarding the opinions of most people, thinking that the general public would likely allow people who have OUD to teach children in public schools (p=0.006) and take care of their own children (p=0.005).

After looking at the data patterns, I realized that those who merely interacted with a person who has OUD does not necessarily mean that the experience was positive. A negative experience could have been why some people who had relationships with someone who has

OUD exhibited stigmatized views. Therefore, I examined whether knowing someone who has been successfully treated for OUD affected the stigma questions. Once again, only three questions elicited significant responses. The results showed that respondents who knew someone who was addicted to opioids and successfully treated (n=15) held greater stigmatized views than those who did not know someone who had been successfully treated for OUD (n=18). Those knowing a person who had successfully been treated for OUD still believed that someone who is addicted to opioids should be denied employment (p=0.002) and denied housing (p=0.012), and that they would not allow that person to be around their kids (p=0.029).

Given the focus on religion as a possible barrier to treatment due to stigma, I also assessed whether more frequent attendees at religious services held more stigmatized views of opioid us. No significant correlations between frequency of attending religious services and stigma emerged.

### **Discussion**

This study analyzed the stigma that is commonly found during public health epidemics. The goal was to tease out possible factors affecting stigmatized views. While the patterns of survey results were largely insignificant in terms of experience with opioid users, other results reinforce the view that there was stigma among the community regarding people who have OUD. Regarding MAT, there were mixed views about whether a person deserved to have MAT as a treatment option. Most respondents did, however, agree that OUD is a treatable illness. This variation in responses shows that there is still doubt about the effectiveness of MAT as a treatment option in Pineville.

The stigma against treatment is a new source of stigma that had not been seen during the HIV epidemic. In the 1980s when HIV was taking hold in the United States, prevention methods, predominantly condoms, were stigmatized by the church due to the moral implications of their use. Those who contracted HIV were also stigmatized due to the path of transmission being primarily via sex, and predominantly among men who have sex with men. The knowledge of transmission via bodily fluids also perpetuated the stigma that a person could contract HIV by drinking out of the same cup as an infected person. Because of this stigma that surrounds the disease, people today still do not seek treatment or strictly adhere to it out of fear that their disease status will be discovered. While the treatments themselves are not stigmatized, likely because antiretroviral therapy can greatly prolong the life of a person infected with HIV, the stigma of the disease creates a barrier to treatment.

The opioid epidemic is unique insofar as that the actual treatment itself carries a stigma. Because of the physiological differences between addiction, a mental health issue, and HIV/AIDS, a viral disease, treatments do not work in the same way. For OUD, MAT is a therapy that helps alleviate withdrawal symptoms and allows patients to have a more tolerable recovery process as opposed to going cold turkey. Unlike HIV, medication treatments are not required to prolong a person's life, although by decreasing the rate of relapsing it does consequently increase life expectancy by reducing the risk of overdose. While the relapse rates are significantly higher without MAT, the experiences of people in Pineville have led them to distrust medication as a treatment option for OUD, even among those who are working towards negating the effects of the opioid epidemic within their community. The identity of suboxone as an opioid also creates distrust around providing people who have OUD with "another drug".

While not a treatment, but rather a means of harm reduction, the syringe exchange also faces stigma. This harm reduction method decreases the chances of contracting HIV along with other infectious diseases. However, because this program provides users with the tools required to inject themselves, community members saw it as supporting the users in their addiction. This stigma creates another barrier to users protecting oneself from compounding diseases.

When analyzing the community stigma survey it was apparent that there was stigma regarding enacted stigma against people with OUD. While stigma was present, upon analysis there were no trends in the source of the stigma. Typically, stigma stems from stereotypes and fear of something, which I hypothesized meant that a person who has greater interaction with a person who has OUD would hold fewer less stigma towards these people. However, there was not significant correlation between stigma and the interactions people have had with persons who have OUD. The few interactions that were observed inferred the opposite—those with greater interaction had slightly more stigmatized views than those who had less interaction.

Acknowledging that stigma arises in each public health epidemic differently allows for those on the frontlines to more effectively reduce the stigma that is leading to treatment and prevention barriers. Anthropology offers the insight that even within these distinct epidemics, each community experiences the epidemic differently. The treatment options found to be successful in one location may not experience the same success elsewhere. Going into communities and determining what the locals think would be beneficial and what they have seen to be unsuccessful can aid public health officials in their program development. The research project with West Virginia University took the first steps of observing the community's preferred programs, but it would be beneficial to learn the background regarding why they feel that way so that officials can better understand why or why not their preferred program would work in a

given location. Regarding this study, the stigma in this community surrounding MAT programs is unique due to the lived experiences and provides reason to pause prior to program implementation.

While reducing the stigma against people who have OUD reduces barriers to seeking treatment, the stigma against treatments themselves merely creates another roadblock that people with OUD must maneuver in order to receive the appropriate treatment. While some people are able to recover without MAT, the relapse rates are much higher when attempting to go cold turkey as the means of recovery. Understanding that individuals respond to withdrawal symptoms differently and may have little success without treatment is key to overcoming the stigma barrier.

While the observations were obtained over the course of two days, the short duration of time spent in Pineville was a source of limitation throughout the study. After spending almost a month and a half working on the survey, only one and a half days were spent in Pineville. This limited my interaction with citizens of Wyoming County, hearing their perspectives and opinions on the opioid epidemic. Due to the controversy surrounding the topic, it was unlikely to gather everyone's true thoughts on the topic. In order to gain trust in participant observation, one must develop relationships and spend significant amounts of time talking with informants. This leads to respondents providing more truthful answers as opposed to answers they think the researcher wants to hear.

It was also limiting to only observe people who are passionate about fixing the opioid epidemic and their discussions of the issue. The general public's voice was only heard in the survey, and even within the survey a representative voice of the community could not be ascertained due to the large number of people who declined participation in the survey. I

attempted to keep track of everyone who entered the grocery store without participating on the second day, but it became difficult as I assisted those who agreed to take the survey. However, I counted upwards of a hundred people who declined to participate. Those who did not participate in the survey were more likely to have apathetic attitudes towards the issue, or have negative thoughts or experiences pertaining to the epidemic. Lack of time may have been another reason for not participating in the survey, or merely thinking that participating in a survey was a waste of their time. This can be determined by the large number of respondents who had no direct interaction with a person who has OUD (n=19). Another factor contributing to the non-representative sample was the sample size. With only 34 surveys, and one that was discarded due to careless response of circling the same number for every question, the small sample created a challenge regarding the possibility of revealing significant correlations.

Additionally, it would have been beneficial to have included a free response on the opinions regarding MAT. After analysis, MAT showed itself to be a point of contention, and although a few people offered up their own stories of success with or without MAT, it would have been beneficial to have the opinions of the general public who are making the decisions of whether or not they want to allow their state's money to fund such treatment programs.

To further this study, it would be beneficial to conduct individual interviews regarding a person's thoughts on MAT and the syringe exchange to determine why these people hold these perceptions of these treatment and prevention efforts. People who had religious reasons brought them up freely, and would likely discuss these in greater depth during an interview. In-depth interviews conducted with people of varying personal relationships with persons who have OUD would provide various perspectives to help analyze the effects of personal experience on stigma. Another factor that should be considered is whether there is significant stigma surrounding MAT

among people who have OUD. One person who spoke during the meeting about being worried of the effects of suboxone in the community had himself successfully recovered without the drug, and three people divulged in conversation that they themselves were in recovery for OUD. Further exploring the thoughts of those who may have used MAT would provide an additional perspective.

Future research may examine the nature of connection with people who have OUD and their impressions of the reality of the disorder and its effects on individual users and their families. For example, experiences such as described by the woman at the Partners in Hope Consortium who knew a person with OUD who manipulated her suboxone with other drugs and then injected the mixture are likely to spur distrust about patients recovering with suboxone. Similarly, even those who do know someone who has successfully be treated for OUD may think of the person before treatment and the negative effects of OUD, which diminish their trust in users and beliefs about their responsibility regarding their jobs and rent payments. Enacting stigma to deny employment to those with OUD would only perpetuate the issue at hand.

Steps are being taken to help minimize the stigma against MAT in the state. As of December 2018, Southern Highlands Community Mental Health Center, one of the organizations that had been present at the Partners in Hope Consortium, received a \$1.5 million grant for drug treatment in the region. The goals of this grant are to make MAT more accessible in rural communities and improve participant retention rates. Mere months before I was in a room with representatives from this organization and numerous other people discussing whether MAT was worth the investment of money. With this specified grant designated for the implementation of MAT programs, it will be interesting to see the effects Southern Highlands is able to make in small communities like Pineville to increase access and retention rates of suboxone use.

## **Conclusion**

Stigma permeates many aspects of how we as humans interact with one another. Based on assumed identities, we make judgments and negative opinions about the other person. This stigma is not absent in the face of public health epidemics, and can even be heightened during this time. At the start of my research, I wanted to determine whether there was stigma surrounding the opioid epidemic within the community of Pineville, West Virginia. Upon finding positive trends of stigma present among survey respondents, I wanted to analyze whether or not there was a correlation between the stigma and the types of interaction people in the community have with persons who have OUD.

Stigma was found to be present within the community, but not solely towards persons who have OUD. The treatment with suboxone, a form of MAT, was seen to be a point of contention both within the survey and at the community meetings. Treatment for OUD is not a one-size-fits-all solution. While some people can cut themselves off of from opioids cold turkey and successfully recover, others find the pains of withdrawal too severe and relapse. With this distinction in recovery options, stigma makes it difficult for those who are unable to recover without medication to find treatment. Another layer of difficulty is added when those who are making decisions about the implementation of these recovery options have split opinions. Those who were supposed to be deciding where to allocate funds for treatment held contrasting views about the implementation of MAT within their community.

By acknowledging where the stigma lies in epidemics such as this one, policy makers and those in decision making positions will know where to focus their prevention efforts. Knowing that MAT is a source of contention, the concerns regarding this treatment option should be

addressed. This will allow those who seek treatment in the future to make decisions based on what will be most beneficial to their recovery rather than deciding out of fear of stigmatization.

While much research has been done on self-stigma regarding mental health and addiction, there are limited studies performed on community stigma. When discussing the opioid epidemic specifically, the anthropological literature is even more limited. While there is a great focus on reducing stigma of opioid addiction, there is not as much mention of MAT as a stigmatized entity. This paper provides a different perspective to the stigma surrounding the opioid epidemic, acknowledging the stigma against treatment.

While stigma presents itself differently throughout public health epidemics. Each epidemic cannot be treated the same way as the last because new issues arise that create difficulties in managing the disease or disorder. With the newly present physician treatment stigmas, a new approach to helping those with OUD must be determined. While many initiatives have been implemented to educate the population on the opioid epidemic so that OUD will become destigmatized, there is a gap in the initiatives towards making MAT an acceptable form of treatment. While this process will require great outreach to individual communities that may have been forgotten, such as Pineville and other small Appalachian towns. When the MAT experiences known by these small communities all resulted in negative outcomes, it becomes important to create initiatives to help successfully implement MAT.

As mentioned, each town, just as each individual, has differing thoughts and experiences regarding the epidemic. Expanding this research project to include interviews would be beneficial to determining the true reasons behind the distrust of MAT. In determining why people do not support this recovery option, programing can be created to help counter this stigma. Implementing this research in other small towns would be beneficial to determine

whether or not MAT is a stigmatized issue in other communities as well. This epidemic is continuing to expand into the far reaches of the United States and measures need to be taken to help those in recovery so that the prevalence rate can be reduced while researchers and policy makers continue to work towards a decrease in incidences of OUD.

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## Appendix 1: Community Stigma Survey

### Opioid Epidemic Community Attitudes Survey

West Virginia University is conducting a survey study to understand people's attitudes towards opioid addiction in their community. We hope to use the information we collect to find better ways to help people and communities that are impacted by opioid addiction. This survey takes about 5-8 minutes to complete. All of your answers will be completely anonymous and confidential, and there will be no way to identify you personally in any reports or publications that result from this study. **Do not put your name or any other identifying information on this survey**.

In exchange for your time, you may choose to enter your name and contact information on a separate card (not attached to the survey or tied to your responses) for a chance to win a \$50 Visa gift card in a random drawing of participating respondents.

For the purposes of this survey, **opioid is defined as** both prescription pain medications such as Oxycontin as well as street drugs like heroin and fentanyl.

Please complete all questions by choosing the answer that best reflects your opinions about people who are addicted to opioids in your community. There are no right or wrong answers to these questions. We are interested in understanding your personal opinions.

## First, we will start with a general question about your community.

1) How big of a problem is opioid use in Pineville? **Choose one.** 

1	2	3	4
Not at all	Minor	Major	Serious
a problem	problem	problem	problem

Please tell us how strongly agree or disagree with each of the statements below by circling the number that best reflects your opinion.

Q#	Statement	Strongly Disagree						Strongly Agree
2	Employers should be allowed to deny employment to a person addicted to prescription pain medication.	1	2	3	4	5	6	7
3	Landlords should be allowed to deny housing to a person addicted to prescription pain medication.	1	2	3	4	5	6	7
4	Most people addicted to prescription pain medication can, with treatment, get well and return to productive lives.	1	2	3	4	5	6	7

5	Effective treatment options are							
	available to help people addicted to prescription pain	1	2	3	4	5	6	7
	medication.							

6) Circling one item on the scale, would you think that a person who is using opioids is:

1 2 3 4 5 6 7 Worthless Deserving

7) Circling one item on the scale, would you think that a person who is using opioids is:

1 2 3 4 5 6 7 Weak Strong

Please tell us about your personal experiences with people who are addicted to opioids by circling the one answer that best applies to you.

٥,	A T 1		•.1	1 111 11		TIEC	3.10
8)	I) I have	interacted	with someone	who is addicted to o	p101 <b>d</b> S.	YES	NO

9) I have a family member who is addicted to opioids.

YES

NO

10) Do you know someone who is addicted to opioids?

YES

NO

11) I know someone who has received treatment for an addiction to opioids. YES NO

12) If the mayor your town supported establishing treatment centers for people with an addiction to opioids, would you support these centers as well?

YES

NO

## Please circle the answer that best reflects how much you agree or disagree with each statement

Q#	Statement	Strongly Disagree	Disagree	Agree	Strongly Agree
13	Most people would willingly accept someone who is addicted to opioids as a close friend.	1	2	3	4
14	Most people believe that someone who is addicted to opioids is just as trustworthy as the average citizen.	1	2	3	4
15	Most people would accept someone who is addicted to opioids as a teacher of young children in a public school.	1	2	3	4
16	Most people would hire someone who has been treated for substance use to take care of their children.	1	2	3	4
17	Most people think less of a person who is addicted to opioids.	1	2	3	4
18	Most employers in my community will hire someone who is addicted to opioids if he or she is qualified for the job.	1	2	3	4

19	Most employers will pass over the				
	application of someone who is addicted to opioids in favor of another applicant.	1	2	3	4
Q#	Statement	Strongly Disagree	Disagree	Agree	Strongly Agree
20	Most people would be willing to date someone who is addicted to opioids.	1	2	3	4
21	People who are addicted to opioids are unable to care for themselves.	1	2	3	4
22	People who are addicted to opioids are morally weak.	1	2	3	4
23	People who are addicted to opioids are not worth the investment of time and resources.	1	2	3	4
24	People who are addicted to opioids are getting what they deserve because of how they have lived their lives.	1	2	3	4
25	People who are addicted to opioids should have access to drug-assisted treatments such as suboxone.	1	2	3	4
26	Most people are afraid of individuals who are addicted to opioids.	1	2	3	4
27	A person who is addicted to opioids brings shame on his or her family.	1	2	3	4
28	I avoid people in my community who are addicted to opioids.	1	2	3	4
29	I would no longer be friends with someone if I knew they were addicted to opioids.	1	2	3	4
30	I would reject a family member because he or she is addicted to opioids.	1	2	3	4
31	I do not want (or would not let) people who are addicted to opioids around my children.	1	2	3	4
32	I am uncomfortable being around people who I know are addicted to opioids.	1	2	3	4
33	A person who is addicted to opioids brings shame on his or her family.	1	2	3	4

Now, we will briefly cover your thoughts on opioid-related programs.

34) On a scale of 1 to 5 (1=Strongly Oppose, 5=Strongly Support), what is your opinion on the legalization of syringe/needle exchange programs in your community? **Indicate by circling a number below.** 

1 2 3 4 5 Strongly Oppose Strongly Support

Briefly, why do you oppose or support syringe/needle exchange programs?

Finally, we'd like to know a little about you. Please answer the following questions.
35) Which gender do you most closely identify with? <b>Please circle one.</b> Male Female Prefer not to answer
36) How old were you on your last birthday?  18-25  26-35  36-50  51-60  61 and over
39) What is your race? Circle one. White Black/African American Other (please specify)
<ul> <li>40) What is your highest level of education completed? Circle only one.</li> <li>a. Less than a high school diploma</li> <li>b. High school diploma or equivalent</li> <li>c. Some college but no degree</li> <li>d. Undergraduate college or associate's degree</li> <li>e. Graduate or professional degree</li> </ul>
41) How often do you attend religious services? Circle one.  a. More than once a week b. Once a week c. Once or twice a month d. A few times a year e. Seldom f. Never g. Don't know/refuse to answer
You have now completed the survey. If there is anything that you would like to add, please include it in the textbox provided below.

You are done! If you would like to enter the drawing for the \$50 Visa gift card, please hand in your survey and ask the researcher for an index card to include your name and contact information, which you will place in the box marked \$50 Visa Gift Card Drawing

Thank you for your time!

**Appendix 2: Data Frequencies** 

	Codes for Data Frequency Tables								
Q1	1=Not at all a problem	2=Minor Problem	3=Moderate Problem	4=Serious Problem					
Q2-5	1=Strongly Disagree	26	7=Strongly Agree						
Q6	1= Worthless	26	7=Deserving						
Q7	1=Weak	26	7=Strong						
Q8-12	0=No	1=Yes							
Q13-33	1=Strongly Disagree	2=Disagree	3=Agree	4=Strongly Agree					
Q34	1=Strongly Oppose	24	5=Strongly Support						
Q35	1=Male	2=Female	3=Prefer not to answer						
Q36	1=18-25	2=26-35	3=36-50	4=51-60	5=61 and over				
Q37	1=White	2=Black/Afri- can American	3=Other (Please Specify						
Q38	1= Less than a high school diploma	2=High School diploma or equivalent	3=Some College but no degree	4=Undergradu- ate college or associate's degree	5=Graduat profession				
Q39	1= More than once a week	2=Once a week	3= Once or twice a month	4= A few times a year	5= Seldom	6=Never	7=Don't Know/refus e to answer		

# **Data Frequencies**

# Frequencies of responses to each of the survey questions.

			Q1		
		Frequency	Percent	Valid Percent	Mean
Valid	2	1	3.0	4.2	
	3	1	3.0	4.2	
	4	22	66.7	91.7	
	Total	24	72.7	100.0	
Missing	System	9	27.3		
Total		33	100.0		3.875

		Frequency	Percent	Valid Percent	Mean
Valid	1	2	6.1	6.3	
	3	5	15.2	15.6	
	4	2	6.1	6.3	
	5	6	18.2	18.8	
	7	17	51.5	53.1	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		5.4375

Q3

		Frequency	Percent	Valid Percent	Mean
Valid	1	3	9.1	9.1	
	2	3	9.1	9.1	
	3	4	12.1	12.1	
	4	4	12.1	12.1	
	5	2	6.1	6.1	
	6	2	6.1	6.1	
	7	15	45.5	45.5	
	Total	33	100.0	100.0	4.9697

		Frequency	Percent	Valid Percent	Mean
Valid	1	2	6.1	6.1	
	2	2	6.1	6.1	
	3	3	9.1	9.1	
	4	6	18.2	18.2	
	5	6	18.2	18.2	
	6	3	9.1	9.1	
	7	11	33.3	33.3	
	Total	33	100.0	100.0	4.9697

		Frequency	Percent	Valid Percent	Mean
Valid	1	1	3.0	3.0	
	2	3	9.1	9.1	
	3	5	15.2	15.2	
	4	6	18.2	18.2	
	5	6	18.2	18.2	
	6	2	6.1	6.1	
	7	10	30.3	30.3	
	Total	33	100.0	100.0	4.7879

Q6

		Frequency	Percent	Valid Percent	Mean
Valid	2	2	6.1	6.1	
	3	4	12.1	12.1	
	4	11	33.3	33.3	
	5	6	18.2	18.2	
	6	3	9.1	9.1	
	7	7	21.2	21.2	
	Total	33	100.0	100.0	4.7576

Q7

		Frequency	Percent	Valid Percent	Mean
Valid	1	3	9.1	9.1	
	2	4	12.1	12.1	
	3	8	24.2	24.2	
	4	13	39.4	39.4	
	5	5	15.2	15.2	
	Total	33	100.0	100.0	3.3939

		Frequency	Percent	Valid Percent	Mean
Valid	0	27	81.8	81.8	
	1	6	18.2	18.2	
	Total	33	100.0	100.0	0.1818

		Frequency	Percent	Valid Percent	Mean
Valid	0	19	57.6	57.6	
	1	14	42.4	42.4	
	Total	33	100.0	100.0	0.4242

Q10

		Frequency	Percent	Valid Percent	Mean
Valid	0	29	87.9	87.9	
	1	4	12.1	12.1	
	Total	33	100.0	100.0	0.1212

Q11

			<b>—</b> · · ·		
		Frequency	Percent	Valid Percent	Mean
Valid	0	18	54.5	54.5	
	1	15	45.5	45.5	
	Total	33	100.0	100.0	0.4545

Q12

		Frequency	Percent	Valid Percent	Mean
Valid	0	14	42.4	42.4	
	1	19	57.6	57.6	
	Total	33	100.0	100.0	0.5758

		Frequency	Percent	Valid Percent	Mean
Valid	1	3	9.1	9.4	
	2	15	45.5	46.9	
	3	12	36.4	37.5	
	4	2	6.1	6.3	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.4063

		Frequency	Percent	Valid Percent	Mean
Valid	1	19	57.6	57.6	
	2	8	24.2	24.2	
	3	6	18.2	18.2	
	Total	33	100.0	100.0	1.6061

Q15

		Frequency	Percent	Valid Percent	Mean
Valid	1	24	72.7	72.7	
	2	7	21.2	21.2	
	3	2	6.1	6.1	
	Total	33	100.0	100.0	1.3333

Q16

		Frequency	Percent	Valid Percent	Mean
Valid	1	20	60.6	62.5	
	2	8	24.2	25.0	
	3	4	12.1	12.5	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.5

		Frequency	Percent	Valid Percent	Mean
Valid	1	4	12.1	12.1	
	2	5	15.2	15.2	
	3	12	36.4	36.4	
	4	12	36.4	36.4	
	Total	33	100.0	100.0	2.9697

		Frequency	Percent	Valid Percent	Mean
Valid	1	9	27.3	27.3	
	2	14	42.4	42.4	
	3	9	27.3	27.3	
	4	1	3.0	3.0	
	Total	33	100.0	100.0	2.0606

Q19

		Frequency	Percent	Valid Percent	Mean
Valid	1	4	12.1	12.1	
	2	4	12.1	12.1	
	3	11	33.3	33.3	
	4	14	42.4	42.4	
	Total	33	100.0	100.0	3.0606

Q20

		Frequency	Percent	Valid Percent	Mean
Valid	1	8	24.2	25.0	
	2	22	66.7	68.8	
	3	2	6.1	6.3	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.8125

		Frequency	Percent	Valid Percent	Mean
Valid	1	2	6.1	6.3	
	2	16	48.5	50.0	
	3	10	30.3	31.3	
	4	4	12.1	12.5	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0	_	2.5

		Frequency	Percent	Valid Percent	Mean
Valid	1	4	12.1	12.5	
	2	20	60.6	62.5	
	3	7	21.2	21.9	
	4	1	3.0	3.1	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.1563

**Q23** 

		Frequency	Percent	Valid Percent	Mean
Valid	1	10	30.3	31.3	
	2	18	54.5	56.3	
	3	3	9.1	9.4	
	4	1	3.0	3.1	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.8438

		Frequency	Percent	Valid Percent	Mean
Valid	1	12	36.4	37.5	
	2	18	54.5	56.3	
	3	2	6.1	6.3	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.6875

		Frequency	Percent	Valid Percent	Mean
Valid	1	9	27.3	28.1	
	2	6	18.2	18.8	
	3	10	30.3	31.3	
	4	7	21.2	21.9	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0	_	2.4688

**Q26** 

		Frequency	Percent	Valid Percent	Mean
Valid	2	6	18.2	18.8	
	3	20	60.6	62.5	
	4	6	18.2	18.8	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		3.0

		Frequency	Percent	Valid Percent	Mean
Valid	1	1	3.0	3.1	
	2	13	39.4	40.6	
	3	14	42.4	43.8	
	4	4	12.1	12.5	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.6563

		Frequency	Percent	Valid Percent	Mean
Valid	1	4	12.1	12.5	
	2	12	36.4	37.5	
	3	13	39.4	40.6	
	4	3	9.1	9.4	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.4688

**Q29** 

		Frequency	Percent	Valid Percent	Mean
Valid	1	6	18.2	18.8	
	2	23	69.7	71.9	
	3	1	3.0	3.1	
	4	2	6.1	6.3	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.9688

		Frequency	Percent	Valid Percent	Mean
Valid	1	14	42.4	43.8	
	2	17	51.5	53.1	
	3	1	3.0	3.1	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		1.5938

		Frequency	Percent	Valid Percent	Mean
Valid	1	2	6.1	6.5	
	2	4	12.1	12.9	
	3	15	45.5	48.4	
	4	10	30.3	32.3	
	Total	31	93.9	100.0	
Missing	System	2	6.1		
Total		33	100.0		2.9688

Q32

		Frequency	Percent	Valid Percent	Mean
Valid	1	6	18.2	18.8	
	2	7	21.2	21.9	
	3	13	39.4	40.6	
	4	6	18.2	18.8	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.5938

		Frequency	Percent	Valid Percent	Mean
Valid	1	1	3.0	3.1	
	2	4	12.1	12.5	
	3	13	39.4	40.6	
	4	14	42.4	43.8	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		3.2903

		Frequency	Percent	Valid Percent	Mean
Valid	1	9	27.3	28.1	
	2	1	3.0	3.1	
	3	11	33.3	34.4	
	4	5	15.2	15.6	
	5	6	18.2	18.8	
	Total	32	97.0	100.0	
Missing	System	1	3.0		
Total		33	100.0		2.9375

Q35

		Frequency	Percent	Valid Percent	Mean
Valid	1	8	24.2	26.7	
	2	22	66.7	73.3	
	Total	30	90.9	100.0	
Missing	System	3	9.1		
Total		33	100.0		1.7333

**Q**36

			-,		
		Frequency	Percent	Valid Percent	Mean
Valid	1	2	6.1	6.5	
	2	8	24.2	25.8	
	3	10	30.3	32.3	
	4	8	24.2	25.8	
	5	3	9.1	9.7	
	Total	31	93.9	100.0	
Missing	System	2	6.1		
Total		33	100.0		3.0645

		Frequency	Percent	Valid Percent	Mean
Valid	1	31	93.9	100.0	
Missing	System	2	6.1		
Total		33	100.0		1.0

		Frequency	Percent	Valid Percent	Mean
Valid	1	4	12.1	12.9	
	2	5	15.2	16.1	
	3	5	15.2	16.1	
	4	5	15.2	16.1	
	5	12	36.4	38.7	
	Total	31	93.9	100.0	
Missing	System	2	6.1		
Total		33	100.0		3.5161

Q39

			400		
		Frequency	Percent	Valid Percent	Mean
Valid	1	13	39.4	41.9	
	2	7	21.2	22.6	
	3	2	6.1	6.5	
	4	2	6.1	6.5	
	5	4	12.1	12.9	
	6	3	9.1	9.7	
	Total	31	93.9	100.0	
Missing	System	2	6.1		
Total		33	100.0		2.5484

# **Appendix 3: Significant Data Correlations**

# One-way Analysis Using IV of "Personal Experience"

Q15.

Q16.

Q22.

p-value	Code	Mean
0.006	0	1.16
	0.5	1.25
	1	2

p-value	Code	Mean
0.005	0	1.37
	0.5	1.25
	1	2.4

p-value	Code	Mean
0.024	0	1.89
	0.5	2.38
	1	2.67

# One-way Analysis Using IV of "Personal Experience" against Stigma Worthiness Scale

Q21, Q23, Q30

p-value	Code	Mean
0.015	0	1.87
	0.5	2.03
	1	2.67

# One-way Analysis Using IV "Know Someone Successfully Treated for OUD"

**Q2.** 

p-value	Code	Mean
0.002	0	4.356
	1	6.467

Q3.

p-value	Code	Mean
0.012	0	4.11
	1	6

Q31.

p-value	Code	Mean
0.029	0	2.76
	1	3.43