The University of Chicago

On the Streets and Left for Dead:

Examining the Neuropolitical Impact of Undertreating Women of Color with Substance Use Disorders in Chicago

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Abstract

This study examines the experiences of women of color with an addiction in Chicago using a mixed-methods approach of qualitative and quantitative data, Facebook group observational analysis and ethnography. Over 9 months of interviews of women of color with an addiction and addiction treatment professionals in conjunction with observational data from 15 Addiction Facebook Groups and the data from the National Survey on Drug Use and Health of 2019 leads to my findings that women of color in Chicago experience undertreatment, inaccessibility, and discomfort when it comes to addiction care and provider experience. Dissatisfaction and lacking treatment lead many women of color to give up on treatment or seek out alternative forms of support from other past and previous addicts in Facebook Groups. The COVID-19 pandemic also sheds light on the opportunities for addiction care telemedicine and novel forms of addiction medicine, including newer and more flexible treatment drugs. I propose policy recommendations occur on 3 levels: federally/state-wide in the form of standardizing the definition of special populations for addiction, in treatment centers by expanding telemedicine and accessible prescription drug treatments, and on an individual level by decreasing stigma towards those with an addiction and changing the way we talk about addiction patients. Above all, this study seeks to empower and center the voices of women of color with an addiction to write their own narratives, rather than be silenced or unacknowledged in treatment contexts or in addiction literature.

Introduction

“It wasn’t until I was foaming at the mouth and my skin had gone blue, convulsing in a South Loop alleyway that I got moved off the waiting list. I was on the waiting list for 3 years. I was homeless. My kid had been taken away. My family kicked me out. It took having nothing left in the world to get to rehab.” -Nyla

Nyla graduated from high school in June of 1993. In July of 1994, she was found contorted and seizing, nearly clinically dead behind a Dunkin Donuts alleyway dumpster. She explained: “I was going to die that night. I just got lucky that my leg in bright pink pants could be seen as hanging out from the alleyway onto the street. Oh, and that Pink Floyd saved my life that night.” Confused, I asked what she meant when she said that Pink Floyd had saved her life. Nyla told me, “On July 12, 1994 Pink Floyd had a concert at Soldier Field and people were out late, singing in the streets and getting food after the concert. It was people from the concert who called the ambulance, not the police in the streets, the late-night shoppers, or the Dunkin Donuts workers. I still hear Another Brick in the Wall when I think about that night. Pink Floyd saved my life and I think even wrote that song about me.”

After years spent on waiting lists for publicly provided methadone clinics and too many negative reactions to count when asking private providers if they take Medicaid, Nyla gave up on trying to seek out treatment. She conceded and decided to try to wean herself off of heroin but the only support system left in her life was her friends who also used and were not quitting anytime soon. After a year of trying to quell her addiction, she gave up and accepted that heroin would end her life one day. She believes her overdose on July 12, 1994

was due to an adverse reaction from taking just a micro-dosage of heroin after a 2-week heroin hiatus. That night, Pink Floyd concertgoers and EMTALA (The Emergency Medical Treatment and Labor Act)[1], saved her life.

Nyla's story is just one brick in a wall of inequity surrounding addiction treatment. More than one million people in the state of Illinois have a substance abuse disorder. More than 800,000 people who self-identify as addicts do not get any addiction care at all (Narconon, 2020). These numbers just represent those cases that we are aware of; the reality is that millions more in Chicago, Illinois, and within the United States are suffering from addiction under the radar: in alleyways, on street corners, and hidden away alone or alongside other users.

Despite numerous advances in medicine and public health, addiction has remained a crisis with no foreseeable resolution. While addiction in itself is a national emergency, certain identity groups fair differently in terms of addiction treatment outcomes. The NIH notes that women and people of color with addiction disorders are less likely to be able to access treatment and other services compared to men and white people (Close 2020, 1).

Existing research closely examines the experiences of people of color and of women seeking out addiction treatment separately but there is limited insight into the experience of women of color particularly. This project localizes the research of women of color and addiction to Chicago by investigating these questions: How can we understand the experience of women of color who seek out addiction treatment in Chicago through

[1] EMTALA: a federal law that requires anyone needing to be admitted to the emergency room to be treated then and there regardless of their insurance status or ability to pay

examining structural disparities and biases within addiction treatment? What are the barriers that limit the quality of addiction recovery treatment for women of color? How has the COVID-19 Pandemic impacted the opportunity of women of color to receive addiction recovery treatment?

This research is important due to the fact that the current moment of the pandemic has put current addicts at greater risk of worsening their addictions. Women of color with an addiction are at heightened chance of relapse and health complications during the COVID-19 Pandemic because of increased social isolation and heightened difficulty of obtaining treatment (Grinspoon 2020, 1). Marginalized populations with substance use disorders are more vulnerable of becoming infected with the virus and more likely to lack sufficient treatment for both COVID-19 and addiction itself (Dubey 2020, 2). The current moment places women of color addicts at even higher risk of death or worsened addiction; this research is relevant and is a matter of life-and-death for many people with an addiction.

A multitude of past research has explored the inequalities of addiction care received by people of color and women; yet no progress has been made on fixing this public health crisis. This project seeks to humanize the past data on this issue and to tell the stories of women of color who have been disenfranchised by the addiction recovery system. The approach of this project was largely qualitative but exhibits quantitative data conducted by analyzing the National Surveys on Drug Use and Health of 2019. I interviewed 20 people entrenched in the addiction sphere of Chicago (consisting of 3 subgroups: women of color with an addiction, addiction treatment professionals, and addiction policy specialists).

Through interviewing key actors within the addiction sphere for women of color in Chicago, I found that women of color in Chicago experience undertreatment, inaccessibility, and disparity when it comes to addiction treatment. Insufficient treatment leads many women of color to seek out alternative forms of treatment from the Internet, and particularly through social media websites. The COVID-19 pandemic also brings to the light the potential that addiction telemedicine and novel forms of addiction prescription drugs have on combatting addiction in accessible ways.

Key Terms for this Study

Addict: The word addict or addicted person is based on a self-identification of participants as someone who, either in the past or currently, could not go without consuming at least one drug (drugs discussed in this study include, but are not limited to: heroin, cocaine, methamphetamines, alcohol, and painkillers)

Substance Use/Abuse Disorder: A disease that affects a person's brain and behavior, leading to an inability to control the use of a drug or medication, synonymous with addiction

Addiction Treatment Provider: A doctor, nurse, therapist, psychologist, psychiatrist, or another medical professional who works at an addiction treatment center or provides addiction care of some kind.

Women of Color: A non-white woman, noted by self-identification in this study.

Addiction Treatment Drugs[2]: Medications prescribed by an addiction treatment provider to quell substance use or abuse. Some examples include, but not limited to: methadone, buprenorphine, and naltrexone.

Methadone: Methadone is an addiction cessation drug that works by reducing cravings for opioids through Opioid Treatment Programs (OTPs). Research has shown that people who receive methadone are more likely to stay involved in treatment, and are less likely to use opioids, die of an overdose, have legal problems, compared with those who are in treatment but don't use methadone. Methadone is an opioid, and if taken in high doses, it is possible to overdose on methadone. For this reason, OTPs follow very specific rules

[2] The descriptions of this drugs are taken from a City of Chicago Research Study that notes the characteristics and qualities of each one through extensive clinical research.

around methadone dosing. Methadone is dispensed at clinics and patients have to go to the clinic at least six days per week during the initial months of treatment. (Arwady 2020)

Buprenorphine: Buprenorphine also reduces cravings of opioids, but is a partial opioid agonist (binding agent), which means that even if it is taken at high doses, it never fully activates the opioid receptors of the brain and is very unlikely to cause an overdose. Buprenorphine can be prescribed outside of a clinic and taken at home, but medical professionals might be specifically trained to dispense it with strict instructions on how to take it. For those who take buprenorphine, all of the same benefits as those of methadone are still found to be true, but buprenorphine has less of a potential for abuse or overdose in itself, making it safer and more accessible option for many patients (Arwady, 2020).

Naltrexone: Naltrexone works differently than methadone or buprenorphine in that it is offered as an injection that remains active in patients' bloodstreams for 28 days, blocking all opioid receptors in the brain during that time period. When these receptors are blocked, using opioids does not lead to any positive effects and cravings can be reduced. Naltrexone is much newer and often more expensive for those without insurance than buprenorphine and methadone. Because it deactivates all opioid receptors, there are often many side effects that come along with it related to suicidal thoughts, loss of interest in life, anxiety, cold and flu symptoms, or nausea due to a rewiring of the pleasure receptors in the brain (Arwady, 2020).

Special Populations (Ilinois):

The Illinois Department of Human Services and the Division of Alcoholism and Substance Abuse identify specific populations who are given priority status when being

considering for admission to addiction facilities. These groups essentially skip the line for addiction treatment. Priority is given to these populations in rank order:

1. Pregnant injecting drug users
2. Pregnant and post-partum women
3. Pregnant, post-partum women and women with children
4. Department of Children & Family Services (DCFS) referred persons
5. Temporary Assistance for Needy Families (TANF)
6. Department of Corrections (DOC) releasees, and Treatment Alternatives for Special Clients (TASC) referrals

Special Populations (Federal):

The federal government also has criteria for special populations but these special populations, as dictated by the Special Populations Office at The National Institute on Drug Abuse, are defined as being racial/ethnic populations that may currently be underrepresented in research. The Special Populations office of the federal government exists to attempt to better include these underrepresented ethnic or racial populations, but does not specifically change the treatment offerings for these groups.

Background

The Neuropolitical Nature of Addiction

To firmly understand the findings of this thesis, it is important to define some and explain some key terms that will be frequently used. Primarily, it is important to consider why this study must be neuropolitical. Neuropolitics is defined as the intersection of neuroscience and political science/public policy that examines the interplay between science

and policy (Schreiber, 2017). Addiction is a disease that plagues the brain but is also intimately impacted by public policy, particularly health policy, interventions. Neurologically speaking, addiction is a dopaminergic disorder. The dopamine receptors in the brain are known as our reward receptors because doing pleasurable actions, ranging from eating dessert to sexual activity to drugs, cause dopamine, a neurotransmitter, to be released into synaptic clefts and bind to receptors (Wise and Robble, 2020). Most gratifying activities lead to a rise in dopamine and then a subsequent fall after whatever satisfying motion has been completed. The brain naturally builds up a tolerance and craving to rewarding stimuli, eventually predicting certain inputs that you perceive to like. When your cravings for sugar, for example, are not satisfied after your brain is used to that input, you may experience feelings of disappointment. Yet, with addiction and drugs, the dopaminergic systems are completely rewired. Drugs in general cause either excessive releases of dopamine or prolonged time for the dopamine to reside in the receptor. This leads to many otherwise pleasurable activities to no longer be as enjoyable because your brain cannot naturally receive as much excitatory input as it does from drugs (Wise and Robble, 2020). Once someone begins to use drugs and the rewiring of the brain occurs unconsciously, the brain begins to predict and seek the same amount of reward received from the drugs taken prior. If someone does not take more and more of the drug (due to a tolerance being built up as your body needs more each time to be even happier), then patients experience extreme withdrawal symptoms which can include being violently ill, extreme irritability, or inability to focus on anything else but receiving the next hit of that drug. Because the synaptic connections for dopamine are restructured in the brain, it is extremely rare to be able to overcome an

addiction without addiction treatment drugs. Unfortunately, access to addiction treatment and prescription medications is often gatekept by the costly insurance industry and high-priced, insurance-based treatment facilities. Insurance coverage, treatment facility availability, and prescription drug prices are all matters of public policy. Thus, addiction is a neuropolitical issue because treatment and accessible public policy structures are needed for most patients to conqueror the addiction.

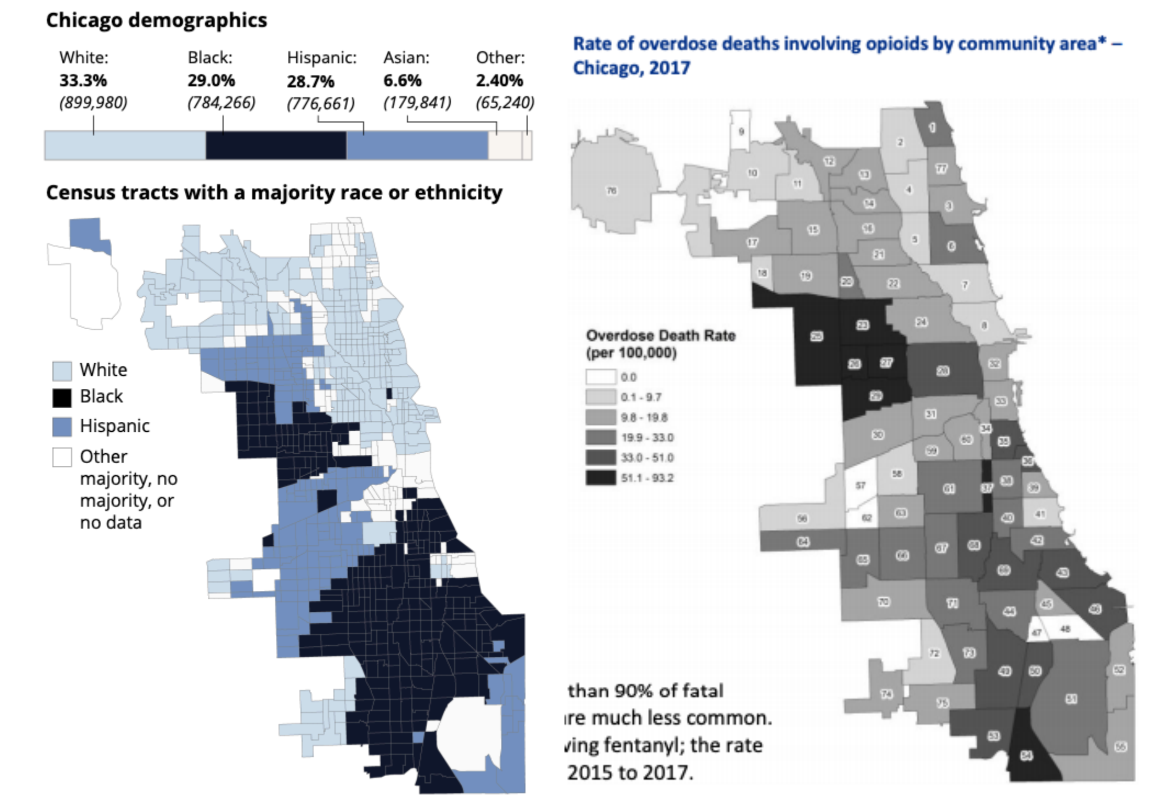
Lacking Addiction Treatment Resources in the City of Chicago[3]

The City of Chicago largely outsources affordable and/or free addiction treatment. Through the City's main website, Chicago.gov, there is a page on Substance Use Disorders and the resources that may be available. In order to find treatment, the city offers pamphlets, an addiction center service finding tool called Chicago Connects, and many different hotlines to call. The pamphlets are free, downloadable pdfs that describe the symptoms of addiction, when to get help, and types of treatment to seek out.

City-run clinics are few and far between as most of the city's addiction treatment funding is allocated towards nonprofits and hotlines to execute the work. Chicago Connects, the City's interactive tool that can be used to filter specific addiction treatment, shows that there are 972 addiction treatment centers within the confines of the city limits of Chicago.

[3] All of the data gathered in this section is compiled from the City of Chicago's website, Chicago.gov, and more specifically on its Substance Use and Overcoming Opioids pages.

Chicago Demographics by Race[4] (Left) and Rates of Overdose Deaths Involving Opioids by Community Area[5] (Right)

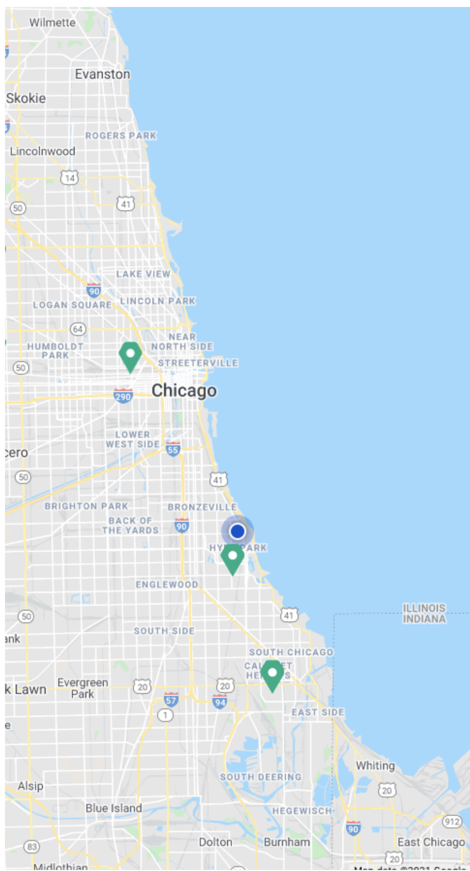


Once you apply the filters for free, low cost, or sliding scale, facilities that take in patients without insurance or with Medicaid, and facilities that take women, the results dwindle from 972 results to three. From this data, we can understand that the majority of treatment centers in Chicago take primarily men with insurance. In the figure below, you can see the 3 treatment centers (in Auburn, West Loop, and Woodlawn) found that take women, are low cost or sliding scale, and accept patients with Medicaid or without insurance juxtaposed to the rates of overdose deaths by community area, as published by the latest City

[4] Photo Credit for the left image is from The Chicago Tribune author Nausheen Husain of July 27, 2020
[5] As taken from the City of Chicago's Opioid Report of 2017 (full citations in the bibliography)

of Chicago's Opioid Surveillance Report conducted in 2017. These 3 centers are Habilitative Systems-Tabitha House (Auburn), The Women's Treatment Center (West Loop), and South Side Center of Hope (Woodlawn). All of these centers are nonprofit-based and have limited in-patient availability that is even lessened during the pandemic.

<u>Addiction Treatment Centers in Chicago that Service Women, Are Free or Low Cost, and Take Patients with Medicaid or Without Insurance:</u>



Starting during the time of the COVID-19 Stay at Home Orders in 2020, the South and West Sides of Chicago experienced the highest rates of overdose deaths and are areas that are known for divestment across a variety of industries (Husain, 2020). Just from January to June of 2020, there was a 55% increase in overdose deaths in Black Chicagoans on the South and West Side and a 60% increase in EMS calls to those same regions for addiction related health emergencies (McGhee, 2020). Every year nearly 60% of fatal overdoses occur in non-white Chicagoans largely on the South and West Sides and limited treatment options within these areas may perpetuate disparity.

In terms of other forms of addiction treatment, the City offers hotlines to call to seek out treatment or support if you are not currently enrolled in treatment. There are 3 hotlines offered on the City of Chicago's website: The Illinois Opioid Helpline, The National Alliance for Mental Illness: Chicago, and the City of Chicago's Substance Use Prevention

Program for Deaf and Hard of Hearing. All three of these hotlines only operate during the business hours of 9 AM-5 PM and on weekdays. The Illinois Opioid Helpline services all of Illinois and wait times on the phone can be upwards of 2 hours long.[6] The National Alliance for Mental Illness: Chicago hotline boasts similar wait times; this is likely due to the fact that this hotline is for anyone to use who self identifies as having a mental illness, not specifically for those suffering from addiction. The City of Chicago's Substance Use Prevention Program for Deaf and Hard of Hearing, as one could imagine, is only to be used for those who are deaf and need substance use treatment. Because the City has limited resources devoted to addiction, acquiring treatment is often restricted to the medical care that someone receives if or when they go to a primary care doctor. Unfortunately, with primary care doctors, there continues to be disparity in prescribing addiction treatment drug medications.

Not all Addiction Treatment Drugs are Created (or Prescribed) Equally

The National Institutes of Health report that non-white patients are more likely to receive methadone, a cheaper and older drug, than buprenorphine, a newer drug that comes in abuse-deterrent formulas (NIH, 2018, 1). Additionally, patients can self-administer buprenorphine at home. While both of these prescriptions are used in addiction cessation, buprenorphine is more expensive, chemically less likely to be abused, and is more accessible for a wide variety of patients since it does not require going to the hospital to take it (Health Care Resource Centers 2020, 1). Vast recovery success disparities have been created by people of color being prescribed methadone, a drug that has a tedious withdrawal period and requires a multitude of expensive hospital visits.

[6] This estimate is as found through my own sampling of calling each hotline 5 times at varying days and times to see how long the wait times are.

Unlike methadone, buprenorphine has a ceiling effect which lessens its likelihood of abuse and has naloxone derivative in it. The derivative of naloxone is often to quickly present overdoses and to deter addictive behavior from progressing. Its benefits persist in that it can be taken at home and over the counter, making it a more flexible option for patients and keeping costs lower by preventing patients from having to go into a clinic for each dose of treatment. Additionally, it is the only addiction drug that is not illegal to be prescribed by a physician outside of a licensed treatment program because while buprenorphine is an opioid cessation drug, it also is an opioid in itself (Hansen 2016, 14). Thus, buprenorphine is a drug that provides flexibility, less ability to be misused, as well as suitable treatment option for pregnant women yet it is found to be under-prescribed in people of color and in women. In fact, a study examining the characteristics of veterans who received buprenorphine versus methadone found that the differences between the veterans receiving buprenorphine or methadone based opioid agonist therapy was largely shaped by demographic characteristics rather than medical or psychiatric or service use characteristics (Manhapra 2016, 82). In a study by The National Institutes of Health, it was found that of those who were prescribed buprenorphine for addiction cessation, there were significant disparities in one-year retention of addiction treatment occurred amongst Black and Hispanic patients (Weinstein 2017, 67). The Journal of the American Medical Association (JAMA) found that the rates of people of color and those without insurance being prescribed buprenorphine is low in itself (Lagisetty 2019, 979). Another JAMA study found that women were less likely than men to be prescribed buprenorphine or naltrexone, addiction drugs that are generally found to be safer than methadone, for their opioid use disorder (Hadland 2017, 747). The disparities amongst

buprenorphine addiction care can even be specified to be limiting to pregnant women. An NIH study of 4 Appalachian states found that providers of opioid agonist treatment, often would not treat pregnant women or prescribe them buprenorphine (Patrick 2019, 5). This data is particularly troubling since buprenorphine has been shown to be safe for pregnant women while other addiction cessation drugs are not. As many studies seem to illustrate a lacking use of buprenorphine amongst minority and women groups, the question is raised of why this is happening to these groups specifically and as to what makes buprenorphine so efficacious amongst many groups?

Literature Review

Theory

Countless studies find that people of color, women, and low-income people with opioid use disorders remain at a disadvantage when it comes to accessing appropriate treatment. Past research has also established that women face greater barriers to both treatment and overdose reversal than men do (Volkow 2019, 1). Despite a myriad of studies over the years noting the inequalities that exist within the substance abuse disorder community, there has been a lack of awareness of this problem and of public policy changes on any scale to amend these issues. The COVID-19 crisis presents increased challenges to the addiction community because of decreased access to addiction services and the shift to telemedicine for addiction care. Patients with substance use disorders (SUD) are more likely to contract the virus and to suffer from greater psychosocial burden which also can lead to worsened addiction (Dubey 2020, 817). While there are studies that exist, which discuss the aforementioned facets of minority women and addiction, there is not a study that combines these elements and examines the impact of minority women with addiction in Chicago

during the COVID-19 pandemic. Historically, Black and Latino Americans are perceived to need less treatment than White Americans by members of their own communities as well as by those of the medical community (Weinstein 2017, 65). The type of care that is sought out by different minority or gender groups also varies in addition to the rates of care that is obtained by these groups.

Saloner and Le Cook posit that on a national scale, people of color are less likely to complete addiction treatment than white Americans due to socioeconomic factors such as housing instability and greater unemployment. People of color tend to enter substance abuse treatment through the criminal justice system more often than not while white addicts' most frequent treatment option is voluntary admittance outpatient programs (Saloner and Le Cook 2013, 135). The National Institute on Drug Abuse furthers these arguments in reporting that minorities and women remain at a disadvantage when it comes to the access of treatment and overdose reversal than white people and men do (Volkow 2019, 1). Though it is true that white people and men tend to encompass the largest percentage of those with an opioid addiction, overdose deaths are higher and rising in minority groups such as Native Americans and African Americans (Volkow 2019, 2). Women of color also experience disparities in the types of treatments that are offered to them. Buprenorphine is disproportionately prescribed to those with higher incomes, white people and men of any race while low percentages of non-insurance holding people, people of color and women receive this drug (Lagisetty 2019, 979). While these disparities in differing elements of care are examined on a national scale across different racial and gender groups, there lacks data and theory directly on minority women as a group in themselves.

Pinedo et al. argues that amongst Black and Latino adults with a substance abuse disorder, their perceived need for treatment is lower than that of white adults. There is not a uniform entry mechanism to addiction treatment and Pinedo and his colleagues sought to determine if correlates can be drawn with how people of color tend to enter addiction treatment. They found that people of color tend to enter addiction treatment through the criminal justice system more so than white people but the perceived need of treatment amongst people with an addiction regardless of race, is complicated and nuanced towards treatment providers (Pinedo et al. 2020, 118). If someone enters substance use treatment through the criminal justice system, that treatment is often mandated by the court as part of sentencing while those who enter treatment voluntarily are likely doing so because they or their family sees a need for treatment. Substance Abuse treatment is often administered through the publicly funded city or state addiction treatment centers if it is mandated by a judge in a criminal trial and these treatment centers are historically underfunded, fragmented, and contain less than satisfactory services (Hutchings 2009, 2).

The summation of findings that impact minorities and women have been explored in microcosms but have yet to be explored on the scale of minority women in Chicago during the COVID-19 crisis. The pandemic has made addiction treatment alter in terms of its accessibility and has forced much of the treatment to be through telehealth services. While the totality of these theories leads to similar but non-conglomerated conclusions about the struggles that women of color seeking out addiction services may face, each study tends to look at an isolated sample of racial groups or gender groups, also usually on a national scale. In using past studies as the basis for this project, the plight of minority women in the addiction sphere is explored on its own.

Thus, studies have shown that minorities have been perceived to need less addiction treatment by medical professionals. Similarly, minorities and women tend to seek out substance use treatment programs less than white people and men. Countless studies have also explored how there are disparities in which groups are prescribed buprenorphine, an addiction drug with many benefits that would be more fitting for a multitude of different lifestyles. This project will seek to further many of these studies while directly examining women of color in Chicago.

Methods

In order to get a better understanding of the experience of women of color with an addiction in Chicago, I undertook a mixed-methods approach. Qualitatively, I gathered data through 20 semi-structured interviews of 3 different stakeholder subgroups and through observational analysis of 15 Facebook Addiction Support Groups. Within these Facebook Groups, I particularly examined the interactions of women of color's interactions in the groups compared to white people and men over a period of 9 months. I also used Photoshop to create Word Association Shapes that depict the frequency of responses used in one portion of my interviews. Quantitatively, I analyzed data from the National Survey on Drug Use and Health's 2019 survey responses.

Qualitative Methodology

Participants

Members of each subgroup below were interviewed for a period ranging from 45 minutes-1 hour in a semi-structured format such that each participant was asked all of the general questions on the interview protocol, as well as more specific questions depending on

which subgroup they fell in. Because of the semi-structured format, some follow-up or further elaborative questions were asked when applicable in an individual interview. As shown in the table below, a total of 20 interviews were conducted. Of the 20 interviews, 12 of the interviewees were women of color who self-identified as a current or former sufferer of addiction, 6 were addiction treatment professionals (doctors, psychologists, psychiatrists, or addiction counselors), and 2 were addiction policy advocates. The rightmost column in the table notes code labels for each subgroup of participants that are used for when referring to participants in the findings section. Every interview participant requested a pseudonym be used in place of their name for reasons ranging from privacy, HIPAA, fear of retaliation by their workplace, or so that they could remain as objective as possible without any potential consequences.

Interview Count by Subgroup and Code Labels

Subgroup Name	Number of Participants	Code Label
Women of color with a current or former addiction	12	W
Addiction treatment professionals (doctors, psychologists, psychiatrists, or addiction counselors),	6	P
Addiction Policy Advocates	2	A

Pseudonyms and Code Label Name by Participant in Subgroups[7]

Subgroup Name	Pseudonym	Code Label
Women of color with a current or former addiction	Christine	W1

[7] Every participant was given a pseudonym for purposes of consistency and anonymity within my results leading to greater objectivity and candidness in answers.

	Nyla	W2
	Shonda	W3
	Maria	W4
	Nia	W5
	Juana	W6
	Alejandra	W7
	Yi	W8
	Luciana	W9
	Aliyah	W10
	Brianna	W11
	Airi	W12
Addiction treatment professionals (doctors, psychologists, psychiatrists, or addiction counselors)	Dr. Grieg from UChicago Medicine	P1
	Melissa, an addiction specialist at Rosecrance Treatment Center	P2
	Charles, an addiction specialist at Banyan Treatment Center	P3
	Tracy, an addiction specialist at a Chicago city-run addiction clinic	P4

	Tracy, an addiction specialist at a Chicago city-run addiction clinic	P5
	Sam, a psychiatrist at SEATAC Addiction Treatment	P6
Addiction Policy Advocates	Adam, an independent addiction policy specialist with experience working at addiction treatment centers and in studying addiction	A1
	Elizabeth, founder of a Chicago Addiction Nonprofit	A2

Recruitment

Recruitment during the COVID-19 Pandemic proved to be quite difficult. I took a multi-pronged approach to finding interview participants due to the unique nature of the world. I used a combination of Linkedin, emails, and Facebook messages to attempt to recruit my participants. I also created a flyer (as visible in the Appendix) to attempt to recruit participants who were currently undergoing addiction treatment in Chicagoland and emailed it to 50 different treatment facilities in Chicago. Only one treatment center responded to the inquiry to post the flyer in their center and I did not successfully recruit any participants through this method; I attribute this to the likelihood that less people than normal are in

person at the facilities that I reached out to and posting a flyer on the wall (even in just one center) may not be reaching as many people as it normally would.

Following some unsuccessful recruiting through email, I turned to Facebook and Linkedin for recruitment. On Facebook, I joined 15 addiction treatment/support Facebook groups in an effort to analyze the interactions within these groups but also as a means for recruitment. Through posting on the timelines of these Facebook groups to advertise taking a part in an interview and through individually reaching out to people who actively posted in the groups, I was able to find 12 women of color who had struggled with addiction to be interviewed. Linkedin and Email were the methods used to recruit addiction treatment professionals and policy advocates. I utilized convenience sampling first by searching for participants within the UChicago network. In total, I reached out to 900 individuals (on Linkedin, Facebook, and Email) and treatment centers. I kept track of those who I had reached out to through a detailed spreadsheet and everyone was met with 1-2 follow-up emails if I never heard from them. I interviewed anyone who responded to be interviewed from my requests.

Ethnography as Seen through the Eyes of Women of Color with an Addiction

I had the opportunity to speak with women who were differing places in their addiction recovery journey. Some of the women I spoke with were fully recovered, some were in the process of recovery and some never finished treatment. All of the interviewed women are over the age of 18 and a "woman of color" will be defined as a self-identifying non-white woman. For the purposes of this study, participants self-reported themselves as currently having or having recovered from an addiction. I asked them what their treatment

experience was like and how they believe addiction treatment for women of color should improve in Chicago. In terms of 2021 and COVID-19 specific questions, I inquired on how COVID-19 has impacted their recovery and about stigmas nowadays that may exist regarding women with an addiction. I interviewed them with the hope to understand their experience and present it as data but also as an ethnography in the project. It is of the utmost importance to me that this project is centered around the stories of the women. Many of these women have been or felt silenced by authoritative and medical structures, and it is time for their stories to be told.

Quantitative Methodology

National and City-Wide Addiction Data

In examining the 2019 National Survey on Drug Use and Health addiction data, I analyzed general trends of addiction and addiction treatment among different identity groups across the nation. This data set has over 400 variables such as drug use (by type of drug), different drug addiction groups by demographic variables, and more. I utilized this data to examine any possible undertreatment or disparities in the quality of addiction care, as well as to compare my findings to USA-wide trends. Because my qualitative data is from a much smaller sample, this data also helps better inform my policy recommendations and contextualized my findings by examining how other states and the country federally may be better treating women of color with an addiction. My primary findings from the quantitative data show 3 main ideas: women of color are just as addicted as other identity groups, underserved in getting treatment in comparison to men and white people and underrepresented in prior research.

Researcher Positionality

As a white woman not from the City of Chicago directly and without a drug addiction, it may appear that I have nothing in common with the women of color addicts whom I am interviewing. However, I am a lifelong Chicagoland-area resident with multiple family members who did suffer from substance abuse disorders. I will minimize bias in the interviews by revealing the same amount about my background in each interview, so as to not invoke partiality in different interviews.

Findings

The Beauty and Misfortune of Being a Woman with an Addiction

"I know that I am a beautiful and strong woman. I know that I have something to give to the world and that I am a good person. But to the government and to the doctors, I am just a no-good black drug addict. I might as well be shit on the street."

Juana was just 14 years old when she tried heroin. After having her first child at 13 years old, the drug dealers told her "You're an adult now. This is some fun that adults have to get rid of their stress." She had no reason not to trust the adults in her life, so she quickly gave in.

Nia was just 16 years old when she tried cocaine. She first started her drug use despite "a very normal and good life. I got good grades. My family loved me." Using once lead to using multiple times a week and once her family found her stash of crack cocaine, they kicked her out of the house at 17 years old. "I don't even think that was legal but when someone is yelling at you that you can't stay anymore, you pack a bag of stuff and go."

Leaving home at 17 meant leaving behind food, shelter, and the stability needed to succeed in making a living. Nia says: “If I couldn’t live with my family because of the drugs, I couldn’t live with my friends either. Their families never would have allowed it. So, I called who I knew would take me in and not only not care if I wanted to use from time to time, but actively encouraged it: my dealer.”

Stories of women getting a young start with substance use, being ostracized by their support network, and creating a new home with other drug users are very common. I spoke with 12 women of color, all of whom lived most of their life in Chicago and faced tedious battles with addiction while living in the Windy City.

The tried and true stereotyped story of addiction being something that comes out of trying to cope with adversity or being an intense obsession was not always the case for the women that I spoke with. At the end of my interviews, I asked my participants in subgroup W whether they agreed or disagreed with the below statements in the table below, on page 29. While 6 out of 12 of my women of color participants with an addiction noted that drug use helped them to come with something in their life, all 12 women agreed that their drug use had to do with an initial curiosity and being around people they would classify as bad influences. All 12 of the women I spoke with stated that they lost friends and family over their drug use to eventual addiction and 12/12 stated that other users and their dealers became a large part of what they would classify as their community. Unfortunately, 7/12 indicated that they lost their entire support network that they had prior to their addiction.[8] All

[8] Support Network is defined as the people who are regularly in your life and that you can most count on. Support Networks tend to not be generalizable across all people. Subgroup W all had varying people and sizes of their support networks ranging from solely family, to family and friends, to solely friends, and many other amalgamations imaginable.

12 women also agreed that they never imagined when starting to use drugs that they eventually would become addicted. From these results, we can understand that addiction often leads to a loss of one's whole support network and finding a new support network in those who use drugs, as well as their dealers.

Frequency of Response Rates in Women of Color with an Addiction on Exclusionary Addiction Treatment Practices

Response Themes Related to Exclusionary Treatment	Frequency of Response in W Subgroup Participants
Yes, I feel that I have been treated differently solely on the basis of my demographic identity of being a woman of color	6/12
Yes, I feel that I have been treated differently due to my socioeconomic status (SES)	10/12 (Note: All of these 10 participants also reported low socioeconomic status)
Yes, I feel that I have been treated differently during treatment due to a demographic factor, a socioeconomic factor, or a combination of the two.	11/12
No, I do not feel like I have been treated differently or unfairly in any way throughout treatment.	1/12

I was aware of different kinds of addiction treatment drugs and addiction treatment options that exist when I went through treatment.	4/12
I was only presented 1 option for treatment and/or medication during treatment (Essentially, I was told to take it or leave it with the option I was given)	9/12
If yes to the question in the row above, I was prescribed methadone as that one option for treatment.	8/12
I feel like male treatment providers treat me differently because I am a woman.	4/12
I would prefer to speak to a female treatment provider over a male treatment provider.	11/12
I would prefer to speak to a treatment provider of my same race(s).	9/12
I would prefer to be in a treatment program with only women.	10/12

The literature suggests that there are disparities and something distinct about the experience of women and people of color who seek out addiction treatment. I sought to understand if the women of color that I interviewed felt that 1. If anything, is there something unique that is shared across women of color with an addiction? and 2. Did they ever feel as if they were treated differently during addiction treatment *solely* on the basis of their demographic identity? The first word frequency shape configuration (displayed on the left in and in the shape of a woman) shown below illustrates the frequency of words used by the 12 women who I interviewed in describing what makes a woman of color with an addiction unique from just anyone with an addiction or in society.

Frequency of Words Women of Color with an Addiction[9] Use to Describe Themselves and their Addiction Fight (left) Versus Frequency of Words They Believe Addiction Treatment Professionals[10] Perceive Them to Be (right)

[9] I created these graphics using graphic design software. Larger words in the shape correspond to being used more frequently while smaller words were used less frequently by interviewees. The colors of each figure are simply for display purposes, and do not correspond to anything about the frequency of responses.

[10] Addiction Treatment professionals is defined as doctors, psychologists, psychiatrists, or addiction counselors

Some words that are notably frequent are strong, brave, beautiful, and exhausted. Women of color in my study when asked to perceive themselves as someone with an addiction note how hard they all fight through their recovery and cite many positive words to describe themselves. There are a few negative words or words that correspond to being exacerbated by all that one has to overcome through substance abuse treatment, yet the majority of the words indicate high self-esteem and are upbeat in nature. There is a stark contrast between the words used when women describe themselves versus how they believe that addiction treatment professionals perceive them. It is important to note that across both of the word frequency configurations, no one image has entirely positive or entirely negative words. This sheds light on how unique each woman of color's experience is with addiction treatment and on individual provider experience. Many of the women who I spoke with have been in and out of many addiction treatment facilities, experiencing a wide variety of providers and care types.

The most frequent words in the word bubble of the addiction treatment professionals are dirty, hopeless, annoying, stupid and waste. The word "dirty" was used 7 times by interviewees and when asked for further clarification on what they meant, 2 of the 7 women used the word to refer to not being sober and 5 of the 7 women defined the word as meaning as words like: "trashy, scummy, or repulsive." When I asked Lola what she meant when she noted the word dirty "definitely had to be on the list", she exclaimed:

“Doctors always think that they are better than you and once they find out you have no insurance, have been homeless, and have not been able to hold a job, it’s like you are disgusting to them. Once I tell one of those addiction doctors that I have been an alcoholic for 15 years, I might as well be walking around with shit all over me because they look at me like I am dirt… I am not a fancy doctor but I don’t think anyone wants to be an addict. We all want to stop and you’d think that doctors would understand that the most.”

Lola’s sentiment of doctors and addiction health specialists looking down on her as someone with an addiction was shared across 9/12 of the women who were interviewed. Conversely, none of the addiction health specialists that were interviewed said that they or other medical professionals at their workplace treated their addiction patients with anything but respect and equally to any other patient who might come into the office. This response was consistent across both the men and women interviewed who worked at treatment centers. Dr. Grieg from UChicago Medicine stated: “I have never treated a patient differently because of a demographic or socioeconomic factor. I consciously try to treat all patients equally and let them dictate the interaction.” Both Tracy, a nurse at a city-run clinic, and Melissa, an intake coordinator at Rosecrance, an addiction treatment center that commonly sees people as being court-mandated to attend treatment from the prison system, noted similar sentiments to Dr. Grieg but specifically stated that they believe that is often more that patients may feel more or less comfortable with certain care providers. Melissa said, “Many patients come in with a preference for whether they want to see specialists, therapists, or even certain genders and races of providers. We cannot always provide due to demand of services, but we do our best to match patients with someone they feel comfortable being treated with.”

When asked if there were differences in how they approach counselling an addiction patient based on the patient's background or any other factors, all of the participants in the P subgroup indicated that while there is "no one-size fits all policy for addiction treatment", the general treatment approach is the same with patients.

"Sometimes they [addiction treatment personnel] talk down to me. I don't know if it's because I'm a teen mom with a heroin and meth addiction or because they think I'm dumb because I don't have a college degree and have fucked up from time to time. I do the treatment to keep my daughter but it really wears you down being talked to like you don't understand anything all of the time."-Luciana

Luciana is 19 years old and has a 2-year-old daughter. When she was 16, she met a dealer at her high school and just within a few months ended up failing her classes, addicted to methamphetamines, and pregnant. She said: "I knew I would never fix my grades and get into college but I wanted to give my daughter a good life. I worked at McDonalds but the hours became too much. I needed another job and my dealer needed a pretty girl to move the drugs to more people. I'm ashamed of it but I needed the money." The drug sales kept her up late into the night and even further distracted from her schoolwork.

When her water broke, she assumed that her childbirth experience would be nothing out of the ordinary. When she got to the hospital, her bloodwork alerted the hospital that she was a "user" and 35 hours of labor lead to a court date and her new baby being taken away by the Department of Children and Family Services. The judge ordered her to complete the

court-mandated detox and to graduate high school in order to get her daughter back. The court-mandated treatment did not come without costs. Luciana told me:

"The treatment was thousands of dollars and weeks long. My dealing money went towards my maternity bills so now I don't have a job, the baby that I got the job for, a mountain-high pile of schoolwork that I knew I could never finish, and I'm expected to pay for this thousand-dollar treatment? I hate to say it but even with all of the stress, all I could think about was my next hit."

Luciana was able to borrow some money prior to going into treatment to front the minimum payments but the stress of impending schoolwork, a court case, and of making it through treatment was all too much: "I was just a kid and I was scared and the only way I was used to coping was through a hit. I left the treatment center in the middle of the night and went straight to my dealer. I'm so ashamed to say it. "

After relapsing and leaving treatment, Luciana knew she had to turn her life around. A few weeks after she left the treatment center in the middle of the night, she went back to the same treatment center, apologized, and begged for a spot back in the program. Upon arriving, she was notified that there were no more Medicaid beds available and that there was nothing that they could do. What she was told is contradictory to the provisions of the Special Populations clauses of The City of Chicago, which should put someone who is post-partum *and* dealing with a Department of Children and Family Services Case (2 distinct criteria for being eligible for expedited treatment) to the front of the line for addiction treatment.

Luciana's story is not one in a million. Stories like this are all too common in considering the misfortune that women of color with an addiction face. Whether it's unfair

treatment by providers, not being aware of one's status as a special population, or not being able to access treatment, women of color have been through it all. Inequity in addiction services often leads to women of color with an addiction to turn to an undeniably accessible treatment substitute: the internet.

Medical Degrees and Facebook Accounts Have More in Common Than you Think: The Many Faces of Addiction Treatment

The healthcare industry is a sore subject for a multitude of Americans. Prescription drug prices are higher than ever. A trip to the emergency room is a financial emergency a few weeks later and obtaining a doctor appointment can be a scheduling nightmare. These problems are compounded when it comes to seeking out addiction treatment as a woman of color. Of the women that I interviewed, all 12 of them indicated that it was difficult to find a treatment facility that suited all of their needs. Individual preferences for a program ranged from woman to woman but many of the interviewees indicated that even getting into a treatment facility that matched their price range or basic structure preference (in-patient versus outpatient, number of days of treatment, and visiting allowances of family members and friends) was unattainable. For women without lofty private insurance plans, these problems are exponentially worse.

"I was trying to call all of the treatment centers within 25 miles of me. There are almost 100 different places but so many of them pick up the phone and say that they don't take Medicaid. The few that do take Medicaid told me that they could put me on a waiting list with the next openings being in over a year in every place. Nobody goes to get addiction treatment if they

have a year to wait. I needed it then. 4 days later, I overdosed by the dumpster on the side of a busy diner. Once I got to the hospital, I got my first dose of methadone ever, a $100,000 hospital bill, and somehow a place off of that waiting list."-Alejandra

Alejandra is 40 years old and has struggled with addiction throughout her life. She moved to Chicago from a rural village in Mexico when she was 18 and never had learned any English prior to coming to the United States. Upon arrival to the country, she immediately went to the workforce but never formally learned English. It was not until the age of 27 that she felt as if she was conversational. Her overdose occurred shortly after she had turned 27. The treatment facility that took her in following her hospital stay only had one Spanish speaking nurse who worked twice a week and no more than 8 hours total. When asked if she could move to a different facility that could accommodate the language barrier, she was told that they only will move someone if it is urgent and her case did not qualify. Alejandra received methadone detox treatment but could not complete the cognitive behavioral therapy portion of her treatment because she did not understand the questions that the therapist was asking her. She was discharged from the facility and had been considered unsatisfactorily sober by the treatment center.

Of the 12 women whom I interviewed, 8 of them are on Medicaid and all 8 indicated that it was difficult to find a treatment center that had availability for Medicaid patients or that was even quality treatment. Airi noted: "We all know that the treatment that rich people are getting with Blue Cross Blue Shield is better than my Medicaid treatment at an office where you're just a patient with a number and a clipboard of things that they need to check off so that they don't get sued for not doing enough." With scarce treatment options,

especially under Medicaid, many patients are left to consult something free of charge: the internet.

In the modern age of rapid and accurate google searches and trillions of pieces of information in our pockets, it is easier than ever to connect with people on the internet. Out of curiosity, my research led me to joining addiction support groups on Facebook as a way to observe interactions amongst people with an addiction. I joined 15 Facebook groups ranging from 107,000 members to just over 1,000 members. One of the main trends that I noticed across the Facebook groups was a list of conduct rules that needed to be followed in order to remain a member of the group. All of the groups had at least 2 admins to oversee the content of the group. The table below shows the 15 groups that I joined sorted by most members to least members and a table depicting whether or not each group had specific rules in place. I hoped to see if the groups with more members had trends as to what their rules were that might make them more popular than smaller groups.

I particularly examined how women of color interacted in these Facebook groups and I found that women of color largely seek out support from other women of color in trying to meet up with other women like them in their area, find virtual meet-ups, or through commenting encouraging messages on the posts of other women of color. I found women of color to post more encouraging messages and to interact more with each other more frequently than other racial or gender groups did. The groups that were solely women were more highly interacted with and posted in, particularly with women of color. This is likely explained by the fact that nearly all of the women of color that I interviewed indicated that they felt more comfortable in women-only treatment settings or in engaging in “girl-talk” with other female addicts.

Facebook Addiction Support Group Names that I Joined for 9 Months and Assigned Code Names (for Purpose of Discussion) Sorted from Highest to Lowest Number of Members

Facebook Group Name	Number of Members	Code Names (Used in the Table Directly Below)
Addiction Recovery Support	107,400	G1
Narcotics Anonymous Recovery Group	83,600	G2
Clean and Sober-Addiction Recovery Support Group	76,000	G3
Grateful Addicts in Recovery	73,000	G4
Alcoholics and Addicts Recovery Group	68,200	G5
Solutions to Addictions	50,600	G6
Addicts Fighting Addiction	39,200	G7
Women in Recovery	35,000	G8
Alcoholics Anonymous AA	30,400	G9
Opiate and Opioid Addiction Support	23,200	G10
Food Addiction Recovery	14,000	G11
Sober Women	8,800	G12
She Recovers Together	7,600	G13

Binge Eating, Food Addiction, Emotional Eating Support	6,300	G14
Women's Sobriety Support	1,100	G15

Analysis of Conduct Rules and Participation Opportunities in 15 Addiction Support Facebook Groups

Group Criteria	Which groups have this criterion in place?	Number of groups that have this criterion in place	Notes
Are there rules that must be followed to be a part of this group?	G2, G3, G4, G5, G6, G10, G12, G13, G14	9/15	G1 is the largest group and specifically notes that it believes rules are detrimental to expression.
Are there support group meetings specifically offered as a part of the group?	G9, G14	2/15	
Does the group post any addiction recovery resources[11]?	G5, G14, G15	3/15	
If they do provide resources, are these	G15	1/15	The information provided by G15

[11] Resources should be defined as anything that could aid someone's addiction treatment journey (hotline phone numbers, pamphlet materials, maps of treatment centers, alcohol's anonymous guides, and more)

resources created by group members (rather than addiction medical specialist-made resources or contact information)?			has limited free access and then requires payment to view the rest of the resources.
Does the group administrators or rules note that treatment opinions and advice from the group are not directly medical instruction or care?	G1, G3, G5, G7 G12, G13, G14, G15	8/15	All of these groups note that this group should not take the place of medical treatment in the rules of the group.
Does the group recommend a certain kind of treatment or treatment program?	G2, G5, G8, G9, G10, G12, G13	7/15	G2, G5, and G13 all recommend Alcoholics Anonymous Program specifically.
Can people in the group post pictures of themselves or of anything else?	G1, G3, G4, G6, G7, G8, G9, G10, G11, G13, G14	11/15	
Can the people in the group recommend addiction treatment medication (i.e. methadone or naloxone)?	G1, G3, G4, G6, G7, G8, G9, G10, G11, G12, G13, G14	12/15	The 3 groups that are not listed specifically note that no drugs of any kind (whether they are addiction treatment drugs or something over

			the counter) can be discussed.
Can the people in the group discuss drug usage (relapsing, deciding to continue to use drugs, or using marijuana for addiction cessation)?	G3, G4, G6, G7, G8, G9, G11, G13, G14, G15	10/15	
Does the group specifically want the posts in the group to be about addiction recovery?	G2, G8, G9, G13, G14	5/15	
Does the group discourage reaching out to other members of the group for friendship, support, or anything else?	G5	1/15	All of the other groups encourage comradery and reaching out to members in the group.

When asking my interviewees about the Facebook Groups that they are a part of, many of the women noted that they were able to better connect with other sufferers of addiction in a way that they could not connect with their therapists or fellow treatment inpatient-mates. These groups allow friends to be made all over the globe, can connect people with virtual accountability partners and ask for tips if someone is really struggling with their recovery.

"Treatment is expensive but Facebook is free. I am able to meet other people, vent out my frustrations, and talk about ways to get out of expensive treatments and medicine naturally. I started boxing and running whenever I get a craving and I have a friend from Facebook to thank for that."-Nia

Like Nia's sentiments, many of the women I interviewed noted that they used Facebook groups for medical advice or in place of a treatment program. "Treatment is expensive and it didn't work for me. Hundreds of people can share with ways to fight my addiction naturally. Why should I pay thousands of dollars?", says Juana. Despite 8/15 Facebook groups that I joined having a disclaimer that no one in the group is a doctor and that medical suggestions are not verified medical advice, 11/12 women that I interviewed said that they would take medical advice seriously from one of these Facebook groups. All 12 of the women noted that they liked the ease of Facebook. "I use Facebook to talk to my friends and to fight my addiction and it's all free.", says Aliyah, a member of 7 addiction Facebook communities, as she calls them. This idea of community is what keeps many people coming back to the groups.

"Addiction destroyed my life in every way. It took my community. Users became my community. Now I am able to get a new community through the virtual Facebook addiction brothers and sisters. I think that there is a rebirth and something really beautiful about that."-Juana

While the reality of many of these Facebook groups being a substitute for otherwise unattainable treatment, the prospects of new beginnings in the form of virtual communities

proved to be effective at keeping many of my interviewees away from their past addiction. This virtual world also proved to be unavoidable starting in March of 2020.

The COVID-19 Pandemic: A Crystallizer and Compounder of Addiction Inequality

When the COVID-19 Pandemic brought the entire world to a halt in the middle of March 2020, every facet of society was left to adapt to a virtual world. Understandably, the healthcare industry was hit particularly hard by the virus as hospitals were taking in patients at multiplicity rates of capacity. As the new normal revealed vast disparities in healthcare, this inequality was clear in the addiction sphere.

Christine notes:

"I was still down bad with wanting heroin at the start of the pandemic but had promised myself that I would start treatment months before March hit and everything went down. I'd call and call around to all of the treatment centers for a few months but I was left with an answering machine or a 'We're sorry that we can't help you. We're really strapped with the virus'. They didn't give a damn that I was still regularly using and even wanted to stop but knew I couldn't do it alone. And if I even had the pleasure of getting to speak to a front desk person, the first question they ask if you had insurance. As soon as I said I had Medicaid, it was all over. Rinse and repeat, time and time again."

This experience was not unique to Christine. Several of the women who I spoke to were in the process of undergoing a rehabilitation program, finishing up Alcoholics or Narcotics Anonymous, or seeking out aftercare following a rehab stay. Nyla told me:

"Do I think that not having fancy private insurance made a difference if I could get into a treatment facility? Well yeah, but that isn't just true during COVID. It's all the time. There always is a limit on how many Medicaid patients they'll take and there always is an excuse why they can't take you. There's always an excuse but now COVID is just the big reason that no one can debate with."

Nyla's sentiment of treatment facilities frequently giving excuses as to how they all seem to never have any openings, especially for Medicaid patients, is shared across 11/12 women that I interviewed. In fact, 10/12 of the women I spoke with noted how addiction medical care under the pandemic actually was not that distinct at all. Shonda and Maria both told me that other than that most care was moved virtually; many elements of addiction care remained the same.

"Rich people always get the best treatment. Medicaid patients are screwed and treatment drugs are expensive either way. Did the pandemic make seeing a therapist easier? Well yeah, but it doesn't mean that that therapist is cheap. He's just on my computer now."-Maria

While COVID-19 rapidly changed the world, telemedicine may prove to be a promising support in place for treatment while many women are stuck on a waiting list. Just like in many other industries, the COVID-19 Pandemic crystallized how systems can be pushed to adapt to be virtual and compounded disparity when it came down to being able to access in person treatment. The Pandemic proved that telemedicine is growing and

promising; addiction treatment can take place in anyone's home; brick and mortar facilities are important but not essential to treatment allocation.

Policy Recommendations and Implementation

"Hope keeps me going. I know that better treatment can happen and I will be strong until that treatment comes around."-Aliyah

Centered around my findings, my policy recommendations are three-fold and reference 3 levels of changes: reforming the special populations categorization on the state and federal level to accomplish more and to include women of color, revising how treatment centers in Chicago offer services, and to reexamine societal and individual level framings of those who have an addiction.

Reforming the Special Populations for Addiction Categorization

Currently, on the federal level, addiction special populations refer to racial and ethnic minorities but are solely concentrated on higher inclusion rates of people of color in research, rather than in expanding treatment. On the state of Illinois level, addiction special populations refer to people who are: pregnant, post-partum, women with children, DCFS-referred, TANF recipients, DOC releasees, and TASC referrals. While some women of color with an addiction do fall into these categories, not every woman of color is included to be considered a special population to be guaranteed a spot in treatment earlier on. This seems counter-intuitive and not equivalent to federal law measures encouraging racial and ethnic minorities to be more included in research. I propose that special populations should have one universal definition for those with an addiction federally, and thus applying to every

state, and this definition should be expanded to include prioritizing treatment for women of color, with higher priority given to women of color who do not have insurance or only have Medicaid, are low-income by determination of the poverty line (rather than solely looking at TANF recipients), or who may be immigrants. This universal definition would allow women of color with an addiction to have a better chance at receiving services nationwide if services are not currently available within their area. Patients could travel to a nearby Indiana facility or engage in telemedicine treatment until a spot opened up in a treatment center closer to their homes. Any treatment, whether it has to start remote or not, is better than receiving no treatment at all and remaining on a waiting list until an in-person spot opens up.

Additionally, the federal categorization of special populations currently including ethnic and racial minorities is a start to equality in addiction treatment, but does not accomplish anything at the moment. Currently, the Office of Diversity and Health Disparities (ODHD) at The National Institutes on Drug Abuse publishes reports on how to better include people of color in research and in brainstorming ways to decrease disparities in medicine. This is an excellent start to solving a problem, but the group is currently just an ideological working network. This group needs to define stronger goals on how to increase accessibility and affordability of treatment for women of color, especially those who are low-income or without insurance. I would propose that the ODHD creates benchmarks for each state to see if they are adequately serving the needs of women of color or those with low socioeconomic status in the state. This way, each state has clear-cut growth modules to accomplish to better provide services to all women of color within their state.

Aside from the federal definition of special populations being standardized, I would propose that the City of Chicago itself creates an addiction special populations category to prioritize services to those who are people of color in addition to the other standards that the state currently considers to be special populations. The evidence shows that women of color in particular are currently being undertreated in addiction services, and having a special populations classification expanded to include women of color will expedite the ability for quicker, and hopefully more high-quality addiction treatment services.

While reclassification of special populations both on the federal and city level will lead to policy change, awareness of the category of special populations is crucial as well. Many of my interviewees had never heard of the term "special populations", nor did they know that some of them already qualified to be taken off of a waiting list because of it. Not every treatment center will take the time to check if someone falls into the special populations group, so educating women of color on their eligibility status for addiction within special populations can also make a difference in treatment acquiring.

Revising How Treatment Centers in Chicago Operate

Prior to even seeking out addiction treatment, many women of color call an addiction treatment hotline to discuss their treatment options. Unfortunately, many of these hotlines only operate during the business hours of 9 AM-5PM Monday-Friday and are also used for mental illness in general or for extremely specific populations (i.e. deaf addicts). There should be a 24 hour, 7 days a week addiction treatment hotline for anyone to call to figure out what their treatment options are if they need care that very moment or if they are hoping to find care down the line. Overdoses and addiction relapses do not only occur during

business hours and weekdays; thus, the significance of having a 24-hour line to call can be extremely helpful for those who are determining their treatment options or may need advice on what to do in the moment regarding addiction. These hotlines are gateways into treatment and if they are only available during business hours and weekdays, they are missing late-night and weekend calls of despair and desperation. At least one hotline needs to be in constant operation in the City of Chicago to immediately ease the pressure of finding addiction treatment.

Some women of color do not seek out addiction treatment due to barriers such as distance, language, price, or other reasons which may make it inaccessible. The COVID-19 Pandemic has revealed how broader public structures can be pressured and constrained to move the entire world online, yet still adequately deliver services like education and healthcare. Because Zoom has proved to be such an effective tool during the Pandemic, it tells us that this was always possible as a means to provide treatment if in-person treatment is not an option for any reason. Because the Background section of this study revealed that only three addiction treatment facilities exist within the city limits that take women of color, of any insurance status, and of any income bracket, online therapy and support groups alongside more flexible medication options may help to fill in this gap before more treatment centers can be expanded or built. While in a perfect world, increasing the reach of the current treatment centers that exist or creating more facilities would be an excellent solution, the cost and space constraints of accomplishing this remain a formidable opponent. Yet, the Pandemic has revealed that physical space is not necessary to provide medical treatment. Virtual treatment along with more flexible medication options, like buprenorphine which can

be taken at home or naltrexone which only requires 1 injection every 28 days, are solutions to the undertreatment of women of color in Chicago. While it is evident that more treatment centers need to be accessible for more grand-scale and long-term solutions, online therapy and more flexible prescriptions can reach many people who are currently underserviced or may not be able to get to current treatment facilities for any reason at all.

In addition to increasing the accessibility of the treatment itself, it is important for addiction center personnel to be trained to understand different cultural backgrounds that patients might be coming from, to hire translators or to know many different languages on their own, and for there to be resources for women who do not have the time or money to be checked into an inpatient facility. As indicated through Luciana's and others' experiences, treatment must be language-accessible. Addiction treatment often comes in a one size fits all policy. This does not work for solving a complex neurological problem that is different for every person who is afflicted with it. Women of different cultural backgrounds often have a substance abuse disorder in the first place due to past trauma or as a coping mechanism for something going on in their life; addiction treatment should be revised to suit different cultural backgrounds and to empower women. Many of the women with whom I spoke with preferred group treatment options for women of their cultural or gender identity. Increasing the availability of virtual support groups or identity affinity groups can heighten the sense of community and support necessary to solve addiction. While Facebook can provide meaningful connections, growing group therapy opportunities can help more women of color to feel connected to other women of color with an addiction such that they do not feel alone

or ostracized in their recovery. Social Media can also help to raise awareness for identity affinity groups that different treatment centers may offer.

Reexamining Societal Addiction Framework: It Starts with You

Addiction can tear apart a woman of color's life and it is necessary for a strong support network to exist for her both during treatment and once she leaves. It is crucial for addiction treatment to have secondary resources of job training, legal support, medical care, domestic violence prevention care, as well as other financial and emotional support systems. Involving a woman's family in the addiction treatment can help to rebuild connections in her family and help empower her in rebranding herself. All of the women who I spoke with found themselves empowered with having other women to look up to their lives or in having treatment programs with just other women. Allowing all women a space to feel comfortable and embrace themselves is incredibly important and empowering.

Offering greater support within treatment facilities is important but truly transforming the addiction treatment space for women of color in Chicago starts with all of us. Adam, an independent addiction policy specialist, noted:

"We have to start humanizing people with an addiction and stop using negative connotations of words to describe people with an addiction. 'Addict' is an easy way to reduce someone to nothing more than their addiction. That is wrong. Words like getting clean or user are harmful too. When we use them, we imply that people who do use drugs are dirty. No human wants to feel dirty."

When we use words like "dirty" versus "clean" or refer to someone as an addict rather than as a person with an addiction, we characterize her as her addiction rather than as her

addiction being just one part of her. Harmful language does affect women of color with an addiction in how comfortable they feel in society both during and after their addiction. Reducing anyone to just one ill by which they are suffering is detrimental to their self-confidence

In addition to language changes, mindset changes of those with an addiction need to come about as well. People with an addiction come in all shapes and sizes from varying backgrounds, but anyone with an addiction is so much more than just an addict. Being framed as just being addicted to drugs is a harmful measure that limits the potential of many women of color. Longer term changes of the decriminalization and legalization of small amounts of drugs can lead to changes in structural biases around women of color who have convictions, but individuals changing the way in which they think about those with an addiction can lead to stronger self-esteem and sense of worth amongst women of color with an addiction.

Conclusion

"You're the first person who has listened to me and not just wanted to tell me what I should be. Thank you."-Brianna

After I completed my interview with Juana and thanked her for her time, she said "Can I pay you?" Stunned and confused, I remarked "What?" She responded "No one, not a therapist, a doctor, or even a friend of mine has let me speak and share my story. They just know that I'm an addict but they never care to let me tell them why. Thank you for listening to me." I clicked on the end meeting button for the zoom call and slumped back in my chair in disbelief. She had the life story of someone who had lived a thousand lives over and had

accomplished so much from her own strength but she had never been given an opportunity to share her voice. That is the moment in which I knew the importance of this work was beyond the confines of this study or in an effort to collect data to answer a question. It was about empowering women to share their voice and to write their own narrative.

Despite this study leading to many novel conclusions, there are most certainly limitations to this research. Most obviously, my background as white, university student without an addiction may have hindered some women from feeling comfortable enough to participate in an interview. Additionally, this BA Thesis had a maximum amount of time to be completed from the end of September 2021 to April 15, 2021, not including time spent receiving approval from the Institutional Review Board. Because of the duration of this research was less than a year long and the pandemic limited my recruitment reach, the findings are limited and separated from the results that could be possible if I could speak to every single woman of color with an addiction within the City of Chicago. My study consisted of 20 substantial interviews and longitudinal observational analysis of the activity of women of color in 15 addiction treatment groups on Facebook, which I believe paints an accurate picture of disparity and struggles that women of color with an addiction in Chicago face.

This study sought to examine the questions of: How can we understand the experience of women of color who seek out addiction treatment in Chicago through examining structural disparities and biases within addiction treatment? What are the barriers that limit the quality of addiction recovery treatment for women of color? How has the COVID-19 Pandemic impacted the opportunity of women of color to receive addiction recovery treatment?

Even beyond answering these questions, this work centers the voices of women of color with an addiction to tell their stories of trials and tribulations. The work here is not done yet. The stories of the future have yet to be written but I hope that they are filled with more than adequate treatment and of closing the gaps of disparities in addiction.

Appendix

Appendix 1: Interview Questions/Script:

Study Number: IRB20-1830
Study Title:
Researcher: Madeline Paoli

following the Oral Consent
Thank you for your participation. I would now like to tell you a little more about the study.

Purpose of the Study:
The purpose of this study is to research the experience of minority women seeking out addiction treatment in Chicago. This study is hoping to reach conclusions about what treatment resources currently are accessible to minority women with an addiction, what might be lacking in terms of addiction treatment, and some policy recommendations on how to improve healthcare policy to better support minority women with substance abuse disorders.

Now that we have explained this study more fully, you may request that we not use the data we collected from you for this research study. If you decide that you do not want the researchers to use the data we collected from you, there is no penalty and we can end the interview now.

Set Interview Questions (more may come up within the interview but these will be asked to every interview participation):

- What has your experience been seeking out (or working at) addiction treatment? Have you sought out publicly-funded treatment, private treatment, or something else?
    - What type of care did you undergo? Did you feel that you were treated fairly and that your treatment lead to a diminished addiction?
    - How did you feel supported and not supported by the addiction treatment facility?
        - Did you ever feel as if you did not receive equitable care to another group?
- Why did you decide to seek out addiction treatment (or work with addiction patients/research them)? Was your addiction treatment what you had anticipated it would be?
- How did you go about choosing an addiction treatment center facility? What factors went into your consideration?
- Were you prescribed any medication for your addiction treatment? If so, can you reflect on the experience of using that medication? Feel free to reflect on the cost, side effects, efficacy of that portion of your treatment to other portions or anything else.
    - Were you offered alternative drug treatment options?
    - How accessible was your prescription drug treatment? Did you have to go into the office for it, was it inpatient or were you able to do it at home?
    - How accessible were prescription drug treatments for you?
- How do you feel that addiction treatment should change in Chicago? Do you think that the state of Illinois and City of Chicago currently are doing enough to support minority women with an addiction? Do you feel as if any groups are more supported than others?
- How did the pandemic affect your addiction treatment (or employment at an addiction treatment facility or your research) or recovery post treatment?

Contacts & Questions:
If you have questions or concerns about the study, you can contact me at madelinepaoli@uchicago.edu or by phone at 847-421-2787.

If you have any questions about your rights as a participant in this research, or to discuss other study-related concerns with someone who is not part of the research team, you can contact the University of Chicago Social & Behavioral Sciences Institutional Review Board (IRB) Office by phone at (773) 702-2915, or by email at sbs-irb@uchicago.edu.

Final Report: If you would like to receive a report of this BA Thesis Project when it is completed, contact me at by email or phone at madelinepaoli@uchicago.edu or 847-421-2787.

Appendix 2: Recruitment Flyer

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