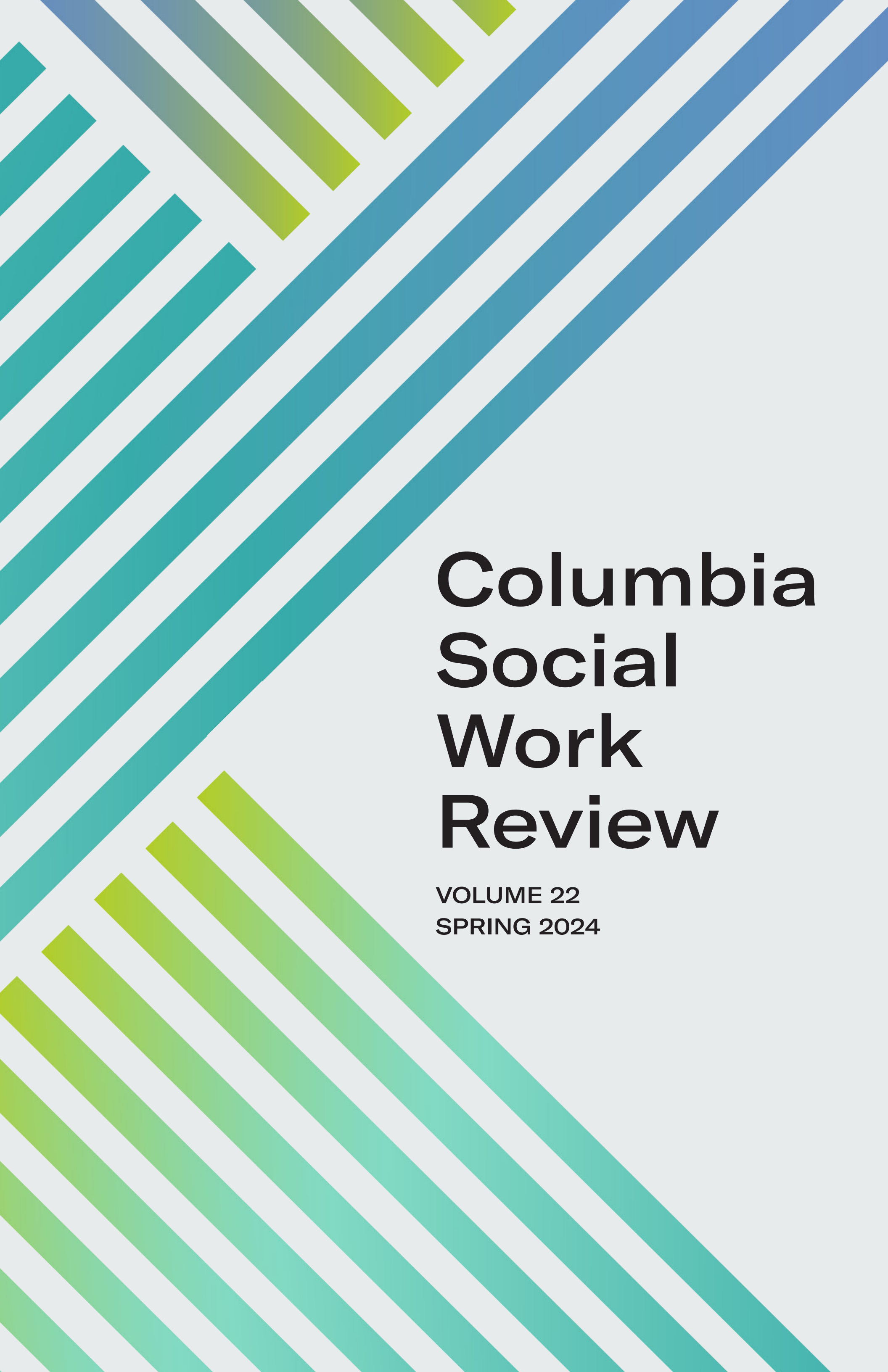

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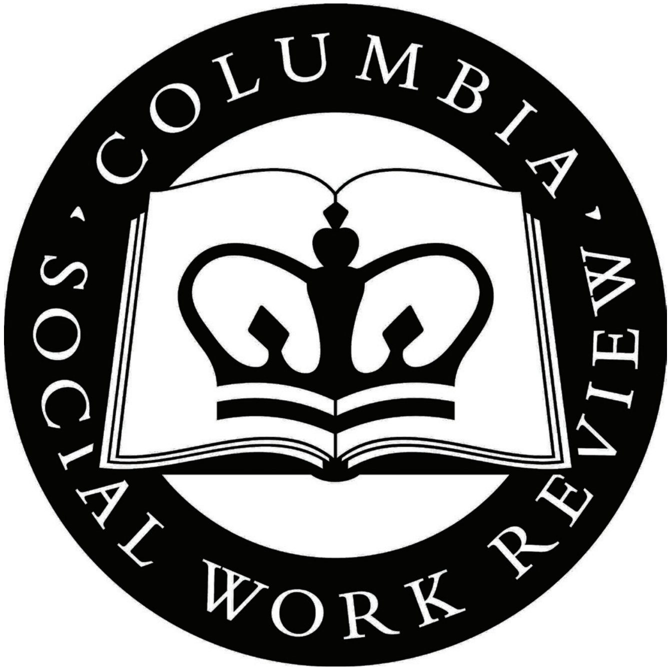
COLUMBIA SOCIAL WORK REVIEW

The mission of the *Columbia Social Work Review* is to provide a forum for the exchange of innovative ideas that integrate social work practice, education, research, and theory from the perspective of social work students. Founded by students at Columbia University School of Social Work in 2003 as the *Columbia University Journal of Student Social Work*, this academic journal provides an opportunity for students and scholars in the field of social work to share their unique experiences and perspectives with fellow students, faculty, and the larger social work community.



Spring 2024

Table of Contents

ACKNOWLEDGEMENTS

The publication of the Review is truly a team effort, and this edition would not be possible without the support and commitment of our amazing partners. In many ways, each year of working with the *Columbia Social Work Review* is a brand new experience, and our Editorial Board has truly made this year spectacular.

Many of our editors were new to the Review this year, and their ability to quickly learn and adapt to the rigor of our editing schedule was essential to our success. Our Creative Editors took on new challenges to promote student submissions to our blog-style platform, *The Amsterdam*, and were able to publish many unique pieces, including a video narrative, poems, and a keynote speech. Our Associate and Executive Editors formed strong editing teams and created a truly welcoming environment for our authors while approaching their work with both expertise and extreme care. Thank you all for your time, effort, and engagement with the team and with these papers. The *Review* would not be possible without you!

We would also like to thank our faculty advisor, Dr. Susan Witte, for her continued support of the Review and her assistance to the Editors-in-Chief throughout the year. Her reliable engagement and expert knowledge of the publishing process are essential in navigating challenges that emerge.

Finally, we would like to acknowledge Adam Pelligrini (Director of The Writing Center), the *Columbia Social Work Review*'s Advisory Board, Savannah Brogan (our design and layout specialist), and Village Copier (our printer) for their contributions to this year's publication. Thank you all for your continued support of academic publication in the School of Social Work. We hope that you enjoy the 22nd edition of the *Columbia Social Work Review*!

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Letter from the Editors

As we introduce the 22nd edition of the *Columbia Social Work Review*, we'd like to reflect on the journey that has brought us to this moment. It has been a challenging year, marked by moments that have tested our resolve and illuminated our strengths as a community within the School of Social Work. In the face of difficult conversations, our collective dedication to advancing social work practice, education, research, and policy has remained steadfast.

In this edition of the *Columbia Social Work Review*, we are proud to highlight six individual voices of our community as they each explore diverse topics and perspectives, revealing the complex landscape of social work. Each contribution offers a unique lens through which to understand and address the critical issues facing our society today. We invite you to see the world through their eyes.

Thank you to our editorial board, whose tireless efforts have ensured the highest quality and integrity of this publication. Their expertise and commitment to academic excellence have been instrumental in shaping the content of this year's review.

As we continue to navigate the ever-evolving landscape of social work, we remain unwavering in our commitment to advancing knowledge, promoting social justice, and fostering meaningful change.

Thank you for your continued support and dedication to the *Columbia Social Work Review.*

Best,

Mackenzie Christensen & Brenna Mayer
Editors-in-Chief, 2023-2024

Columbia Social Work Review

Social Work and the New York State Medical Aid in Dying Act

STEPHANIE VERONICA SMITH

STEPHANIE VERONICA SMITH

Originally from California, I am focusing on Integrated Practice and Programming at CSSW. I work as a Research Assistant at the Center for Prolonged Grief, where I interview survivors of the 2001 World Trade Center attack about their grief experiences. My goal is to work as a medical social worker and provide psychotherapy to bereaved people and communities.

INSPIRATION FOR ARTICLE

When my mother died in 2018, I became one of many people throughout human history irrevocably impacted by grief, and a reverent student of its power to disrupt, transform, and heal. When the COVID pandemic began, I supported people in the throes of grief and worked with people at the end of life. I heard patients and families inquire about medical aid in dying during my second-year practicum in oncology social work. I wrote my final research paper on the topic for Dr. Hara's policy course because I wanted to better serve patients and their loved ones. Although I have my own views on the topic, it was important to me to write this article with a social work lens, and with respect for multiple perspectives and lived experiences. It is my hope that readers see the humanity of multiple perspectives when reading it. Thank you to the primary editing team who made this publication a reality: Angelyn, Chloe, and ClaraGrace. Thank you also to the Editors-in-Chief Brenna and MacKenzie. I dedicate this article to my beautiful mother, Cherylyn Smith, for bringing me into this world and for teaching me so much when she left it.

ABSTRACT

Medical Aid in Dying (MAiD) is garnering increasing attention throughout the world. Since 1998, 14 states and Washington D.C. have MAiD laws in the United States. For the eighth time in as many years, the New York State legislature has introduced MAiD legislation, and the Medical Aid in Dying Act is currently in committee in both the Assembly and the Senate. Although this legislation has failed in New York State in the past, it is increasingly supported by New York voters (Granquist, 2024). The MAiD debates in New York state, along with data from U.S. jurisdictions with MAiD laws, highlight important considerations about end-of-life choices and how they intersect with social work values. Social workers can gain valuable insight into supporting people at the end of life, engage in self-reflection on their own beliefs and biases related to end-of-life choices, encourage self-reflection of medical professionals, and advocate for equity in healthcare within medical institutions and through social welfare policy (Schroepfer et al., 2022). This discourse can benefit patients interacting with the health care system regardless of MAiD's outcome in New York State.

As of April 2024, the Medical Aid in Dying (MAiD) Act is in committee in both the State Assembly and Senate (A995/S2445) in New York State (N.Y. Legis. Assemb, 2023). It proposes the legalization of a process by which terminally ill people can access medication that will end their life. The MAiD Act specifies that this option is only available to people diagnosed with a terminal illness, which is defined as a physician determining they will live six months or less due to their illness. Multiple safeguards are defined in the legislation to prevent coercion from medical institutions and people who might benefit financially or otherwise from a person's death. For example, MAiD outlines the process by which terminally ill patients can request medication: patients must make both an oral and written request to a physician, the physician will then examine the patient to confirm whether they are terminally ill and have the capacity to make the decision, and a consulting physician must confirm. Though it is not a requirement, if physicians have concerns about any patient's capacity to make the decision, they are recommended to refer the patient to a licensed psychiatrist or psychologist to assess the patient's mental health and capacity (N.Y. Legis. Assemb, 2023).

There are also guidelines governing how physicians engage in consultations with potential MAiD patients. These include a requirement for physicians to provide education about the patient's treatment options and alternatives to MAiD such as hospice and palliative care. If prescribed the medication, there are strict guidelines that a patient must administer the medication to themselves and ingest it, and it must not be taken in a public space. Patients can also revoke their request for the medication at any time or simply elect to not take the medication even if they receive it. Physicians also have the right to choose not to incorporate MAiD in their practice or refer any patient who is interested in MAiD to another physician (N.Y. Legis. Assemb, 2023).

The MAiD Act aims to ethically expand the options for people at the end of life when they are terminally ill so they can die with choice and dignity. Although it is not explicitly stated in the Act, MAiD also attempts to address the problem of society's limited conceptualization of autonomy at the end of life, especially as it relates to suicide. As a result, part of what is being addressed is a societal exploration of what is ethically permissible when choosing to end one's life. The MAiD Act aims to address these problems through collaboration with patients, healthcare providers, and policymakers in New York State (N.Y. Legis. Assemb, 2023). Although social workers are not explicitly mentioned in the MAiD Act, the policy impacts the role of social workers and their engagement with people they serve. Whether or not MAiD passes in New York, the related discourse is crucial for social workers to understand. This paper will explore the nuances of the MAiD debate and its interaction with social work values. It will also provide information about the spectrum of end-of-life options currently available to New York residents, how social workers can prepare individually and within their workplaces for end-of-life conversations, and advocacy possibilities for a just and equitable healthcare system.

MAID CONSIDERATIONS

THE DISCOURSE ABOUT MAID AND SUICIDE

A major MAiD debate involves its relationship to suicide. Some people classify MAiD under the umbrella term "Physician-Assisted Suicide," which includes practices like euthanasia that are completed by physicians rather than the patient (Schroepfer et al., 2022, p.820). Proponents of the Act generally argue that MAiD is distinct from suicide. On a practical level, characterizing a death by MAiD as suicide can prevent life insurance beneficiaries from receiving claims (Parker et al., 2004), meaning that a patient's end-of-life wishes may not be honored. Conflating MAiD with suicide also means that prescribing physicians might be vulnerable to legal ramifications including felony charges. Although suicide is no longer considered illegal in any state, there are state laws, including in New York, that outlaw aiding suicide. New York Penal Law deems "a person guilty of promoting a suicide attempt when he intentionally causes or aids another person to attempt suicide" and classifies it as a class E felony with a 2-to-5-year sentence in prison (Promoting a Suicide Attempt, 2014). By distinguishing MAiD from suicide in legal documentation, a patient's end-of-life wishes are more likely to be honored, and there will be less liability for physicians and healthcare institutions if they choose to engage in MAiD.

Beyond practical considerations, framing MAiD deaths as suicides reflects deep sociohistorical ties to Western nations' perspectives on suicide. The legal codification of suicide enforced government control over what constituted sin, crime, and property rights. While there are efforts by mental health professionals to avoid stigmatizing language such as "committing suicide" in modern times, the language of "commit" is rooted in the idea that ending one's life is a crime with legal consequences. Historically, this included government forfeiture of property to the detriment of non-elite families and communities (Chang, 2018). Social stigma was generally a horrific byproduct for the people most impacted by a suicide death, and this legacy persists for many people. Attempts to conflate MAiD with suicide–and potentially punish the patients, communities, and physicians who prescribe MAiD medications–perpetuates stigma for people suffering from a terminal illness who seek options at the end of their lives.

OPPOSITION TO MAID

New York State legislators who voted against MAiD prevailed in past legislative sessions. It most recently failed in 2022 despite polls indicating voter support. According to a 2021 poll of New York voters, 58% supported MAiD, 37% opposed, and 5% were unsure (Marist College, 2021). Opponents of MAiD, primarily disability rights organizations such as the Center for Disability Rights in New York (CDRNYS) and Not Dead Yet, advocate against MAiD and argue it should be categorized as suicide. CDRNYS calls the bill an "existential threat to disabled New Yorkers," claiming that the government will "abdicate its responsibility" to equal protection related to suicide prevention services for people living with disabilities if it is passed (CDRNYS, 2022). Not Dead Yet echoes these concerns, stating that people living with disabilities will experience increasing levels of coercion to end their lives rather than seek life-saving care, especially those of low socio-economic status who cannot afford expensive medical treatment (Not Dead Yet, 2022). The New York State Catholic Conference joins these organizations, claiming that "ambiguous" aspects of the bill weaken accountability for healthcare professionals, diminish protections for people living with disabilities, and create further risks for those choosing to live with a terminal diagnosis despite treatment possibilities available to them (New York State Catholic Conference, 2024).

Organizations such as CDRNYS distrust the safeguards put in place to ensure coercion is not active in MAiD. Experts from the United Nations (UN) join them in warning about a global slippery slope toward eugenic-influenced pressures and ableist assumptions in medical practices that may eventually engulf low-income, terminally ill people along with other people living with disabilities. These warnings were issued in 2021 as a response to Canada's decision to expand MAiD to people with disabilities in addition to people with "grievous and irremediable conditions" (Quinn et al., 2021, p.1). Even before the expansion of Canadian MAiD laws, a 2019 UN report that investigated MAiD practices in Canada determined that "there is no protocol in place to demonstrate that persons with disabilities deemed eligible for assistive dying have been provided with viable alternatives" (Devandas-Aguilar, 2019, p. 13). There were also reports from people living with disabilities in institutions regarding pressure to seek MAiD.

U.S. disability rights organizations echo similar concerns to those from Canadian activists. CDRNYS (2022) states that the current language of the New York MAiD legislation deems people living with disabilities and conditions which could be life-threatening without treatment, such as diabetes, eligible for MAiD even if treatment options exist. They argue that people who cannot afford expensive treatments may experience financial pressure to pursue MAiD. As such, many disability rights advocates do not welcome an expansion of end-of-life options to include MAiD (CDRNYS, 2022).

While it is not yet possible to know how MAiD will impact New York, statistics from other states with similar laws provide insight. Kozlov et al. (2022) analyzed 23 years of aggregated data across 14 states and Washington D.C. The data determined that patients who died by MAiD "tend to be older, white, educated, and diagnosed with cancer across all jurisdictions where MAiD is legal" (p. 3042). These statistics are consistent in New York's neighboring state New Jersey where MAiD has been legal since 2019. According to a 2022 MAiD data report from the Chief State Medical Examiner's office, 90% of people who received medication for MAiD were white, 83% were over the age of 65, and 58% had at least a bachelor's degree. The report also states, "heart disease was the leading cause of death in the general population in New Jersey…followed closely by [cancer]. However, for those participating in the [MAiD] program in New Jersey, [cancer] is the leading underlying illness accounting for 48% of cases," while cardiovascular disease accounted for 14% of cases (The Office of the Chief State Medical Examiner, 2023, p.6). MAiD advocates interpret this data as evidence that MAiD is neither abused or misused to target people living with disabilities in states where it is legal.

Perhaps what is more important than countering MAiD opponents' critiques and conjectures with statistics from other states is to understand and acknowledge their concerns. The eugenics movement that swept the world through the late 19th and early 20th centuries had an indelible impact on the United States. The disability rights groups that oppose MAiD are speaking to the history of forced institutionalization, sterilization, and euthanasia rooted in a pseudoscientific endeavor to undermine people with disabilities as less worthy of dignity and autonomy (EveryBody, 2013). Recounting this history leads disability rights groups to draw parallels between the past and the present when legislation such as MAiD arises.

Part of their concern also stems from international aid-in-dying practices. In addition to UN experts' concerns in Canada, disability rights groups look to examples in Europe. The Netherlands has practiced euthanasia since 1985. It was initially an unofficial but tolerated practice and was eventually codified into Dutch law in 2002 (Groenewoud et al., 2021). The Dutch have expanded their practice from focusing solely on terminally ill people to include people suffering from psychiatric disorders that are deemed "unbearable and irremediable," and many of which are considered disabilities in the United States (van Veen et al., 2022, p.1). In April 2023, the Dutch law expanded to include children of all ages who have a terminal illness (The Guardian, 2023). Although many safeguards are part of MAiD laws in U.S. jurisdictions, including age restrictions, disability rights groups view the evolution of Dutch laws as an example of a gradual return of eugenics.

SUPPORT FOR MAID

The MAiD Act is sponsored by the Assembly Health Committee Chair Amy Paulin in the New York State Assembly with 50 co-sponsors, and the New York Senate Judiciary Chair Brad Hoylman-Sigal with 12 co-sponsors. The reintroduction of the bill in 2021 (then A.4321/S.6471) led to unprecedented advocacy with supporters sending more than 3,600 letters to state lawmakers (Granquist, 2024). Although the Act did not pass in 2022, a 2021 Marist poll showed that 58% of New York voters supported MAiD at that time (Marist College, 2021, p.27). Recent polling data conducted by YouGov and commissioned by Death with Dignity and Completed Life Initiative revealed that 72% of New York voters support MAiD, 23% oppose, and 6% are not sure (Hoffman, 2024). The poll shows that support is consistent across demographics. This includes Catholics (65%) and people with disabilities (73%) even though Catholic leaders and disability rights organizations are MAiD's most vocal opponents. MAiD is also supported in New York by organizations who seek to expand options to terminally ill people at the end of life, including End of Life Choices New York (2021) and Compassion and Choices (2024).

As the names of organizations who support MAiD emphasize, they view the legislation as empathetic support for terminally ill people who wish to die with choice and dignity. They also make a distinction between MAiD and suicide. Death with Dignity (2024) defines the difference by explaining that suicide is "the act of taking one's own life voluntarily and intentionally," whereas MAiD involves "an adult patient with terminal illness who is deemed mentally competent [who] chooses to hasten their death through a physician's assistance." Some national professional associations agree with these distinctions. The American Public Health Association (2014) explains that MAiD is part of a "patient's right to self-determination," and that a terminally ill person can assess what constitutes a "good death" according to their circumstances. The American Medical Women's Association and the American Medical Student Association also emphasize MAiD as part of patient autonomy (Schroepfer et al., 2022).

In January 2024, the New York State Bar Association (NYSBA) Task Force on Medical Aid in Dying released its Report and Recommendations on MAiD in New York. The report included a summary of statements from a public hearing conducted in November 2023. Advocates included people living with life-threatening illnesses who described their fears of not having MAiD available if treatment is no longer viable or desirable. Others were family members and loved ones of people who died with terminal illnesses while experiencing excruciating pain. Some described the attempts, completions, or requests from their now deceased loved ones to end their own lives knowing that MAiD was not an option in New York and the trauma they experienced as part of their bereavement. Other supporters were family members and loved ones of people who were able to utilize MAiD as residents in states where it is legal. They described the dignity, peace, and community support these people were able to experience by having more control over the circumstances of their death (New York State Bar Association, 2024).

While the NYSBA Task Force ultimately endorsed the New York MAiD Act, the final report contained recommendations for safeguards for “special populations,” as well as funding, insurance, and training for healthcare professionals (p.6). The overall aims of these recommendations are to ensure that patients fully understand their rights and end-of-life options and that MAiD is an equitable option available to people with terminal illnesses despite their insurance coverage or socioeconomic status. This last concern is based on federal laws that prohibit federal funding to pay for MAiD prescriptions which precludes people dependent on federal insurance options such as Medicare and Medicaid from utilizing MAiD. While this recommendation is counter to the concerns of opponents who worry that low-income people will be coerced into utilizing MAiD, the NYSBA supports the recommendation with data indicating there are people interested in utilizing MAiD in states where it is legal but are unable to do so because the prescription is prohibitively expensive. Furthermore, the report points to biases and inequities throughout the healthcare system that prevent adequate access and education about end-of-life options to people from lower socio-economic and socially-marginalized groups. They claim these inequities largely contribute to underutilization of MAiD in marginalized communities (p. 29).

CURRENT END-OF-LIFE OPTIONS IN NEW YORK STATE

There exists a spectrum of end-of-life choices for patients to legally explore in New York, and social workers already engage in conversations and practices with patients around these choices. If MAiD passes in New York, social workers are likely to be instrumental in providing education and support to patients through MAiD. Fujioka et al. (2018) conducted a literature review from jurisdictions where MAiD is legal, and concluded, “social workers… are integral in the execution of MAiD in tandem with physicians and adopt a wide range of roles” (p. 1572). As such, social workers and the communities they serve can benefit from understanding patient rights and the spectrum of end-of-life options for terminally ill patients regardless of MAiD’s success in New York.

The best-known options related to end-of-life care are advanced directives. Advanced directives are documents that explain a person’s medical care choices if they are unable to communicate them. This includes orders that can be specified in a Living Will such as Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders as well as Medical Orders for Life-Sustaining Treatment (MOLST) that guide families and medical professionals in determining whether life-saving measures should be utilized for a patient during critical situations. Another advanced directive is the health care proxy, which cedes control to one or more persons whom the patient appoints to make medical decisions on their behalf if they cannot communicate their wishes. Health care proxies can use a Living Will to carry out a person’s wishes, but if no Living Will exists, they can still legally make decisions on behalf of the patient (New York State Attorney General, n.d.). If a health care proxy is not assigned and a person cannot communicate their wishes, state laws determine who can make decisions on behalf of a patient (U.S. Department of Health and Human Services, 2022). In New York State, that person would likely be a legal guardian, a spouse or domestic partner, or an adult child (New York State Department of Health, *n.d.*). Health care professionals such as social workers can provide education and serve as witnesses for advanced directives.

Hospice and palliative care services are also available to terminally ill New Yorkers. Hospice provides support to patients who are terminally ill when curative approaches are either not desired by the patient or are not available to the patient at any point from diagnosis through treatment. It includes comprehensive services such as nursing, pain management, social work, and spiritual care. Palliative care is available to patients with chronic illnesses that are not necessarily terminal and who desire pain management assistance and other supportive services either with or without treatment (U.S. Department of Health and Human Services, 2021). Both services are fully covered by Medicare and Medicaid and are generally fully covered by private insurance plans as well (VITAS Healthcare, n.d.).

Two New York State laws, the Palliative Care Information Act (PCIA) and the Palliative Care Access Act (PCAA) require physicians, nurse practitioners, general hospitals, nursing homes, home care agencies, enhanced assisted living residences, and special needs assisted living residences to offer information and counseling concerning palliative care and end-of-life options and facilitate access to such care. Despite these laws, New York State ranks last in the United States for hospice utilization with reports that PCIA and PCAA are largely ignored and unenforced (New York State Bar Association, 2024). When education, counseling, and referrals to palliative care and hospice do occur, social workers are generally involved in some or all stages of the process. Robust and consistent practices in providing education about hospice and palliative care are recognized as crucial MAiD safeguards for proponents and opponents alike.

Another legal option for terminally ill patients is Voluntary Stopping of Eating and Drinking (VSED). Although VSED is not without controversy, it is generally protected as a patient's right to determine their own treatment, including refraining from treatment. It is an option that can be specified in an advanced directive, which includes refusal of feeding tubes to sustain a patient's life (End of Life Choices New York, 2021). Although it is generally differentiated from suicide, there is no standardization about how it is characterized on a death certificate which can impact a patient's life insurance policy and end-of-life wishes (Uemura et al., 2023). It is also a difficult, physically grueling process that requires a strong will on the part of a patient and their caregivers. As such, some families of New Yorkers who died by VSED are strong advocates for MAiD (New York State Bar Association, 2024).

If a terminally ill New York resident is interested in pursuing MAiD, it is possible to travel to another state or country where MAiD is legal. While most other states require a person to be a resident, Oregon and Vermont lifted the ban on non-residents in 2023 (Paine, 2023). Traveling for MAiD is not ideal for many people at the end of life, primarily because it can be emotionally difficult, which is a major impetus for proponents of the law in New York State (N.Y. Legis. Assemb, 2023). It is also prohibitively expensive for many people and requires time, planning, and resources that many people at the end of their lives may not have. Families of New Yorkers who suffered because they were unable to travel for MAiD are also strong advocates for the legislation (New York State Bar Association, 2024).

MAID AND SOCIAL WORK

SOCIAL WORK ASSOCIATIONS AND MAID

There are currently neither standards about social workers' engagement with MAiD nor specifications in the New York MAiD Act about social workers' roles. Most social work associations do not take an official position on the issue but affirm that the profession's ethics and values support and advocate for patients' rights and end-of-life choices. The National Association for Social Workers (NASW) *Standards for Practice in Palliative & End of Life Care* states,

> Social workers working in palliative and end of life care are expected to be familiar with the common and complex bioethical considerations and legal issues [including MAiD]. End of life issues are recognized as controversial because they reflect the varied value systems of different groups (NASW, 2004).

This statement emphasizes the holistic nature of social work in navigating the complexities of end-of-life issues with individuals and families. Cultural awareness and sensitivity are upheld as important aspects for social workers engaging in palliative and end-of-life care.

The Association of Oncology Social Work (AOSW) expands on the NASW statement by upholding "the right of every patient to make decisions about living and dying that are reflective of their goals and values and are consistent with the law of their jurisdiction" (Schroepfer et al., 2022, p. 823). Both associations highlight the importance of self-reflection in social work when supporting individuals and families addressing end-of-life concerns. Although these statements point to social work values, they do not explicitly explore end-of-life care options, including MAiD, through the lens of social work values. Such an exploration reveals that some social work values align with MAiD policies and practices while others do not.

SOCIAL WORK VALUES ALIGNED WITH MAID

Arguments in favor of MAiD emphasize it as an end-of-life choice that promotes a patient's dignity. This directly relates to the social work value of upholding the dignity and worth of a person (NASW, 2021). A 2022 comprehensive review of data from Oregon, collected from the time the law passed in 1998, reveals that these values are consistent with utilization of MAiD in the state. The main concerns reported by Oregonians who utilized MAiD related mostly to their loss of autonomy and dignity and their inability to engage in activities that made life enjoyable (Oregon Health Authority: Public Health Division, 2023). This indicates that MAiD is serving terminally ill Oregonians as intended by centering and upholding their choices and dignity.

The MAiD Act also respects the desires of many terminally ill people to experience their end of life within the meaningful and comfortable environment of their own home. The New York MAiD Act explicitly mentions the highly publicized death of Brittany Maynard, a 29-year-old resident of California who died from a brain tumor. Maynard traveled to Oregon for MAiD and advocated for its enactment in California as she was dying so that others could have the option to die at home. Her advocacy strongly contributed to the enactment of California's law in 2015 (N.Y. Legis. Assemb, 2023). Citing the example of Brittany Maynard, proponents of the law aim to support terminally ill New York residents so they do not have to cross state lines to receive MAiD. This resonates with statistical data showing that terminally ill people generally prefer to die at home. Roughly 93% of MAiD participants in Oregon have chosen to die at home since the law was passed (Oregon Health Authority: Public Health Division, 2023). New Jersey reported similar statistics in 2022 with 92% of patients utilizing MAiD dying at home (The Office of the Chief State Medical Examiner, 2023). The New York bill contains similar language to Oregon's law and is likely to promote dignity for terminally ill people who utilize it in New York as well.

SOCIAL WORK VALUES UNALIGNED WITH MAID

There are also social work values that do not align with MAiD, particularly with regard to social justice. Oppositional arguments cautioning against a slippery slope towards eugenicist practices resonate with some communities of color who have been impacted by abuses of the eugenics movement. A comparison of two recent polls of New York voters demonstrate a correlation between trust in medical providers and support for MAiD, particularly among Black voters. A 2023 Siena College poll found 58% of respondents support "legislation that would allow a doctor to prescribe lethal drugs that a terminally ill patient with demonstrated decision-making capacity could take on their own in order to end their own life" (Siena College Research Institute, 2023, p. 5). Just two months later in January 2024, a poll conducted by YouGov found 72% of respondents support pending legislation that "would allow a terminally ill patient–for whom two doctors have determined has under six months to live–the right to request and receive a prescription for medication to end their life" (Hoffman, 2024, p. 1). Support for MAiD among New Yorkers proved far higher in the YouGov poll (2024) emphasizing patient autonomy compared to the Siena College poll (2023), which highlights doctors prescribing "lethal drugs" to patients. Black voters were particularly attuned to the nuances of each poll's phrasing: 66% of Black voters stated that they support MAiD in the YouGov poll (Hoffman, 2024) while only 28% stated that they support MAiD in the Siena College poll (2023). Although it is significant for New York voters in general that the MAiD Act centers patient autonomy over the power of medical providers, this is especially true for Black Americans who have historically suffered, and continue to suffer, life-threatening and sometimes fatal harms at the hands of medical institutions.

Considering social workers' commitment to social justice, it is crucial to examine these nuances and their implications. Structural racism in health care is deeply rooted in U.S. history. Harriet Washington's book *Medical Apartheid* (2008), for example, illustrates the lack of transparency, medical experimentation, intentional harm, and even murder of Black Americans throughout history at the hands of medical institutions and how this history reverberates across the U.S. healthcare system today. A 2019 study by Cain & McCleskey further emphasized the impact of structural racism in U.S. healthcare. By conducting focus groups in Los Angeles, California, they determined that while there are a variety of nuanced opinions based on race and ethnicity, African American and Latino participants who opposed MAiD highlighted structural racism in healthcare as a major reason (Cain & McCleskey, 2019, p. 1185).

In light of this history and its enduring impact, MAiD raises complex social justice concerns related to inequitable healthcare access for people of color, both across the lifespan and in end-of-life options. Data show people of color generally do not utilize MAiD in states where it is legal, with 95.6% of those who do identifying as white. This seems to refute opponents' concerns about race-based coercion into MAiD on the part of healthcare institutions. At the same time, it is worth noting that similar disparities exist in hospice and palliative care, which are also underutilized by people of color (Teano, 2020). This is especially true in New York State which has the lowest hospice utilization rate in the nation (New York State Bar Association, 2024). Both proponents and opponents of MAiD point to this data, but for different reasons. MAiD proponents argue that structural racism in health care leads to physicians not discussing hospice and palliative care options with patients of color, even though this information is generally shared, understood, and accessible for white patients. MAiD opponents, however, claim that the underutilization of hospice and palliative care relates to a lack of trust between physicians and communities of color. Overall, this complex landscape indicates that despite low rates of MAiD utilization among communities of color, constant vigilance is needed to ensure misuse does not emerge and to promote social justice in end-of-life care. Social workers have a key role to play in this endeavor.

PREPARATIONS FOR MAID AMONG NEW YORK SOCIAL WORKERS

Given the increasing support for MAiD in New York, it is prudent for social workers to consider their role in relation to this issue. Understanding the MAiD laws in the context of history, cultural considerations and nuances, social work values, and other end-of-life options available to New York residents covers many crucial elements. The NASW and AOSW encourage social workers to engage in self-reflection to understand whether they can ethically serve a client and to refer them elsewhere if they are unable to do so. Social workers must therefore reflect on their own beliefs and attitudes toward end of life experiences and care and how this shapes their personal views of MAiD (Schroepfer et al., 2022). If they are able to ethically engage, social workers can also explore navigating cultural nuances and different belief systems in relation to MAiD with patients and their families. The holistic perspective of social work provides a unique opportunity to serve as additional safeguards against misuse and abuse of MAiD. By understanding the concerns of proponents and opponents alike, social workers are equipped to ethically discuss MAiD while centering the dignity and rights of all patients, regardless of their medical and end-of-life choices.

Social workers should also encourage and support self-reflection, education, and advocacy on the interdisciplinary teams in which they work. Given MAiD's complex relationship with social justice, it is important for other professionals who engage in conversations about end-of-life options to investigate their own beliefs, biases, and ethics. Social work associations and social workers engaging in end-of-life care can prepare training workshops and materials to guide health care professionals through education and self-reflection on topics such as ableism and racial biases in medicine. They can also collaborate on interdisciplinary practices and procedures in relation to end-of-life options and conversations with patients. Providing opportunities for stronger interdisciplinary teams that are informed and equipped to navigate the nuances of challenging end-of-life conversations can provide a stronger support system for patients, increase possibilities for patient-centered collaboration, and provide more robust advocacy for patients engaging with interdisciplinary healthcare teams.

Given the social justice concerns and underutilization of hospice and palliative care in New York, social workers can also strengthen their advocacy roles in relation to MAiD. They can work to inform patients about their rights and the spectrum of end-of-life options available to them while also advocating for more equitable healthcare for patients in general. While proponents and opponents of MAiD come to different conclusions about whether the law should pass, they agree that healthcare equity is a strong safeguard against MAiD abuses. By strengthening equity in the health care system through advocacy, social workers can serve not only as a unifying force in the divide around MAiD but also as social justice leaders serving to remedy longstanding structural inequities in the United States.

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What’s in a “Latinx?”: Considerations When Utilizing Pan-ethnic Identifiers of *Latinidad*

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INSPIRATION FOR ARTICLE

I began writing this paper while writing my doctoral dissertation. I felt compelled to justify, in detail, why I choose to utilize Latine in my writing instead of "Latinx." This led me to spend a lot of time going down a lot of research rabbit holes in search of the perfect citation, one that encompassed my full perspective on the need to use gender-inclusive – but not gender-neutral – language when referencing my pan-ethnicity. Realizing that the empirical article I was looking for didn't exist yet, I decided to write it myself. It was important to me to publish this piece in the Columbia Social Work Review because of the connections between CSSW and the topic of my article. One thing I hope readers take away from it is a greater understanding of the term "Latinx" including how it came to be and how its usage has grown. I'm really excited to see this paper in print and share it with family, friends, colleagues, and professional partners, in the hopes that it will provide them with a well-researched basis to explain why and how they choose labels of Latinidad, without having to complete a systematic review of research like I did!

ABSTRACT

People of Latin American origin use many different terms to self-identify their ethnicity. To date, there are very few scholarly articles that have investigated the growing use (and potential outcomes) of the term "Latinx." Over the past decade, this pan-ethnic identifier has been wholly ascribed to a group of people who do not all identify with it. The dearth of empirical understanding on this topic is especially concerning given its significant implications on one's positive identity development and overall psychosocial functioning. This conceptual essay is meant to introduce readers to the role that U.S. colleges and universities played in the promulgation of the word "Latinx." It also aims to stimulate discussion amongst readers who may question how "Latinx" came to be the pan-ethnic identifier for this community as well as those who may question whether they should adopt or reject the label. To address the aforementioned inquiries, this composition includes a brief history of the most commonly used pan-ethnic terms for the Latin American diaspora. The implications of ascribing gender-inclusive vs. gender-neutral labels on positive identity development, as well as recommendations and best practices for social work researchers, practitioners, and other stakeholders, are also discussed.

The first time I heard the word "Latinx" was on September 6, 2011. It was my first day of classes in pursuit of a graduate degree at the Columbia University School of Social Work. While a fellow first-year student was describing what brought them to the field of social work, I heard them say a phrase that sounded like "*Latines* in this country." I mistakenly attributed the pronunciation of this word to their regional accent, not to an intentional effort by a non-binary person to utilize a gender-inclusive form of *Latinos*.

As someone who was born and raised in New York City, I have often observed that people can pronounce the same words in different ways. However, my new colleague informed me that, although they were from Boston and spoke with a distinctive accent, they had indeed intended to say *Latines*, not *Latinos*. Moreover, even though the word was pronounced with an E, it was spelled "Latinx," with an "X." They also told me it was understandable if I had never heard the word "Latinx" before; they had only ever heard it used amongst genderqueer people.

Over time, I heard more of my social work peers utilizing the word "Latinx," but enunciating it more like "Latin Ex." This was distinct from the way I first heard my associate from Boston pronounce it as someone who was a heritage speaker of Spanish. Moreover, I did not hear anyone besides other social workers using "Latinx" until December of 2015 – when I began working at a university in the Midwest. Through my academic and vocational networks, I learned that "Latinx" was quickly being adopted at institutions of higher education across the country at that time. However, I did not observe its usage in any other contexts, and I sought to comprehend why.

AUTHOR'S POSITIONALITY

The lens through which I examine the usage of "Latinx" is informed by my background in Social Work as a practitioner specializing in Immigrant and Refugee Issues in addition to my background in Education as both a scholar of psychosocial development and as an adolescent educator. I also carry the perspectives and biases that come as a result of over two decades of experience working with Latina/e/o/x youth in both formal and informal learning environments. I self-identify as a cis-gender, heterosexual woman whose parents migrated to the U.S. as children after forced displacement from their homeland. My own process of self-identifying as a Nicaraguan-American first, a Central American second, and a Latina third was shaped by having resided in six different cities across the U.S. (as well as in Nicaragua) and the impact that interacting with other Latinas in each of those places had on my own self-perception. In my personal and professional experiences, I have seen how my many intersectional identities frame not only how I have come to understand ethnic identity development but also how I continue to learn about labels of *Latinidad* (which I translate as "Latineity" – the quality or state of being Latina/Latine/Latino/Latinx).

UNDERSTANDING "LATINX"

Numerous studies have observed a correlation between one's ethnic or gender identity development and many aspects of well-being. Positive identity development is characterized as forming a healthy self-identity and a secure sense of self. This can be achieved at both the personal and the social level with beneficial outcomes such as high self-esteem, successfully engaging with others and developing/maintaining healthy relationships, and a positive sense of agency to accomplish goals (Brandon-Friedman, 2019). According to Erikson's (1963) theory of psychosocial development, which describes how an individual's personality develops and how their social skills are learned, adolescents must confront the challenge of ego identity vs. role confusion. During this stage of development, the main tasks that need to be resolved for healthy outcomes include constructing one's own unique sense of identity, finding social environments where one feels a sense of belonging, and establishing a confident sense of where one fits into society.

One way that adolescents accomplish these tasks is by developing their ethnic identity which includes adopting an ethnic–or pan-ethnic–identifier. For example, "Latinx" is a pan-ethnicity, a term that refers to the organization of ethnic subgroups perceived by outsiders to be homogenous under an umbrella category of collective interests and shared socio-political goals (Espiritu, 2019). Under this umbrella category, there are dozens of other ethnicities, such as Central American and Nuyorican. Notably, there are very few scholarly articles that have investigated the growing use (and potential outcomes) of the term "Latinx" as an ethnic identifier. This dearth of empirical understanding is especially alarming given the significant implications for one's sense of self and ability to engage with others on identity development and overall psychosocial functioning (Umaña-Taylor et al., 2002).

Young people from across the Latin American diaspora make up the second largest racial/ethnic group enrolled in K-12 schools (KidsData, 2021) and post-secondary institutions (Institute of Education Sciences, 2022) in the U.S. today. In addition, research demonstrates that students of Latin American origin more often rely on schools than other systems as their primary provider of mental health services (Franco, 2018). This should be of particular concern to social workers who make up the country's largest group of mental health services providers according to the National Association of Social Workers (NASW, n.d.).

This conceptual essay is meant to introduce readers to the influential role that U.S. colleges and universities played in the promulgation of the word "Latinx." Schools, as sites of socialization, are influential in the psychosocial development of students, including their racial identity, ethnic identity, gender identity, and sexual identity development. Subsequently, the staff and other students at one's school have the potential to support or hinder psychosocial functioning and development outcomes (Verhoeven et al., 2019). It is therefore possible that the usage of "Latinx" may have a developmental effect that we do not yet fully understand on students of Latin American origin.

I also aim to speak to readers who may question how "Latinx" came to be the pan-ethnic identifier for this community as well as those who may question whether they should adopt or reject the label–which may be utilized by individuals or groups in different contexts and for different reasons. For example, in the past decade, I have spoken to dozens of people (whose heritage traces back to what is now called Latin America) from all walks of life about their decision to use "Latinx" or not. Although the majority of them expressed that it would be ideal to have a unanimously-accepted identifier of *Latinidad* that is non-patriarchal and inclusive of everyone in the community regardless of national origin, race, ethnicity, gender, sexual orientation, and sociolinguistic background, they felt that the umbrella of *Latinindad* encompasses so much diversity that there may never be one term that is truly inclusive of all. Ultimately, whenever they decided to utilize "Latinx," it was often based on the same strategies they usually employed while code-switching–they adjusted their word choice based on what they perceived their audience would find acceptable.

My exploration of the propagation, and by whom, of the term "Latinx" is not an argument against using it (see Scharrón-del Río & Aja, 2020; Milian, 2019; and Guidotti- Hernández, 2017 for further reading on the significance of the term). I wholeheartedly believe that gender-inclusive language is absolutely necessary not only in the field of social work but whenever the Latin American diaspora is referenced. It is not at all my intention to argue otherwise. Rather, I caution against the usage of "Latinx" without critical self-reflection, particularly in a color-blind, gender-blind, and sexuality-blind fashion. I also call on and encourage my fellow social workers in particular, in accordance with our Code of Ethics (NASW, 2021), to not only seek out a nuanced understanding of the adoption and rejection of pan-ethnic labels of *Latinidad*, but to advocate for practices that highlight our ethical obligation to

both promote social justice and respect our clients' right to self-determination. This includes enhancing each of our clients' capacities to set their own boundaries regarding which, if any, pan-ethnic term we should use when referencing their identity. With that charge in mind, the following section offers a brief history of the most commonly used terms.

BACKGROUND ON PAN-ETHNIC LABELS OF *LATINIDAD*

HISPANIC

Although "Latino" and "Hispanic" are often used interchangeably in the literature, there are significant differences between the two. Grace Flores-Hughes (1996), a self-identified Mexican American who is credited with introducing the term "Hispanic" to U.S. public policy, has said herself that it is not at all synonymous with "Latino" (Flores-Hughes, 2006). The identifier "Hispanic" was set in 1976 as the government term for anyone living in the U.S. whose origins can be traced to a country or territory where Spanish is an official language (U.S. Pub. L. No. 94-311, 1976), including Spain itself. At the time, that also included the Philippines. However, a focus on Spain makes this term Eurocentric (Mora, 2014), and people who are of African (Gonzalez-Barrera, 2022), Asian (UnidosUS, 2021), and/or Native American (Parker et al., 2015) descent may not identify with "Hispanic" (Taylor et al., 2012) even if they are native Spanish speakers (Lopez et al., 2023). It is also important to note that many people do self-identify as Hispanic even if they do not speak Spanish; most adults who identify as Hispanic say it is not necessary to speak Spanish to be considered Hispanic (Mora & Lopez, 2023).

With the institutionalization of "Hispanic" as a pan-ethnic identifier, both widespread adoption and resistance to the term developed soon after. Many argued that the term represented an attachment to the Spanish legacy of colonialism and genocide in the Americas, and the utilization of the term "Latino" (short for *latinoamericano*) as a more progressive alternative quickly grew in popularity. It is important to note that people of Latin American origin living in the U.S. had been calling themselves *Latino* since the years following the wars of independence in Spain's former colonies, and also in response to being sociopolitically ascribed an ethnic label that they did not identify with (Gutiérrez, 2016).

LATINO

The identifier "Latino" refers to any person whose origins can be traced to any country or territory in Latin America. It was later added as a government term to "Hispanic" (62 FR 58782, 1997), but the two terms have since been used interchangeably. As a result, in government directives (U.S. Census Bureau, 2022), "Latino" also does not include anyone living in the U.S. with roots in countries or territories where Spanish is not an official language. Therefore, people who are from Brazil, French Guiana, Guadeloupe, Haiti, Martinique, Saint-Barthelemy, and Saint-Martin are not considered "Latino" by the U.S. government, even if people from these countries self-identify as such.

Pushback against the term "Latino" also began in the 1970s from feminist communities in the U.S. who called for a less patriarchal, more gender-inclusive term. This opposition included the emergence of various new expressions such as "Latin@" as alternatives, although widespread adoption would not take place for several decades. However, the specific origin of these alternatives are unknown. Nonetheless, scholars agree that–with the advent of replacing Spanish morphemes "o" and "a" with "e" or "x"–the initial usages of *Latine* and "Latinx" likely came soon afterward (Papadopoulos, 2022).

LATINE

Álvaro García Meseguer (1976) argued that Spanish–as a gendered language that defaulted to the usage of masculine terms even when referring to mixed-gender groups–was sexist, and there was a need for greater gender-inclusive usage. García Meseguer further posited that, since "e" morphemes in Spanish are already gender-inclusive, people should replace "o" and "a" morphemes with "e"s when referring to mixed groups as well as those who do not want their gender identified. Morpheme replacements in words that refer to people (e.g. *los niños/las niñas* ➢ *les niñes*; see Lemus Sandoval, 2001 and Lamas, 2005 as scholarly examples from El Salvador and Mexico, respectively) have remained in use throughout Latin America since the 1980s as well as the use of gender-inclusive ethnic identifiers such as Latines (Politi, 2020; Vidal-Ortiz & Martínez, 2018). However, there is no definitive explanation for why, in the U.S., "Latinx" was propagated instead.

LATINX

The origins of the usage of "Latinx" are undetermined. It was first seen in a published work by Elizabeth Horan (2004) where she used the identifier as an alternative to "Latin@" without explaining why. Although the intended audience of this publication were feminist scholars of Hispanic and Latin American Studies, Horan has stated (Rivas, 2017) that the term's usage began in online forums sometime in the 1990s (Milian, 2017). The renowned queer scholar Gloria Anzaldúa (1990) has herself noted that the voices of women of color are often silenced in academia, and their perspectives are frequently disqualified and excluded from academic discourse. One can only presume that there may be a connection between the origins of replacing the "o" in "Latino" with "x," and the origins of replacing the "a" in "woman" with "x," a practice first seen in 1971 at the University of California, Davis in an effort to be inclusive of trans women and women of color (Salinas & Lozano, 2021). It is also unclear what the connection is between the emergence of "Latinx" in the U.S. and the emergence of replacing "a" and "o" endings with "x" amongst Spanish-speaking feminist circles in Europe (see Sau, 1998 for the earliest traced example), if there is any connection at all. Nonetheless, scholars have found that when "x" morphemes were utilized, they were still pronounced as "e" since it is more easily pronounceable when replacing vowels in Spanish (Vidal-Ortiz & Martínez, 2018). In addition, throughout Latin America, utilizing "e" morphemes was more common than using "x," particularly because plural words with "x" endings are unreadable in Spanish (Alexgaias, 2014).

“Latinx” was first seen in a scholarly article by Macarena Gómez-Barris and Licia Fiol-Matta (2014) who argued for its usage “to signal a route out of gender binaries and normativities” (p. 504) and further posited that the use of “x” endings challenged the dichotomy of gender representations. In 2014, Columbia University became the first known institution in the U.S. to formally utilize “Latinx” when student members of the planning committee for their Latino Heritage Month celebrations changed the name to Latinx Heritage Month (Salinas, 2020). Student groups at other colleges and universities across the country swiftly followed suit, citing the need to use terminology that is inclusive of all gender identities (Logue, 2015).

According to a Pew Research Center analysis (Noe-Bustamante et al., 2020) of Google Trends data, broader interest in the word “Latinx” began increasing in June of 2016, which coincides with a variety of media reporting a mass shooting during a Latin Night event at Pulse, a gay nightclub in Orlando, Florida (Schneider, 2016). During interviews, many survivors used “Latinx” to describe themselves. Soon after, mainstream media (Finkel, 2017) began utilizing “Latinx” as well, and it was also added to the Merriam-Webster (n.d.) dictionary. With wider usage of “Latinx” came an increase in documented reactions (de Onís, 2017) to the word adoption, especially on college campuses (Mora et al., 2022). By this point, the usage of “Latinx” had become so common among students and faculty at academic institutions that education research articles and professional conference presentations usually utilized the term without defining it; it was implicit that anyone hearing or reading “Latinx” would already know what the word meant (Salinas & Lozano, 2019). However, Google Trends (n.d.) data also shows that the most common search query related to “Latinx” is still on the meaning of the term.

It is therefore safe to assume that there are more people in the U.S. and across the world who are unsure of what “Latinx” means than there are people who do know (Salinas & Lozano, 2019). Lozano and colleagues (2023) have posited that the hasty adaptation of “Latinx” can seem performative given the lack of a full examination and understanding of the term and greater input from the Latina/e/o/x community. I agree with Lozano and colleagues (2023) that it is consequently imperative to ask: How inclusive, and of whom, is the term “Latinx?”

IDENTIFICATION VS. ASCRIPTION, AND THE EXCLUSIVITY OF INCLUSIVITY

A number of scholars have observed that in spite of its initial intentions to be gender-inclusive (i.e., affirming of all gender identities), “Latinx” has come to be utilized more often as a gender-neutral (i.e. neutralizing or disassociating any reference to gender) term. This can perpetuate overlooking or even invalidating gender identity-based oppressions (Contreras, 2017). For example, trans women–such as Latina transgender rights activist Silvia Rivera–are women, and calling them “Latinx” solely because they are transgender potentially ignores and denies their sociopolitical struggles and right to self-determination. When “Latinx” is ascribed in such a way that neutralizes all gender identities and expressions, it may serve to further obscure the very people that “Latinx” originally sought to give greater visibility and recognition (del Río-González, 2021; Lozano et al., 2023).

Scholars posit that this shift in intentionality is a consequence of how “Latinx” has been increasingly adopted over the past decade to categorize all peoples who identify with *Latinidad* but without a thorough analysis of how “Latinx” has been defined, used, or perceived and by whom (del Río-González, 2021; Lozano et al., 2023). Trujillo-Pagán (2018) found that many people were utilizing “Latinx” merely because they heard others doing so or because it is what “other universities do” (p. 400), and that her colleagues at other institutions felt obliged to utilize “Latinx.” In addition, Trujillo-Pagán (2018) found multiple instances where the label had been applied to the scholarly work of others who had not employed the term, such as a book review that utilized “Latinx” but the book’s authors did not, as well as other book advertisements that utilized “Latinx” even though the authors themselves had not.

Trujillo-Pagán (2018) argues that crossing out self-chosen gendered identifiers serves to perpetuate patriarchy at the expense of cis- and trans women of color in particular; much like color-blind ideologies can operate to obscure systemic racism, gender-blind ideologies can operate to obscure structural sexism.

Even those who view "Latinx" as a gender-inclusive term may still perceive it as excluding other social identities that are salient to them. In his study on how Latina/e/o/x undergraduate students understand, relate to, and identify with the word "Latinx," Salinas (2020) found that most participants used "Latinx" within their school environment but not at all within their home communities. Participants felt that since the word originated in academic and activist spaces of privilege, it might seem like they were imposing an agenda on family and friends who did not have the same access to those spaces or privileges. Some participants also stated that they utilized "Latinx" at their institutions because they felt compelled or pressured to do so (Salinas, 2020). Others may find "Latinx" to be a term that excludes their racial or sociolinguistic identity. For example, the letter "x" does not exist in the Quechua language, spoken by Indigenous people of South America, nor in the Garífuna language, spoken by Afro-Indigenous people of Central America (Salinas & Lozano, 2021).

Furthermore, "Latinx" has been utilized to be inclusive of queer identities but in a way that synonymizes gender with sexuality (Contreras, 2017). This has the potential to lead to misunderstandings about gender nonconformity and sexual orientation, including the misguided assumption that all genderqueer people are inherently non-heterosexual (Vidal-Ortiz & Martínez, 2018). Interchanging gender with sexuality could result in further marginalization of people with gender identities and sexual identities that have been minoritized and oppressed. Studies have shown that the more often an individual's membership in the gender and sexuality group with which they identify is invalidated, the higher their risk of experiencing negative outcomes such as low self-esteem, anxiety and stress, and impacted health (Howansky et al., 2022).

Self-concept, and consequently self-expression, can change over time and through experience. It is understandable that the terms one uses to self-identify can change over time as well. For instance, U.S. public policy and institutionalized definitions of ethnic and racial identifiers, in addition to mainstream media usage, can impact the acceptance or rejection of identifier terms, which in turn affect the ethnic and gender identity development of individuals. Pew Research Center analysis (Lopez et al., 2023) shows that significant changes can be seen in demographic data from one Census count to the next, depending on how respondents' understanding of the terms on the survey have changed within that particular decade. It is possible that even generational identity may play a role in how, for instance, members of the Gen Z cohort choose to self-identify racio-ethnically, compared with members of the Gen X population–who were born and/or came of age during the rise of LGBT+ activism. Similarly, scholars have shown that first-generation Americans are more likely to self-identify with their national origin compared with their second-generation children who are more likely to self-identify with racial and pan-ethnic terms that have been institutionalized in the U.S. given their greater experience navigating U.S. institutions such as public schools (Santos, 2017).

Very few studies have explored the intersection of social identities, and fewer have studied the intersectionality of racial identity development, ethnic identity development, gender identity development, and sexual identity development. The limited scholarship available demonstrates that, in alignment with intersectionality theory, our social identities work in concert with each other–we see our experiences of one social identity through the combined lenses of our other social identities (Cerezo et al., 2020; Rogers et al., 2015; Veenstra, 2011). The very definition of the term "inclusive language" is that it does not exclude identities, and intentional efforts need to be made by practitioners, researchers, and affiliates of academic institutions from all fields to ensure that if and when "Latinx" is utilized, it is done so in a way that clearly defines its usage as a gender-inclusive term, as well as its meaning and significance, with input from the Latin a/e/o/x population and community.

CONCLUDING THOUGHTS

None of these terms–Hispanic, Latino, Latinx, Latine–should be considered the (in)correct pan-ethnic identifier. Instead, consideration should be taken to explicitly learn which term each individual prefers to utilize. Social workers cannot assume that their understanding of the meaning of "Latinx" is the same as that of their clients, and we cannot ascribe the term to any individual without knowing if they want to be referred to as such.

Adolescence is a critical period for identity development and is a phase when our self-concepts are flexible and impressionable. Therefore, adolescence is also a critical period where caretakers, peers, educators, and practitioners can impact our perceptions and understandings of our intersectional social identities. Research has already shown that positive identity development can lead to improved outcomes in physiological and psychological well-being which, in turn, can also lead to higher self-esteem. For ethnically minoritized groups in particular, healthy psychosocial functioning can strengthen one's sense of agency in the face of adverse experiences such as discrimination. More research is needed to better understand the implications of ascribing an ethnic identifier to over 60 million people living in the U.S. and in such a way that potentially excludes the intersectionality of their multiple identities.

It is imperative not only for social workers, but all stakeholders of all fields to understand why–and how–pan-ethnic identifiers of *Latinidad* are used and promoted. A critical self-examination of the utilization of these terms is necessary to ensure that they are being used intentionally and not simply as a performative act. In other words, "Latinx" should not be the only term you use to refer to people of the Latin American diaspora, every time you reference them; Latina(s), Latino(s), Latine(s), and other identifiers of *Latinidad* can be the more accurate and appropriate term to utilize depending on the person/people being referenced. Accordingly, I invite you to take some time to reflect on your responses to the following questions:

- Why have/do I use the word "Latinx?" Is it because I felt compelled to do so simply for the sake of political correctness?
- How am I using the word "Latinx?" Am I using it to reference all Latines or only the ones whose gender I don't know?
- When and where am I using the word "Latinx?" Am I using it in all social contexts or only in my academic/professional spaces?
- Most importantly–have I asked my Latina/e/o/x clients how they would prefer to be called?

Utilizing gender-inclusive language is not only the ethical thing to do, but is necessary–and doing so appropriately requires that we each grapple with our own intersectional and privileged identities, our roles in dismantling social injustice, and gaining a deeper understanding of the complexities of pan-ethnic identifiers for a community with immense intra-group diversity. In sum, simply using "Latinx" does not confront and eradicate the institutionalized oppressions that genderqueer people confront daily. What are you doing to challenge and address cisnormativity in your teaching, research, and/or practice?

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What can social workers do to help the growing number of people experiencing homelessness?

The view from an urban hospital Emergency Department

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I am a Licensed Clinical Social Worker in Connecticut and a graduate of Columbia University's School of Social Work. My work experience includes Yale Child Study Center and Yale University's SHARE Program. Presently I work at Yale New Haven Hospital's Emergency Service, both with adult and pediatric patients.

INSPIRATION FOR ARTICLE

As a hospital social worker for nearly ten years, I've worked with patients experiencing homelessness and was aware that solutions are sorely lacking. But it was only when I started working at the Emergency Department that I saw head-on the catastrophic outcomes of lives lived at the margins, without a safe place to stay. A few months into my new role, a patient arrived in critical condition. He presented with a high fever and was unconscious, appearing thin, soiled, wearing only boxers. The paramedic reported he was picked up from a tent encampment, and "who knew" how long he had been like this. It was jarring to see another human being in this shape. As with other patients in critical condition, I contacted the emergency contact, only to learn he had a loving family who lived out of state and had been unable to help him with severe substance use disorder. They were now distraught to hear about his condition. One of my co-workers said it best: "to someone out there, he is somebody." This case became a catalyst for me to want to learn more, and – even if in small ways - improve my practice with patients experiencing homelessness.

“Homelessness is, in a way, just the visible tip of the iceberg of problems in the country. The affordable housing crisis, poverty, racial inequities, substance and drug abuse addictions, mental health. All of them are sort of manifest when you see people living in the streets. Tackling homelessness is in fact a kind of triage, it’s just dealing with a part of these larger problems”
(Kimmelman, 2022, 0:55).

Homelessness is a growing problem nationwide. According to the U.S. Department of Housing and Urban Development (HUD), the number of people experiencing homelessness rose 12% from 2022 to 2023 (HUD Exchange, 2024b). Low vacancy rates, increased rent costs, and income inequality all comprise difficult structural factors locking people out of the housing market. Those who most harshly bear the brunt of this crisis are people with social vulnerabilities. This paper analyzes the social problem of homelessness from the perspective of an urban hospital Emergency Department (ED), Yale New Haven Hospital (YNHH) in New Haven, Connecticut. Social workers in these settings have a dual role: working directly with individuals and families to connect them with available services and resources and advocating for structural interventions that can ultimately ease this problem. Social workers are also at the forefront of combating any stigma unhoused persons face by both approaching patients experiencing homelessness with dignity and respect while educating others that this problem is not one of the individual, but is rather a consequence of multiple other social problems we have collectively failed to address.

ED social workers are consulted to help address the entire spectrum of psychosocial problems being faced by patients. Social workers are key team members in addressing cases of abuse and neglect and take primary responsibility for compliance with mandated reporting requirements. Because YNHH is a Level-1 Trauma Center, social workers also prioritize patients who arrive with full or modified traumas. Those arriving as cardiac arrests or needing urgent life-saving measures are also referred to social work. In all these cases, social workers act as liaisons to family members and provide support while also assisting with next steps. The role of a social worker in the ED also involves addressing any issue that impacts effective care or treatment of a health problem.

PREVALENCE, TERMINOLOGY, AND DEMOGRAPHICS

According to the U.S. Department of Housing and Urban Development, homelessness has steadily risen since 2017 (HUD Exchange, 2024b). Based on the 2023 nationwide point-in-time (PIT) count, 650,000 people were experiencing homelessness in the United States, and homelessness in families with children rose by 15.5% (HUD Exchange, 2024b). Past studies have found, however, that flawed methodology and varying execution may lead to undercounting the persons who are homeless through the PIT count, with the annual number of people who are homeless being 2.5 to 10.2 times greater (National Law Center on Homelessness & Poverty [NLCHP], 2017).

The PIT count is a measure mandated by HUD and seeks to count all sheltered and unsheltered people within a specific area one day per year. The most recent PIT data available for the state of Connecticut is from the January 24, 2023 count. The number of individuals found to be experiencing homelessness across Connecticut at that time was 3,015, which represented a 2.9% increase from 2022 (Advancing CT Together [ACT], 2023). According to the count, the number of persons experiencing chronic homelessness remained stable at 117 (ACT, 2023). The PIT count also found that homelessness among youth (ages 24 and younger) had increased by 7.06% (ACT, 2023). As of 2023, Connecticut's rate of homelessness was 8.1 people per 10,000, which was lower than the national rate of 18 out of 10,000 (National Alliance to End Homelessness [NAEH], 2023a).

HUD categorizes types of homelessness into four groups: literally homeless, at imminent risk of homelessness, homeless under other federal statutes, and fleeing/attempting to flee domestic violence. *Literally homeless* means having a primary nighttime residence not meant for human habitation, staying in a shelter, or a person being discharged from a facility where they remained less than 90 days and have no other residence (HUD Exchange, 2024c). *Imminent risk of homelessness* is defined as a person who will be homeless within 14 days, with no place to go or resources to secure permanent housing (HUD Exchange, 2024c.). *Homeless under other federal statutes* refers to unaccompanied youth less than 25 years of age or families with children and youth who do not otherwise qualify as literally homeless under HUD, but may qualify under other federal programs (HUD Exchange, 2024c). For example, the Department of Education defines homelessness as lacking a "fixed, regular, and adequate nighttime residence" (Parolin, 2021, p. 46), which may capture a wider number of people. Finally, *fleeing/attempting to flee domestic violence* refers to an individual or a family fleeing intimate partner violence, including dating violence, sexual assault, stalking, and other dangerous or life-threatening conditions that relate to violence and having no place to go or resources to secure permanent housing (HUD Exchange, 2024c).

HUD also has a longer definition for persons categorized as *chronically homeless*: people who have been without a residence for extended periods of time. The definition, as delineated in section 401(9) of the McKinney-Vento Assistance Act (42 U.S.C. 11360(9)) is as follows:

> Lives in a place not meant for human habitation, a safe haven, or in an emergency shelter, and has been homeless and living as described for at least 12 months or on at least 4 separate occasions in the last 3 years, as long as the combined occasions equal at least 12 months and each break in homelessness separating the occasions included at least 7 consecutive nights of not living as described (HUD Exchange, 2024b, para. 4).

People who are deemed chronically homeless qualify for specific HUD programs. However, because of the intricacy of the definition, it is often difficult for people to provide proper evidence to qualify as chronically homeless with barriers such as difficulty obtaining identification or documentation and long wait periods (Wusinich et al., 2019).

Further exploration of the demographics of homelessness makes it clear that "the hazard of experiencing homelessness is not uniformly distributed across different populations" (Willison et al., 2023, p. 1).

According to the NAEH, the marginalized groups with highest incidence of homelessness also have “extensive histories of experiencing oppression, including displacements from land and property and exclusions from housing opportunities” (2023a, para. 9). HUD data from 2022 shows that rates of homelessness are highest among Native Hawaiian or Other Pacific Islanders (121.2 out of 10,000), Black or African American (48.2 out of 10,000) and American Indian (44.9 out of 10,000) (NAEH, 2023a). Comparatively, the rate for the white population is 11.6 out of 10,000 (NAEH, 2023a). In 2020, nearly 40% of those experiencing homelessness were Black, and 23% were Latino, while they comprise only 13% and 18% of the population, respectively (Center on Budget and Policy Priorities [CBPP], 2022). These numbers are not a new trend. Homelessness data from 2007 to 2017 shows that Blacks, American Indians, and Native Hawaiians were at least twice as likely than whites to experience homelessness (Willison et al., 2023).

It is also worthwhile to explore the distinction between persons who are sheltered and unsheltered. Being unsheltered means having a primary nighttime residence that is a public or private place not meant for human habitation; for example, a city sidewalk, vehicle, an abandoned building, a park, under a bridge, a train station, or a tent encampment (NAEH, 2023a). A sheltered person is anyone who is temporarily residing at a publicly or privately operated shelter; for example, congregate shelters, transitional housing, a hotel or motel paid for by charitable organizations, or an institution such as a hospital or treatment facility. Notably, anyone who is couch-surfing, doubled up with others, or paying for their own hotel room is not considered homeless but may be considered at-risk for homelessness (HUD Exchange, 2024a).

Persons who are unsheltered often have generally poorer health and face a higher risk of premature death when compared to those who are sheltered (Richards & Kuhn, 2022). The data also shows that those from marginalized communities have higher rates of being unsheltered, as noted below. According to HUD 2022 data, Native Hawaiian or Asian Pacific Islanders, Asian Americans, and Native Americans have the highest incidence of being unsheltered – with 53%-55% of their homeless population living unsheltered (NAEH, 2023a).

People of marginalized genders also have a higher incidence of being unsheltered, based on HUD 2022 data, with 56% of transgender people who are homeless being unsheltered and 78% of homeless gender-questioning individuals being unsheltered (NAEH, 2023a). Connecticut law requires shelters to accept people based on their gender identity, regardless of sex assigned at birth. However, this law does not necessarily stymie the bias or microaggressions that people who are gender-nonconforming may experience in shelter settings. An analysis of the 2015 U.S. Transgender Survey by the Williams Institute at the UCLA School of Law found that close to 85% of transgender adults who are homeless reported not seeking shelter at a homeless facility because of concern for mistreatment (O’Neill et al., 2020).

CONTRIBUTING CAUSES TO HOMELESSNESS

What leads any one person or family to become homeless can be examined as the interplay of three types of factors: structural factors, precipitating or adverse life events, and individual vulnerabilities. Structural factors can include rental market conditions, housing policy, income inequality, and the social safety net or lack thereof. Adverse life or precipitating events may include sudden loss of income, catastrophic health problems, exposure to a natural disaster, loss of family member, divorce, or foreclosure, to name a few. Individual vulnerabilities include non-heterosexual identity, low educational attainment, unemployment, veteran status, a history of incarceration, mental health and substance use disorders (Nilsson et al., 2019), and involvement with child welfare and juvenile justice systems (NAEH, 2023b). However, while individual factors increase the risk of becoming homeless, according to Colburn and Aldern (2022), the root causes of high rates of homelessness are primarily housing market characteristics–structural forces out of the control of any one person. Simply stated by Colburn, “in places that are expensive, homelessness is high, and in places that are cheap, homelessness is low” (KingCountyTV, 2022, 5:03).

In their book *Homelessness is a Housing Problem*, Gregg Colburn and Clayton Aldern (2022) made an exhaustive study of data comparing rates of homelessness across cities and counties along with factors usually associated with homelessness. They examined poverty rates, weather, mental illness rates, substance use, and areas with generous welfare benefits. The data clearly indicated that those factors did not correlate with rates of homelessness. Colburn and Aldern (2022) noted that, in fact, the areas with the highest wealth distribution paradoxically experience the highest rates of homelessness. Conversely, a state such as West Virginia, where the opioid epidemic has hit hardest, does not have the high rates of homelessness seen elsewhere (KingCountyTV, 2022). At the same time, the vast majority of the 40 to 52 million people who experience substance use or psychiatric disorders are not homeless (Pitkin, 2022). Colburn and Aldern (2022) showed that it was ultimately rent levels and rental vacancy rates that were most associated with regional rates of homelessness. This explains why places like San Francisco and New York have such high numbers of homeless people–there are simply not enough affordable dwellings for people to inhabit. Once this housing crunch is a set condition, like a game of musical chairs, those with vulnerabilities will be more likely to end up without a spot. While it is important to consider individual comorbidities, particularly when advocating for treatment, shifting the view to structural factors is helpful because it reduces the tendency to blame the individual for the problem they are experiencing, and it helps divert attention to structural interventions that can actually make a difference (Colburn & Aldern, 2022).

When looking at structural or root causes of homelessness, it is worth examining how these factors contribute to minority communities being disproportionately affected by homelessness. The dynamics involved are complex, entrenched, and undeniable. Centuries of discrimination, from slavery to segregation, weigh on present generations. Racist policies such as neighborhood segregation and exclusion of Blacks from federally-backed mortgages led to wealth disparities between white Americans and people of color (Willison et al., 2023). These wealth disparities now "exacerbate risks of housing insecurity and homelessness for people of color due to a lack of protections, including at community and family levels, to mitigate or bounce back in cases of financial hardship" (Willison et al., 2023, p. 2). Interventions intended to help–the systems of support for homeless persons–do not help Black persons equitably (Pitkin, 2022). The disproportionate presence of the child welfare and criminal justice systems in communities of color have long-term effects and carry risk into later adulthood (Pitkin, 2022). Other factors that contribute to housing instability among communities of color include higher cost burden among renters of color and the inadequacy of housing stock to meet the needs of multigenerational families of color (Lake, 2020). Based on an analysis of yearly HUD surveys, Desmond (2023) also finds that "Black renters continue to face routine discrimination when searching for apartments" (p. 69). Considering the sum total of these facts, perhaps this is why Balasuriya et al. (2020) writes, "Regardless of mental health status, people who are homeless generally have a history marked by poverty and social disadvantage… and they are likely to belong to an ethnic minority" (p. 3).

HOMELESSNESS, MENTAL HEALTH, AND SUBSTANCE USE

As discussed earlier, there is a public perception that mental health problems or substance use disorders are a direct pathway to homelessness (Pitkin, 2022). In fact, the relationship between homelessness and mental health problems is more complex. Studies have found a bidirectional association between homelessness and mental illness (Nilsson et al., 2024). While mental illness may contribute to loss of housing or inability to remain housed (and is a vulnerability as discussed earlier), homelessness itself contributes to worsening mental health (Padgett, 2020). It follows that depression, suicidal thoughts, symptoms of post-traumatic stress disorder, and substance misuse are more prevalent among the homeless population (Substance Abuse and Mental Health Services Administration [SAMHSA], 2011). Rates of more severe mental illnesses, such as schizophrenia, are at 25%–30% among homeless persons (Padgett, 2020) and were noted to be at 26.2% of all sheltered persons in 2010 (SAMHSA, 2011).

Significantly, homeless and marginally housed individuals do appear to have a more than 50% rate of traumatic brain injury (TBI), which is much higher than the general population (Padgett, 2020). TBI can influence a person's executive function, for example increasing impulsivity and impairing working memory (Ozga et al., 2018). Deficits in executive function may complicate efforts to maintain stable housing and thus become a vulnerability.

More than one-third of people experiencing homelessness have been found to have a substance use disorder (SUD), with two-thirds of those individuals having a lifetime history of SUD (Polcin, 2016). Again, as with other health problems, "the relationship between homelessness and substance abuse is complex, with studies suggesting that substance use can be both a cause and consequence of homelessness" (Polcin, 2016, p. 2). One thing is clear: being homeless is not a condition that supports recovery. Polcin (2016) argues for housing options that offer harm reduction and built-in options for treatment.

HEALTH AND HEALTHCARE BARRIERS

People experiencing homelessness contend with a higher burden of health problems (Morris & Gordon, 2006). Canham et al. (2018) discuss *tri-morbidity*, meaning the confluence of physical health problems, mental health problems, and substance use disorders that leads to higher mortality rates. There are varied numbers describing mortality rates among people experiencing homelessness. Franco et al. (2021) report that homeless patients have twice the mortality rate of non-homeless cohorts. Meanwhile, Omerov et al. (2019) place the number much higher, describing excess mortality at eight times higher for men and twelve times higher for women, although this estimate also includes other high-risk groups, such as prisoners and sex workers.

Medical problems most heavily experienced by homeless patients include chronic pulmonary obstructive disease, arthritis, musculoskeletal disorders, seizures, hypertension, diabetes, liver diseases, tuberculosis, hepatitis C, HIV, dental problems, skin problems, and foot problems (Canham et al., 2018). People experiencing homelessness also faced twice the mortality rate from COVID-19 as compared with the general population (Gavidia, 2022).

Conditions associated with homelessness have obvious adverse effects on health and can include exposure to the elements, living in crowded conditions, exposure to violence, poor nutrition and sleep, and lack of access to bathing. Barriers to accessing healthcare, delays in seeking care, and difficulty adhering to treatment also contribute to poor health outcomes (Canham et al., 2018). Omerov et al. (2019) further describe barriers to care faced by homeless patients such as lack of health insurance, lack of identification, lack of mail or telephone service, poor transportation, and limited knowledge of where to receive resources.

Beyond these barriers, Omerov et al. (2019) found that stigma and bias can also prevent adequate provision of healthcare to patients experiencing homelessness. Based on a research review, unhelpful relations with medical providers and social care professionals were characterized by a lack of respect or empathy toward clients, judgment for appearance, patient feeling invisible, unrealistic follow-up advice, and restricting freedom or autonomy. They further highlight the problem of some healthcare professionals showing "insensitivity to ethnic disparities or the unique needs of people of color" (Omerov et al., 2019, p. 6).

On the flipside, Omerov et al. (2019) also describe the experiences of homeless patients with professionals the patients believed were supportive. Positive experiences include respectful social interactions, feeling comfortable showing vulnerability, being able to laugh together, flexibility regarding appointments, feeling listened to, providers remembering details of their lives, and when patients were given decision-making power.

EMERGENCY DEPARTMENT USE

Given the wide range of health problems, and the propensity of these problems to worsen while homeless, these patients understandably have higher utilization of the ED. Franco et al. (2021), who conducted a study focusing on the YNHH ED and the greater New Haven area, explain that people experiencing homelessness represent a disproportionate share of ED visits compared to housed cohorts. Unhoused patients have approximately three times more usage and are four times more likely to return within three days as compared to housed individuals (Franco et al., 2021). Homeless patients are also more likely to present with injuries acquired while in the community; for example, assaults, both physical and sexual (Morris & Gordon, 2006).

Franco et al. (2021) describe the ED as a “de-facto shelter and sobering center [which] serves not only as medical but also social safety net” (p. 9). In effect, the ED provides respite from conditions faced in homelessness and serves as a 24-hour drop-in center. Notwithstanding, Franco et al. (2021) highlight that this higher frequency of ED care does not translate to improved health outcomes for homeless patients, and it places a strain on an already stressed system. Franco et al. (2021) conclude that “homeless patients require social needs to be met alongside medical ones,” and that this can be best achieved through collaborations with community partners (p. 8). Social workers are uniquely positioned to create those connections.

ROLE OF SOCIAL WORK IN THE EMERGENCY DEPARTMENT

ED social workers can play a role in improving outcomes for persons who are experiencing homelessness. In Canham et al.’s (2018) article Health Supports Needed for Homeless Persons Transitioning from Hospitals, the authors provide a clear guide as to the six realms of intervention that can make the most impact. They conducted a literature review and analysis and concluded that stopping the cycle of hospital discharge and readmission of homeless patients requires attention to a full range of needs–both medical and basic needs. Canham et al. (2018) acknowledge that systems are insufficient to meet the needs of homeless patients; for example, lack of access to specialty health services, lack of affordable step-down care, and lack of rehabilitation beds. The efforts made by professionals can, at the very least, improve the probability of success. The six themes related to health support cited by Canham et al. (2018) are a respectful and understanding approach to care, conducting housing assessments, communication/coordination/navigation with outside providers, support for after-care, complex medical care, and medication management, basic needs, and transportation.

Drawing from personal experience as a social worker in the ED, the recommendations by Canham et al. are an effective guide to direct practice. As mentioned earlier, people experiencing homelessness may arrive for care to the ED having experienced stigma and bias in the past (Omerov et al., 2019). A respectful and understanding approach can counter this and helps to facilitate the development of a collaborative working relationship in which an effective housing assessment can be conducted. As delineated above, homelessness can be experienced in multiple ways, and a patient’s particular circumstances should drive specific recommendations. Obtaining nuanced information is key in determining the appropriate next step. The same can be said for assisting patients in seeking services to address mental health services or substance use treatment. Conversations that help identify possible barriers or obstacles to obtaining this care are important to avoid making unrealistic recommendations.

The YNHH ED is located in a state which has an established hotline, 211, to assist callers with housing and other needs. The hotline is the entry point for services for people and families experiencing homelessness. The process entails an initial interview in which personal data is gathered and leads to an appointment for a housing assessment by a state-contracted agency. It is essential for social workers to understand the local system of support with clarity to be able to explain it to patients.

Likewise, being familiar with community resources is imperative, as is establishing relationships with community providers and maintaining up-to-date information on service and resource availability. Finally, a warm hand-off to community healthcare providers or other agencies, when possible, may improve chances that the patient will have continuity of care.

FUTURE TRENDS

Two emerging demographic trends among the homeless population should be highlighted. First, as individuals with chronic patterns of homelessness age, they require more medical services and help with activities of daily living. While symptoms of severe mental health or substance abuse may become less acute through the lifespan, chronic health conditions progress and worsen. Communities, states, and the federal government would be wise to begin planning to address this need today by perhaps investing in permanent supportive housing units for the elderly with healthcare personnel on hand.

Second, the number of young people experiencing homelessness is also growing at alarming rates. Homeless youth may include young people who are part of families, head of households, or individuals (CBPP, 2022). Young people with involvement in the child welfare or juvenile justice systems, those who identify as LGBTQ, pregnant and parenting youth, young people with special needs, and young people of color may be at higher risk of homelessness (NAEH, 2023). Simultaneously, the current cohort of teens who are estranged from the educational system may struggle to become earners as young adults and will thus have greater vulnerability to becoming homeless. Without comprehensive prevention and early intervention efforts by communities, states, and the federal government, this trend will result in a whole new generation of people with established patterns of homelessness.

SOLUTIONS

Ending homelessness is neither out of reach nor an impossible goal. The CBPP recommends expanding housing choice vouchers, including providing universal housing vouchers to reduce hardship for all families (2022). They further recommend shoring up the social safety net. More specifically, we know that for people with chronic homelessness or those having difficulty maintaining a residence, a permanent supportive housing model works, as it provides on-site support including case management and ease of access to healthcare, mental health, and substance use disorder treatment. For those experiencing transitional homelessness, a rapid-rehousing model with a rental subsidy, even if time-limited, is effective. Partnering with developers to build affordable housing is also a critical component in easing a housing shortage. Communities and states would be wise to begin today to expand all these programs. It will require financial resources and investment like any other federal, state and local initiative.

In continuing to think about solutions to homelessness, it is crucial to hear the voices of people experiencing it as they are the primary stakeholders. A hopeful development occurred in New Haven last fall when six tiny houses were installed in the area where tent encampments had been torn down (Grace-Flood, 2023). The prefabricated units were assembled and installed by former tent encampment residents and neighborhood volunteers. While small, it is a worthwhile effort that can perhaps be scaled up in the future, and it demonstrates that creative and grass-roots solutions can play a role in ending homelessness, one person at a time.

CONCLUSION

Social workers are uniquely positioned to contribute to positive solutions to help address homelessness. Working directly with individuals to help address health, mental health, and substance use needs is important. Helping folks problem-solve to exit homelessness and maintain housing is essential. Providing guidance in navigating the complex systems set up to help is valuable. Because a social worker is one strand in a community safety net, they can be most effective when partnering and collaborating with local resources. Educating others regarding factors that contribute to homelessness is important, particularly when it comes to acknowledging system failures, housing market conditions, and entrenched inequities in our social environment. Simultaneously, maintaining a view on the broader context and advocating for solutions on the macro-level has to take precedence. This problem will only be solved when communities, states, and the federal government make meaningful investments to increase affordable housing and fortify safety nets.

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“Diagnosed with New Health”: Social Security Policy Recommendations for People With Cystic Fibrosis in Ohio Transitioning to a Longer Lifespan

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I am a 2024 graduate from the Columbia School of Social Work on the Integrated Practice and Programming track and specializing in the study of health, mental health, and disabilities. I am currently living in Columbus, Ohio, and excited to see where this field takes me next.

INSPIRATION FOR ARTICLE

My practicum is at Nationwide Children's Hospital in Columbus, Ohio, where I am a social work intern in the division of pulmonary medicine. Nationwide Children's is home to one of the highest ranked Cystic Fibrosis Centers in the country and serves around 500 people with CF in Ohio, West Virginia, and Kentucky. Through this placement, I have worked with many people of all ages who have CF, and have recognized the psychosocial impact that new, revolutionary medications have had on the lives of these individuals. I have been so inspired by the resilience and strength of those that I have worked with. As there is limited research on this topic, I hope this paper becomes part of a larger conversation on how we can support the unique experiences of people with CF.

ABSTRACT

Cystic fibrosis (CF) is a chronic, progressive, genetic, and life-limiting lung disease that impacts approximately 105,000 individuals globally, including 40,000 individuals in the United States. In 2019, a revolutionary new drug, elexacaftor/ivacaftor/tezacaftor (ETI), was approved to manage some of the major symptoms of CF and dramatically increase the lifespan of people with cystic fibrosis (pwCF). Many individuals with CF cannot work full time and require Medicaid, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and other financial assistance programs to pay for treatments and medical expenses. Yet in recent years, pwCF who are on ETI have been increasingly losing benefits. A possible explanation for this is the effectiveness of ETI in improving lung function, creating the perception that pwCF are no longer disabled by their condition. Even with this “miracle” drug, pwCF continue to experience significant complications and vulnerabilities to their physical and mental health as well as limitations on daily living and employment. The compounded vulnerabilities these individuals experience leave them without a safety net. Social Security policies for pwCF require revisions to prevent further biopsychosocial damage to this population. Two policies will be recommended: leniency in redetermination, and CF education for those who make determination decisions.

INTRODUCTION TO CYSTIC FIBROSIS CARE

“What do you do when you’ve lived your whole life diagnosed with a terminal illness and then are suddenly diagnosed with new health? For me, it was not a whimsical or magical moment.”
Luisa Palazola (BioNews Staff, 2021, para. 4).

Cystic fibrosis (CF) is a chronic, progressive, and life-limiting multisystemic genetic disorder, impacting approximately 105,000 individuals globally, including 40,000 individuals in the United States (Cystic Fibrosis Foundation [CFF], n.d.-a). Impacting the lungs, pancreas, gastrointestinal (GI) system, reproductive system, and other organs, CF presents differently from person to person but commonly causes coughing, difficulty breathing, frequent lung and sinus infections, and poor weight gain. Managing a demanding condition like CF brings significant social, physical, and psychological challenges. Socially, it is an isolating disease, as people with CF (pwCF) are not allowed to share spaces due to their susceptibility to bacterial infections and the risk of spreading infections to other pwCF. This, in turn, prevents community building through means such as in-person group therapy or sharing classes in schools. Physically, pwCF typically need to spend several hours per day managing their condition, whether through administering medications and lung therapies, preparing special diets, or attending doctors’ appointments. Mentally, this heavy treatment burden can take a psychological toll, putting pwCF at increased risk for developing a mental illness, while the required isolation creates additional psychosocial challenges (Vines et al., 2018; Bathgate et al., 2022).

In 2019, a revolutionary new drug, elexacaftor/ivacaftor/tezacaftor (ETI), which targets the genetic cause of CF, was approved by the Food and Drug Administration (FDA) under the brand name, Trikafta (U.S. Food and Drug Administration [FDA], 2019). CF is caused by mutations in a gene called the cystic fibrosis transmembrane conductance regulator

(CFTR). All people possess two copies of the CFTR gene, but for pwCF these genes are mutated, leading to dysfunctional CFTR proteins that interfere with proper cell hydration, causing the mucus covering these cells to thicken (CFF, n.d.-a). ETI combines three types of CFTR modulators to help correct these protein defects (FDA, 2019; CFF, n.d.-d).

This new medication has dramatically increased life expectancy for pwCF. Prior to the emergence of ETI and similar therapies, the projected lifespan for pwCF was approximately 37 years old (Lopez et al., 2023). If ETI is started between the ages of 12 and 17 and taken as directed by a patient with good lung health, ETI will nearly double one's projected lifespan to 82.5 years old (Lopez et al., 2023; FDA, 2019; Ladores & Polen, 2021). In addition to life expectancy, ETI also increases pwCF's ability to get pregnant and improves pulmonary function to the extent that patients are able to withdraw from lung transplant waitlists (Ladores & Polen, 2021).

An estimated 90% of pwCF have the F508del gene mutation that makes them eligible to take ETI, while around 10% of other pwCF have different gene mutations that make ETI and other modulator therapies ineffective (FDA, 2019). ETI and other modulator therapies are treatments, not cures. This means that despite these remarkable medical advances, CF remains a complex and often disabling condition requiring frequent medical checks and a high level of medication and diet adherence while continuing to pose an increased risk of lung infections and other physical and mental health issues. As a result, many individuals with CF require Medicaid, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and other financial assistance programs to maintain a stable foundation (CFF, n.d.-b; CFF, n.d.-c). Medicaid is a critical resource and can help cover ongoing costs of treatment for pwCF, including ETI's hefty price tag of more than $300,000 per year in the United States (McConnell et al., 2020; Wexler, 2023). Yet Medicaid does not cover anything beyond what is considered medical care (CFF, n.d.-b). This means SSI and SSDI are crucial supports for individuals

disabled by CF-related conditions, particularly those who remain unable to work (CFF, n.d.-c).

As a social work intern at a CF center at a hospital in Ohio, I have been exposed to the countless biopsychosocial struggles of pwCF and have had many questions about what can be done to support this population. One trend identified by patients at this hospital in the last few years has been a significant increase of pwCF on ETI losing their Social Security Administration (SSA) benefits. The multidisciplinary hospital team attributes this to ETI's effectiveness in improving lung function so much that on the surface, pwCF appear to be no longer disabled by the disease.

This trend raises concerns since, even while taking this "miracle" drug, pwCF continue to experience considerable physical and psychological challenges and vulnerabilities and are frequently still admitted to hospitals for surgeries, pulmonary exacerbations, lung infections, GI issues, and other complications. Since ETI is not a cure, adults with years of lung scarring may only see minor improvements in lung function or simply may not see further damage (K. Pasley, personal communication, March 22, 2024). For many on ETI, they are not thriving, just surviving.

While official data on rates of removal of financial benefits are limited, the increase in first-hand accounts is alarming, and CF social workers and other professionals who have observed the financial consequences of losing this support have struggled to identify resources to help pwCF (CBS News, 2019). This population has struggled with this disease for their entire lives, and because CF was previously considered a "death sentence," they were not adequately prepared for such an increase in life expectancy without financial support. Their previous prognoses meant they often did not invest in their education, personal relationships, financial investments, and careers, and as a coping strategy "often 'do things now rather then [*sic*] later' as a strategy to experience their limited and precious lifetime to the fullest" (Moola, 2019, p. 360). Now that the SSA appears to be increasingly removing benefits for those on ETI, those impacted are forced to seek employment. However, due to the nature of the disease, the demands of daily treatment, and having limited lung function, many are physically unable to attend school or work full time. The compounded vulnerabilities these individuals continue to experience make the loss of a safety net even more challenging.

Social Security policies pertaining to pwCF need to be revised to prevent further biopsychosocial damage to this population. Two case studies from Ohio will be shared to provide further insight into the struggles these individuals face as they transition to this new era with ETI. Policy recommendations will then be discussed, including leniency in SSI and SSDI redetermination and CF education for those who make determination decisions. Lastly, social work implications will be discussed, including disparities and best practices for supporting this population with the life changes that accompany ETI therapy.

CASE STUDIES FROM OHIO

One individual seen in the CF clinic at a hospital in Ohio exemplifies why vulnerable pwCF benefit from Social Security coverage even as their health improves (K. Pasley, personal communication, November 11, 2023). This individual is a 24-year-old who grew up thinking he would die young due to this disease. He struggled to get an education, never learned how to adequately take care of himself, and was unable to generally thrive. He was 22 years old when ETI became available. After ETI dramatically improved his respiratory health, he lost Social Security benefits. He has not been able to maintain a steady job as his lifelong illness prevented him from learning critical skills, and, despite his improved lung function, he has struggled to regularly attend work hours due to being sick, often taking leaves of absence. As a result, his financial situation remains unstable and he has continued to rely on the financial safety net of Social Security.

Another individual seen in the CF clinic, a 50-year-old male with CF, was able to work for years before becoming disabled by his illness. He had never experienced any interruptions to receiving SSDI benefits until ETI became available. He was the first person in this CF clinic to raise concerns about what might happen to his SSDI if he became healthier when he took ETI. At 50 years old, he was accustomed to his quality of life with SSDI and was not interested in trying to re-enter the workforce due to his age and health. He said that he would even choose to stay off of ETI in order to keep his benefits.

These stories have become increasingly common. In 2019, an attorney who runs the Cystic Fibrosis Legal Hotline noted,

> We’ve seen a five-times increase in the number of people with cystic fibrosis that have been reviewed in the past 18 months. And we think that Social Security is targeting young people with chronic illness in an effort to reduce the number of people getting benefits (CBS News, 2019, 2:45).

Given this pattern, many pwCF are understandably concerned about choosing between their health, their job, and Social Security benefits.

RATIONALE FOR ACTION

BENEFITS OF SOCIAL SECURITY AS A SAFETY NET

Financial benefits, including SSI and SSDI, are an important lifeline for pwCF. SSI redetermination, which evaluates financial resources and living arrangements, occurs every 1 to 6 years, and Continuing Disability Review (CDR), which evaluates the medical condition of SSI and SSDI recipients, occurs every 1 to 3 years (Social Security Administration [SSA], 2024a; SSA, 2024b; SSA, n.d.-c). If one has a medical condition that is not expected to improve, such as CF, SSDI redetermination will occur every five to seven years, though usually seven years for pwCF (SSA, 2024b; CFF, n.d.-c). Redetermination considers whether one’s health has improved over 12 months; financial benefits are rescinded if one’s health has improved to a point where one can work (CFF, n.d.-c).

The SSA also discontinues benefits if someone earns more than $1,550 per month (SSA, 2024c). If a person with CF earns more than the maximum limit, even if their health is still precarious, they lose benefits, and if their illness later prevents them from working, they become financially vulnerable. A social and financial safety net is therefore vital for improving employment and housing stability, maintaining continuity of health care, and avoiding added financial stress (Crane et al., 2019). SSI and SSDI programs provide this much-needed safety net while the loss of benefits puts an already vulnerable population at even greater risk.

MENTAL HEALTH CONCERNS FOR PWCF TRANSITIONING TO A LONGER LIFE EXPECTANCY

A number of studies have found ETI to impact mental health and social functioning in pwCF in complicated and even paradoxical ways. Several studies found, for example, that improved pulmonary health was correlated with improved mental health (Hjelm et al., 2023). However, some studies looking at the effects of ETI found that, while the medication improved physical symptoms, ETI was correlated with worsening mental health symptoms, sleep issues, and increased rates of changing or initiating psychiatric medication (Zhang et al., 2022; Bathgate et al., 2022). Other studies found paradoxical results on ETI's impact on mental health (McCoy et al., 2023; Piehler et al., 2023; Zhang et al., 2022), and some found no statistically significant improvements in anxiety scores, depression scores, emotional functioning, or perception of body image (Zhang et al., 2022; Finlay et al., 2021).

One explanation for this lack of improvement or worsening of mental health symptoms may be the sudden change in longevity and quality of life. Prior to these new modulator therapies, CF was known as a "child killer," and many pwCF were told from a young age they would have a limited lifespan (Kempner, 2022). One individual reflected, "I was just living day-to-day instead of planning for the future," (Kempner, 2022, p.3) while another stated she had "never pictured a future for herself beyond the next five years" (Kempner, 2022, p.1). As a result, many pwCF who grew up without these new modulators have not invested in their life, health, education, or careers. They may not have created long-term goals nor developed independence or coping skills. This is exacerbated by the fact that many PwCF experience high rates of comorbid mental health diagnoses, including depression, anxiety, obsessive-compulsive disorder (OCD), medical traumatic stress (MTS), attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), oppositional defiant disorder (ODD), and disordered eating (Bathgate et al., 2022; Lord et al., 2022; Guta et al., 2021). Having grown up with a terminal illness mindset, many are now struggling to establish long-term goals as they adjust to a sudden and unexpected increase in life expectancy. Additionally, the risk of early mortality did little to motivate pwCF to establish positive health habits such as routines around eating, sleeping, and CF medical care.

This adjustment is also compounded by the fact that, even with ETI, PwCF often have difficulty completing instrumental activities of daily living (IADLs), which include managing medications, money, and transportation. This makes full-time work challenging, leading to lower employment rates and, consequently, lower rates of employment-based insurance (Callahan & Cooper, 2007). PwCF who do work often end up needing to take long leaves of absence due to susceptibility to illness, CF exacerbations, and hospitalizations. As a result, they rely on Social Security benefits to help cover living and medical expenses. A 2019 study on the experiences of Ohioans with co-occurring chronic health conditions and mental health impairments found many experienced financial hardships such as unemployment and/or financial instability and, in turn, had difficulties paying for food, rent, and other necessities (Crane et al., 2019).

According to one individual with CF who started ETI as a young adult, "to fathom what life would look like with stable health was incomprehensible to someone who never had that" (BioNews Staff, 2021, para 3). One study found that an individual who began ETI "encountered unanticipated internal turmoil" due to this change in life expectancy and no longer being seriously chronically ill (Ladores and Polen, 2021, p. 2). This individual elaborated that this transition period caused them anxiety as they thought that ETI would stop working: "I'm so nervous because I feel so good and I’m not used to living this way, and I’m so afraid I’m gonna lose it” (Ladores and Polen, 2021, p. 3).

The Cystic Fibrosis Foundation recommends that pwCF ages 6 and older be seen by an accredited CF clinic at least 4 times per year (CFF, n.d.-e). There are more than 130 accredited CF clinics throughout the United States, each with a multidisciplinary team of doctors, nurses, nutritionists, respiratory therapists, social workers, and psychologists to provide comprehensive care for CF patients. These appointments require patience through a lengthy process of medical tests, scans, blood tests, and pulmonary function tests (Finlay et al., 2021). Social workers on these teams play an important role in identifying psychosocial and transitional needs of pwCF, meeting with patients yearly to conduct psychosocial reviews and assist with resource navigation and support (Finlay et al., 2021). Now, with these new modulator therapies, social workers are faced with the additional challenge of supporting a CF population as they adjust to the prospect of a longer life than they ever anticipated.

PROPOSED POLICY OPTIONS

To improve the livelihoods of pwCF, two policies are proposed in the state of Ohio which could be adapted across the country based on each state’s specific SSA policies. The first is a higher level of leniency when redetermining eligibility for social security (SSI/SSDI). The second is a CF-specific training for consultative examination (CE) providers who complete SSDI evaluations and redeterminations. Currently, SSI/SSDI recipients who disagree with a reconsideration determination can request a hearing to appeal the decision (SSA, n.d.-a). However, this puts an undue burden on pwCF who may be physically unable to file the appeal or attend the hearing due to their condition and struggles with ADLs.

POLICY #1 - LENIENCY

A standard that allows for more leniency would help protect this vulnerable population from losing SSI or SSDI benefits simply because they have been more physically healthy since beginning ETI or other modulators. As seen in research studies, improved physical health when taking a modulator does not necessarily mean one’s mental health or ability to work will improve (McCoy et al., 2023; Bathgate et al., 2022). As this population transitions to having longer lives, a financial safety net would alleviate stress by providing stable resources to be used for basic necessities.

To implement this, the SSA would alter the qualifying definitions of “severity” and “frequency” of CF symptoms to make the removal of benefits a more medically-informed and thorough process. This change would occur in the SSA’s evaluation manual at the state and local SSA offices in Ohio. The SSA does not publicly release eligibility criteria and only provides a “Listing of Impairments,” which broadly mentions that the SSA will consider past work experience, severity of medical conditions, age, education, and work skills (SSA, n.d.-a). Due to this ambiguity in criteria, approval varies by each CE evaluator. To improve this system, eligibility requirements could be amended to include a section for pwCF that takes into account their age when beginning a modulator therapy, long-term goal planning, pulmonary function test levels, and other relevant medical complications. These factors would provide a more comprehensive picture of one’s health and how they are coping with the transition to taking a modulator and having an extended lifespan. When considering job history, the criteria could be changed from “ability/inability” to work to “stability/instability” in work. This subtle yet significant change in language would expand eligibility to include those who experience leaves of absence due to CF-related medical issues. This more holistic framing better addresses the complexity of this disease and the careful management it requires.

POLICY #2 - TRAINING

In each state, disability claims are reviewed by CE providers, made up of physicians, psychologists, and other health professionals recruited by the SSA's professional relations officers (SSA, n.d.-b). Although these providers undergo extensive training, they are not experts in every disease and its respective challenges. Without training in CF specifically, they are unlikely to recognize that, although on paper the health improvements from ETI therapy may give the impression that someone with CF can work full time, the mental and physical effects of their illness often remain debilitating. A second policy recommendation, therefore, is a one-time CF-specific training for CE providers to help them understand the nuances of this complex, lifelong disease and how important SSDI is for someone trying to manage it.

To implement this second recommendation, a committee from the Cystic Fibrosis Foundation (CFF) would select medical professionals in Ohio to provide training to the CE providers who process SSDI determinations and redeterminations. These one-time training sessions would be an hour long to remain cost-effective and would include subject matter experts (SMEs) who work with pwCF. CE providers who receive this training would be certified in CF redetermination and be primarily responsible for reviewing CF cases. The end goal would be to help evaluators make more informed decisions. The CFF would work with the SSA to continually monitor and review SSDI cases to ensure that pwCF are receiving proper support.

Allowing the most vulnerable pwCF to remain on Social Security would reduce costly hospitalizations and additional medical care. Someone who has their SSI/SSDI revoked will be forced to work more, putting them at increased risk of stress and infection. The safety net of Social Security allows them to work as much as they can within their own limitations, helping to reduce that risk.

SOCIAL WORK IMPLICATIONS

Social workers have continually played an important role in providing support to pwCF, and now with ETI, they must rise to the additional challenge of helping this population navigate the adjustment to a longer lifespan. One important way social workers can do this is by providing career counseling to pwCF who have a newly extended life expectancy and did not anticipate having to plan for a long-term career.

Social workers follow the guiding principles of competence, challenging social injustice, and promoting the dignity and worth of all people as they work to address social problems such as health inequity (National Association of Social Workers, 2021). As such, there is an important role for them to play in confronting racial and economic disparities among pwCF as treatments and technology improve. Because of the health disparities caused by structural racism, people of color with CF experience: overall lower lung function, nearly doubled rates of death before the age of 18, delayed diagnosis, higher rates of pulmonary infections, limited access to care, lower access to lung transplants, lower rates of health literacy, and are less likely to be represented in clinical research (Zampoli, 2023; CFF, 2020).

In terms of economic disparities, many low-income countries have less access to modulator therapies; in fact, only an estimated 12% of pwCF globally have access to CFTR modulators, like ETI (Guo et al., 2022, as cited in Zampoli, 2023). Low to middle-income countries in Central America, South America, the Middle East, South Asia, and Southern Africa have not been prioritized for negotiating contracts for accessing ETI (Zampoli, 2023).

While the U.S. does have contracts for manufacturing and distributing ETI, the U.S. government does not negotiate prices with drug manufacturers, leading to exorbitant costs (Martins, 2020; Ginsburg & Lieberman, 2021). The yearly $300,000 list price for ETI is not feasible for the vast majority, leaving pwCF to rely on crucial government-funded insurance or employment-based insurance to afford this life-saving treatment. In addition, the multidisciplinary team at the CF center where I intern has noticed that several insurances are no longer covering ETI, creating an even greater need for these cost-assistance programs.

Social workers must work to lessen these disparities by centering the experiences of disproportionately impacted populations, providing education to care teams, and advocating for healthcare equity.

Finally, it is important for social workers to continue studying the unique psychosocial needs of this population. The current best measure of psychosocial functioning for pwCF is the Cystic Fibrosis Questionnaire-Revised (CFQ-R), which includes assessment questions for physical health as well as social-emotional health. Yet this does not include questions on the effects of taking ETI. Social workers can advocate for questions on the impacts of this transition to ETI to be included in the assessment, which should then be used in clinical trials for any new CFTR modulator therapies. Accounting for these psychosocial factors can provide a more comprehensive picture of how the whole person is affected, moving beyond a narrow physiological perspective. Lastly, social workers should make sure to facilitate transparent and sensitive conversations with pwCF about potential and unanticipated impacts these life-altering medications may have (Ladores and Polen, 2021).

CONCLUSION

There are many unknowns about the quality of life for young people with CF who will grow up with these new medications. It is hoped that they will adjust well, need fewer safety nets, and plan and achieve long-term goals. However, it is clear that the current CF cohort who are suddenly facing a longer lifespan will need additional support. Social Security, including SSI and SSDI, has long provided a stable foundation for these individuals and should not be prematurely taken away. Advocates, such as social workers, should appeal to the SSA to be more lenient in redetermining eligibility and promote and provide CF-specific training to the CE providers who are assessing these cases. If this vulnerable population continues to lose benefits, it will have detrimental impacts on their physical and mental health and their overall quality of life. Because the successful increase in longevity from ETI treatment had the unintended consequence of creating new mental health challenges, the impacts of the stressors, real-life complications, and financial burdens associated with this drug should be studied further. Additionally, more research should be prioritized to understand racial and economic disparities of access to care for pwCF. While ETI has been revolutionary in improving the lives of people with cystic fibrosis, more work at the policy level must be done to show these individuals that their health and success matters.

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Exploring Redevelopment and Police Presence in Bushwick, Brooklyn, Using Photovoice Methodology

AYANA COLVIN

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During my twenties, I worked as an educator and gained valuable insights that prepared me for a career in social work. After two empowering years in Columbia's MSW program with a significant emphasis on community-focused, evidence-based interventions, I am thrilled to begin my studies toward my Ph.D. in Social Policy and Practice at the University of Pennsylvania this fall.

INSPIRATION FOR ARTICLE

I have lived in the Bushwick community for five years, and during this time, I have witnessed several changes. The chance to regain some of the power within an ever-changing process has inspired me to write this paper. I use the photovoice methodology to integrate images into the narrative and highlight the intersections and real consequences of redevelopment and policing in my neighborhood. The paper was written within a year, and the challenges posed by the changes within the city, such as budget cuts and fluctuations in the number of police, were constant. I hope that readers can understand the impact of gentrification and the significance of community through this piece.

ABSTRACT

The relationship between redevelopment and police presence is demonstrated in many neighborhoods by the influx of new residents from suburban or rural areas and shifts in police response. As property values increase, police may prioritize order maintenance policing, also known as "broken windows" policing (Beck, 2020, p.247). This is disproportionately felt by Black and Brown residents who often suffer the consequences of rising costs, displacement, increased surveillance, and police presence. This paper explores the relationship between urban redevelopment and policing in one of the most popular neighborhoods in the borough of Brooklyn–Bushwick. As a social work researcher of color, I want to share the narratives that often go overlooked. I felt secure and empowered to conduct research and report my findings as a community member who is seeking to support and collaborate with my community. Photovoice allows me to do just this by highlighting the daily realities in my neighborhood. However, having more voices from long-term community members is imperative and will be essential in further exploration of this topic.

Keywords: gentrification, redevelopment, policing, police presence, Bushwick, Brooklyn, New York City, photovoice, etc.

PART I: RESEARCH QUESTION

BACKGROUND

After years of protests against police brutality and what critics called a racial reckoning in the summer of 2020 (Payne, 2021), the urgency to center racial justice, community, and police relations has shifted in the past four years. Before taking office, current New York City Mayor Eric Adams campaigned heavily on a tough-on-crime platform that emphasized prosecuting low-level offenses and reducing gun violence by pledging to spend up to $5 billion on the New York City Police Department (NYPD) (Goldenberg & Anuta, 2022). New York City has recently announced budget cuts that will affect the funding of important community services. While the NYPD will not face any budget cuts in 2024, New Yorkers will have to adjust to significant reductions in services such as library services, school summer programs, and universal pre-kindergarten (Cramer, 2024).

The NYPD has increased its presence in all five boroughs, especially in areas with Black and Brown populations (Morales & Nickeas, 2022). According to the NYPD's end-of-year citywide crime statistics, the overall decline in crime can be attributed to their policing strategies, including deploying more officers in the neighborhoods deemed most needed (2024). One of the neighborhoods where I have felt an increase in police presence is Bushwick. As per the NYC Planning (2018) publication, Bushwick's growing population was about 121,000. I have been residing in Bushwick since the summer of 2019; however, the current heavy police presence in the area under the Adams administration has changed the way many of us, including myself as a Black woman, navigate our neighborhood.

INFLUENCE OF REDEVELOPMENT

Bushwick has a diverse history. It was originally a Dutch settlement in the 17th century; later, through an influx of European immigrants around the turn of the 20th century, it became known for its small family homes and factories (Valli, 2015). The neighborhood significantly contributed to the brewery industry but never fully recovered after the prohibition era (Saraniero, 2022). The Great Migration resulted in the influx of Black people from southern states, Mexicans, and Puerto Ricans moving to northern cities, including Bushwick. This caused many white working-class families to leave the neighborhood (Valli, 2015). Despite becoming desolate to some, the neighborhood remained a significant residence for Black and Brown families and small business owners. During the early 2000s, The Bushwick Initiative was introduced to enhance the quality of life and promote economic growth within the neighborhood (City of New York, 2006). These initiatives encouraged several new businesses, and redevelopments were established. As of 2019, the white population has more than doubled, while that of Latinos has shrunk from 70% to 54% (Murphy, 2019). This research aims to find an answer to the question; to what extent does community policing influence redevelopment?

Most scholarship on redevelopment explores the process of gentrification as a response to public investments in fostering environmental sustainability. Gentrification reinforces the dominant methods of creating physical space while neglecting the disempowered ones. In areas undergoing gentrification, gentrifiers and developers exercise their power to shape the environment while economically and socially vulnerable groups have limited access to space production capabilities (Stabrowski, 2014). Studies concern the growth of new residents in urban areas from more suburban or rural areas, arguing the link between redevelopment and police presence in low-income neighborhoods intensifies during these periods (Beck, 2020). These changes make lower-income neighborhoods more desirable for inhabitants who previously lived outside of urban areas (Harris et al., 2020). The research shows that criminalization disproportionately affects Black and Brown communities, often leading to the displacement of communities of color due to systemic inequalities (Beck, 2020; Fayyad, 2017; Harris et al., 2020). Social dynamics and expectations undergo a shift when higher-income residents move into low-income neighborhoods, which can lead to long-term residents being targeted by the criminal justice system for minor offenses deemed "quality of life" crimes (Fayyad, 2017, para.7).

PART II: METHODS

This study was conducted independently through photovoice, a qualitative research method. The research was conducted in my neighborhood, which gave me a better understanding of the photos selected. I am familiar with the areas where the police are usually present and have witnessed people recycle cans at local stores. I have personally visited the locations that represent the tension and unity within the community. Photovoice captures images that portray a research topic's realities. This methodology was chosen because it emphasizes visual aspects over written words, uses photography for knowledge development, and is a powerful tool for critiquing law enforcement in a safe and accessible way (Evans-Agnew & Rosemberg, 2016). It is a strategy for advocacy and can assist in raising awareness of community needs and showcasing the structural barriers imposed on achieving those needs. Over three days in March of 2023, I photographed everyday life and its intersections with signs of redevelopment and police presence in the neighborhood of Bushwick in Brooklyn, New York. The photographs were analyzed in conjunction with scholarly research. As a woman of color living in the neighborhood, the images I captured showcase the impact of redevelopment and policing in my community.

More than seven photos were taken, but the ones included in this study highlight the topic of policing and redevelopment. There was a significant police presence on the three days the photos were taken. To grasp a better understanding of the information obtained from the captured images, I searched for supporting materials, academic articles, and research studies using relevant keywords like "redevelopment and policing," "gentrification and policing," "displacement," and "Bushwick."

Although the images in this paper were taken individually, photovoice can also be done collaboratively with colleagues and members of communities. This allows more people to participate in research meaningfully and can lead to advancements in areas that may have remained hidden from the direct experience of readers. By incorporating participant voices, themes that reflect a wider range of perspectives can be developed (Evans-Agnew et al., 2016). Photography is a quick process that allows images to be captured for research purposes. This approach also ensures safety when the research subject is unpredictable. As a Black woman who moved from low-income to the fringes of the middle class as an adult, I have always been cautious of law enforcement, recognizing the implications of their presence and the challenges of navigating it. This caution has only increased as my research aims to hold our current legal systems accountable by documenting what is truly happening and focusing on individuals and communities that may be overlooked. This is especially important during times of redevelopment and increased policing, when communities may be subject to displacement and over-surveillance without any say in the matter. Through photovoice, I can support my community without risking getting too close to or aggravating law enforcement.

PART III: NARRATIVE OF PHOTOS

During the mornings of March 1-4, 2023, I walked around the Bushwick neighborhood to explore the impact of policing and redevelopment in the area. I planned to capture photos showcasing police tactics such as patrolling the neighborhood streets and subways. Additionally, I aimed to document examples of redevelopment and how it has affected the historically Black and Brown communities. I walked between subway stops on the L train line from Dekalb Ave. to Jefferson St. and captured numerous examples of policing, redevelopment, and community impact. The following best represents my findings.

POLICING IN THE COMMUNITY

Three images were selected to depict the current police presence in the Bushwick community. Figure 1, taken on the morning of March 1, 2023, shows two officers standing beside their squad car. Graffiti, a common sight in the neighborhood, can be seen in the background. Apart from a delivery man, no one else is on the street. It is common for men to spend time socializing by listening to music, smoking weed, and drinking, especially during warmer weather. Although their group may have evolved, they have always been present. Since Figure 1 was taken close to where I live, I better understand what their presence means.

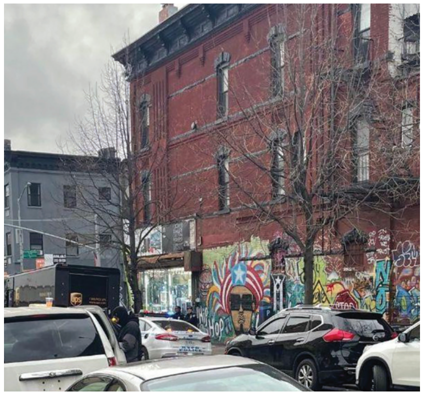

Figure 1. Cops on corner.

On this day, there was no sign of these men or anyone else on the street corner, raising the question of where they had gone. Studies have shown that as more white and middle-class people move into a neighborhood, the level of policing tends to increase (Harris et al., 2020).

In a recent article by Brenden Beck (2020), the impact of police presence on low-level arrests in gentrifying neighborhoods is explored. Beck highlights the correlation between rising housing costs and increased police spending, particularly in terms of order maintenance policing, which concerns maintaining social order and the monitoring of minor offenses.

Figure 2 regards the police presence in the community, which was captured near subway stations within walking distance. I have noticed that most people use the train stations during weekday mornings to commute to work or school. I spotted two police cars parked near the entrances, which may result from the current city administration's efforts

Figure 2. Cops at subway.

to crack down on lower-level crimes such as fare evasion.

Being a woman of color with my own experiences of law enforcement, I maintained a safe distance while capturing these photos. It was unclear whether the officers were in the car or inside the station. Being able to document such an apparent police presence during commute hours is concerning given that their presence results in the absence of others or induces stress if one cannot pay the current $2.90 fare for a subway ride. Figure 3 depicts the police presence in a Bushwick community that is prominent and appears to focus more on minor offenses, which will have a disproportionate impact on the lives of the Black and Brown residents.

Figure 3. Additional cops at subway.

REDEVELOPMENT IN THE COMMUNITY

The community is connected to Manhattan via four different subway lines, making it an ideal location for development. By the time the 2007 recession hit, redevelopment was underway and continued as the vulnerable conditions that followed the recession allowed many developers to take advantage of the situation (Parés et al., 2017). The change in the community continues rapidly, and more local businesses are closing their doors due to rising costs, further accelerating the transformation of the community. While walking home, I came across Figure 4, an infrastructure with development for sale sign, nestled between the Jefferson St. and Dekalb Ave. L train stops. Seeing signs of redevelopment in my neighborhood makes me reflect on my positionality, as I belong to a demographic that is privileged in terms of economic status but underrepresented in terms of ethnicity.

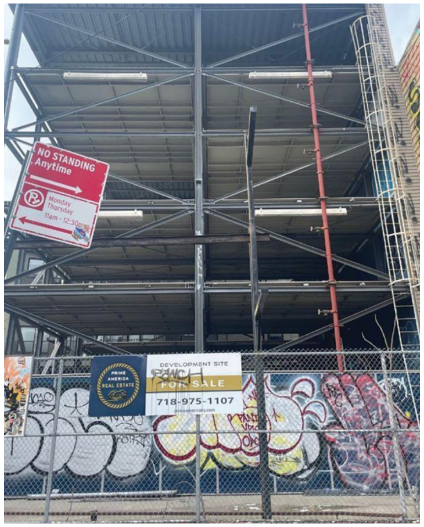

Figure 4. Redevelopment.

My economic status grants me access to established businesses that are owned and run by the community, as well as new establishments. However, community members who look like me but are not as economically privileged may not have the same access.

Figure 4 could represent the beginning of many things for the Bushwick community, such as a new bar or business. However, there is reason to question the intentionality when new infrastructures appear, as Figure 4 illustrates. “In what Wilson (2018) terms the ‘racial development machine’, gentrification in once low-income communities of color become an intentional strategy to create capital accumulation as low-value properties are replaced by infrastructure valued by white newcomers” (Harris et al., 2020, p. 3).

The location of the building situated between two patrolled stations raises the question of whether there are any underlying reasons or advantages for those who support the presence of law enforcement beyond addressing low-level crimes. Only time will reveal the true nature of this new infrastructure; however, the concerns and questions that arise within communities like Bushwick represent the tension that gentrification presents and its links to police presence.

IMPACT ON COMMUNITY

ECONOMIC EFFECTS

New spaces may not be inclusive to people of color in gentrification. It is incumbent upon people of color to prove their credibility and justify their use of these new spaces. Figures 4, 5, and 6 showcase the Bushwick community and illustrate the impact of redevelopment in different ways.

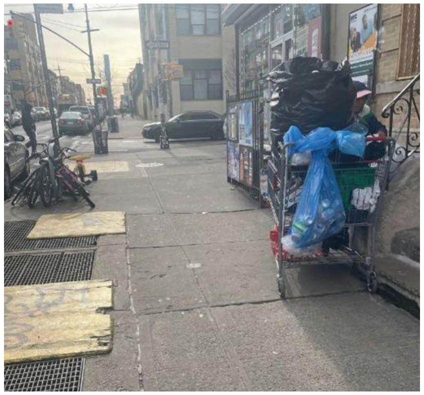

Figure 5. Woman recycling.

Figure 5 depicts a woman bundled up for the cold morning weather and placing recyclable cans and bottles in plastic bags. A large shopping cart, which had come from a nearby grocery store, accompanied her. There are a few places in the neighborhood where one can exchange recyclables for money. What caught my attention the most about Figure 5 was the size of the bags and the significant number of recyclables she had gathered. Juxtaposed with myself as a fellow community member, the quality of life also comes into question. It again brings up how positionality plays a role in what is expected of us to navigate within our neighborhood. Questions came to mind such as how long this woman had to work to collect as much as she had and how much she would be paid for her labor. As the cost of living continues to rise, the compensation for the number of cans collected in the reverse vending machine should shift to match a shifting economy. The current budget cuts are having a noticeable impact on city agencies which need help to provide essential benefits and services to New Yorkers at historically high levels (Honan, 2023). This will affect everyone, but the extent of the impact may vary depending on individual circumstances.

INCREASE IN POLICING

Figure 6 shows a smoke and convenience shop, which has become a familiar sight across the city since the legalization of recreational marijuana in 2021. It is located on the same side of the street as the development site that is for sale. The shop faces a subway entrance that is regularly patrolled by law enforcement. The presence of police and ongoing redevelopment activities have no end in sight.

Figure 6. Smoke shop.

An immigrant man from India owns this convenience shop. He was able to employ a recent immigrant as a store clerk. However, the store has faced numerous challenges from law enforcement since its inception. Such attention can be detrimental to smaller businesses like this one which may lack the resources to recover from financial losses and the potential for increased surveillance. As Eric Adams enters another year as mayor, he remains focused on establishing robust policing (Cramer & Mays, 2023). Figure 6 symbolizes his commitment to this promise. It highlights the impact of these changes on primarily Black and Brown neighborhoods, including their businesses.

SOLIDARITY

During my walk, I came across the contents of Figure 7, which caught my attention. The scene depicted a painting, Our Lady of Guadalupe (unknown, n.d), enclosed by candles, plants, and debris. Although Figure 7 does not relate directly to redevelopment or policing, it reflects the community's solidarity amidst the transformation.

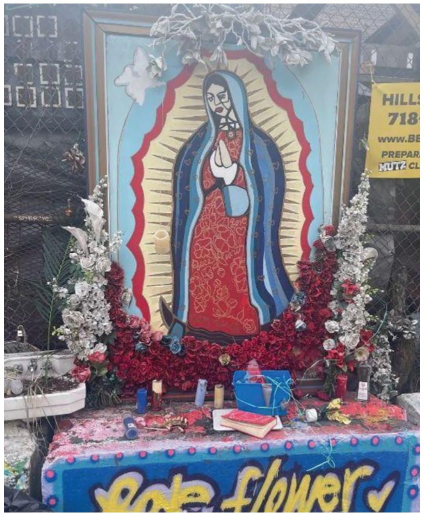

Figure 7. Community art (Source: Unknown, n.d.).

"Our Lady of Guadalupe" is a significant icon in Mexican culture (Janzen, 2020). It can be seen throughout the neighborhood as artwork in store windows or printed on candles in bodegas. When I see this symbol, I see the people in my community. The painting was placed outside the Bushwick flea market and has been there for quite some time. The flea market is only open on certain days of the week and is home to many plant shops, record collections, antiques, and vintage finds. The flea market is one of the few places in the neighborhood where you may see people of all demographics existing in the same space as people who work and sell at the flea market are from the community. "Our Lady Guadalupe" is ubiquitous within the neighborhood. The artwork stood out as a symbol of different cultures and an appreciation of those who have historically been here.

PART IV: DISCUSSION

By showcasing the Bushwick community, I aim to encourage conversations among those who find themselves at the intersection of representation within our communities. In various boroughs of New York City, you may encounter people who live their lives differently than you, and that is a chance to examine what privileges our social positions offer us. The photographs portray individuals from the community who may be negatively impacted by increased police presence and gentrification of their neighborhood.

The community of Bushwick in Brooklyn has undergone multiple restructurings over time, and this article aims to shed light on the effects of redevelopment and policing in the area within the context of the broader changes taking place in New York City. The photovoice methodology provided me with a better understanding of the context of the images as the photos were taken in my neighborhood. The redevelopment of an area can have lasting impacts on the community and demographic composition. Scholarly research has found a link between rising housing costs and increased policing spending, particularly order maintenance policing, which focuses on maintaining social order and monitoring minor offenses (Beck, 2020). Community members congregating outside may feel uncomfortable due to loitering interpretations and economic pressure from rising metro costs as aspects of daily life in the community are scrutinized more closely. Communities often undergo changes which may result in individuals being marginalized and neglected, and there are opportunities to consider the privileges our social positions afford us, learn about our communities' history, and show solidarity with them in various boroughs of New York City.

PART V: LIMITATIONS

While this research method allows for an extended investigation beyond the location of a photo, which in turn provides more time for reflection and a thorough interpretation of the research data, some things could be improved by this methodology. One significant limitation is the risk that my own bias as the photographer and researcher affects how the data is collected and interpreted. Therefore, there is a need to expand this methodology and incorporate the voices of the community to achieve a more comprehensive approach.

I conducted my research in my neighborhood, which gave me a better understanding of the photos. I am familiar with the areas where the police are usually present and have witnessed people recycle cans at local stores. I have personally visited the locations that represent the tension and unity within the community. However, if the photographs are not analyzed in conjunction with scholarly research, they may not hold any significance. My insights might have differed if I had chosen to conduct research in a neighboring area. Using this methodology challenged my positionality within Bushwick, shifting from neighbor to voyeur. Understanding one's social location and remaining cognizant throughout the process is crucial to avoid skewing the research. To enhance the understanding of the paper, it would be beneficial to involve long-term community members in the research process.

PART VI: CONCLUSION

This research sheds light on the relationship between redevelopment and policing in the growing neighborhood of Bushwick, Brooklyn. Under current Mayor Adams, there has been an increase in officers on foot as part of his push to decrease crime; however, daily experiences are left out when understanding what this looks like on the ground. Many scholars and researchers have found that police behavior tends to change as the demographics of a community change (Beck, 2020; Fayyad, 2017; Harris et al., 2020). Additionally, much of the focus of police work is on order maintenance policing, which perpetuates harmful and inaccurate narratives about Black and Brown community members in Bushwick. Photovoice aims to promote advocacy through images to better understand a community's daily experiences. The selection of images showcased various aspects of policing, such as preventing loitering and fare evasion as well as signs of redevelopment and daily life experiences of community members. By observing these images, we can gain insight into the effects of increased policing on the area.

By capturing and sharing visual representations of communities around us, people can effectively humanize issues and convey the need for policies that are truly inclusive and considerate of citizen needs. As a researcher using the photovoice methodology, I was aware of my social identity and privileges and how they could affect the results and interpretations of the study. Social work researchers like me must be mindful of our positionality when employing this methodology as photovoice can help document and advocate for overlooked individuals and communities, holding our legal systems accountable. Including a participatory component for long-term community members would further enrich the paper's insights. Ultimately, the paper emphasizes the potential of the photovoice method to generate critical knowledge so that the experiences of those often ignored can be heard.

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Alcohol and Substance Use Among Different Subgroups/Ethnicities of East Asian American Youth in the United States

ADELA JANSEN

ADELA JANSEN

I'm a proud Southeast Asian, born and bred in Indonesia. Before pursuing a Master's in Social Work at Columbia, I served as the youngest policy analyst in the Governor's Delivery Unit of Jakarta, the capital of Indonesia. My research interests are mainly in social and psychosocial determinants of health and empowerment of vulnerable communities.

INSPIRATION FOR ARTICLE

After moving from the other side of the globe to the U.S., I realized I am viewed just as 'Asian' here. It was as if all my cultural experiences and diverse ethnic backgrounds were deliberately ignored. After I started talking to other BIPOC folks who are non-citizens, immigrants, or first-generation immigrants, I found that many feel the same as I did. Eventually, I learned about different ethnicities that fall under the Asian, Latinx, and Black umbrella terms and how different they are. For instance, it is rare to find an Indonesian American to drink beyond their capacity due to the extremely conservative culture in Indonesia. On the other hand, Korean Americans are likelier to drink because it is part of their culture in Korea. This was basic knowledge for myself and many around me. Hence, when finding that data collection in the U.S. disregards, I instinctively knew that many ethnic groups are currently overlooked, but also ironically very much acknowledged though only as a monolithic group. This inspired me to look into disparities in social and health issues impacting different ethnicities under the same racial umbrella.

ABSTRACT

This reading challenges the prevailing Model Minority Myth perspective which influences the examination of substance use patterns among different subgroups of East Asian American (EAA) youth. A disaggregated analysis of existing literature reveals significant variations in substance use across EAA subgroups. This article explores influencing factors such as acculturation, cultural norms, and peer dynamics, emphasizing distinctions between Chinese Americans, Taiwanese Americans, Korean Americans, and Japanese Americans. Several EAA subgroups show a higher prevalence of cigarette or alcohol use than their white counterparts, a finding normally hidden by the aggregation of Asian American data. These unrealized differences prompt a call for tailored and culturally appropriate treatment approaches. Data shows EAA youth are more likely to not seek treatment or to drop out after beginning treatment (Wang & Kim, 2010 as cited in Ong, 2023). Understanding the typical family dynamics as well as the discrimination faced by EAA communities, including cultural stigma and culture-specific syndromes, plays a crucial role in improving treatment adherence. Additionally, studies of treatment preferences show that implementing family-based programs, outreach efforts, and involving culturally attuned treatment providers is crucial to actively address the unique needs of youth of different EAA subgroups (Lee et al., 2004).

Keywords: substance use, treatment approach, culturally appropriate care, East Asian American, model minority

Asian Americans (AA) are the fastest-growing minority group in the United States (Budiman & Ruiz, 2021). Often referred to as the “model minority,” the AA community is perceived as a monolithic group that is successful and stays out of trouble. The Model Minority Myth has created distortions and misperceptions about the actual struggles of many Asian Americans which range from mental health to other areas of health (Blackburn, 2019). The stereotype that Asian Americans are “doing well” ignores how many Asian American youth face dual exposure to strict parenting (i.e. tiger parenting with punishment and shaming tactics) and holding a bicultural identity, which can result in poor coping behaviors such as substance abuse (Saraiya et al., 2019). In reality, a 2002 study shows that compared to girls of other ethnocultural groups, Asian American girls have the largest increase in use of alcohol (from 9.5% to 28.4%), cigarettes (from 7.4% to 17.1%), marijuana (from 2.4% to 9.1%), and other stimulants (from 1.5% to 2.3%) from 8th to 12th grade (Wallace et al., 2003). Moreover, since research on alcohol and substance use often lumps all subgroups within the Asian American (and sometimes Pacific Islander) community together, this aggregate data masks high rates of substance use within specific groups (Kane et al., 2017). This creates an increased danger of overlooking and ignoring the needs of the AA community.

EAST ASIAN AMERICAN (EAA) YOUTH

Compared to other Asian American subcultures, East Asian Americans currently fit the mold of the Model Minority Myth the most. EAA ethnicities include Chinese Americans, Hong Kong Americans, Japanese Americans, Macau Americans, Mongolian Americans, North Korean Americans, South Korean Americans, and Taiwanese Americans (Asia Society, n.d.). The 2019 American Community Survey (ACS) data from the U.S. Census Bureau shows that the Asian American groups with the highest median household income and the highest percentages of adults (age 25 and above) with at least a bachelor’s degree are mainly in the EAA category (Jin, 2021). Within this group, the Taiwanese, Chinese, Japanese, and Korean American subgroups stand out the most in terms of economic and educational achievement. When referring to Asian Americans in the U.S., most only consider East Asians, further perpetuating the misconception of Asian Americans as a “successful” monolithic model minority. The common perception is that Asian Americans in general are as successful as their white counterparts, at least from an economic and educational standpoint. This translates into a double-layered assumption that East Asian Americans are economically successful and, therefore, not at high risk of substance use. However, simply earning a high income or a bachelor’s degree does not define the population’s well-being, especially in terms of mental health and substance use. Additionally, even if rates of substance use for Asian Americans are lower than other racial groups, most data do not show the variances among different Asian American subgroups/ethnicities nor their experiences of racial or minority stress (National Survey on Drug Use and Health, 2021).

Many East Asian Americans are from immigrant families where using certain substances, namely alcohol, is common or seen as a norm in their country of origin. This paper focuses on the high prevalence of substance use, especially alcohol and cigarette use, among some EAA subgroups. Furthermore, cultural norms in the Asian American community mean these groups are already less likely to seek professional help, and false assumptions of substance use among different EAA subgroups have further contributed to limited availability and accessibility to treatment for those who do need help (Guarnotta, 2023). In general, public health researchers and practitioners have been led to deprioritize analyzing the patterns of substance use among East Asian Americans and Asian Americans (Kane et al., 2017). Hence, it is unsurprising that policies and programs tend to ignore the need for prevention and treatment for this population.

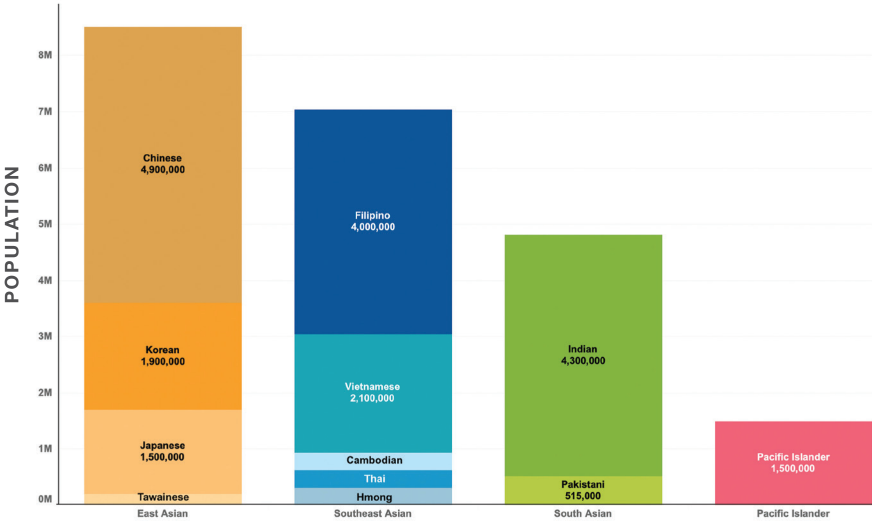
The relationship between different subgroups of EAA youth and substance use, as well as treatment approaches appropriate for this population, should be examined. Youth populations are prioritized in this paper since this is a crucial stage for intervention in the development of alcohol and substance use issues.

FACTORS INFLUENCING SUBSTANCE USE ACROSS SUBGROUPS

The 2019 ACS data from the U.S. Census Bureau shows that the East Asian American subgroup has the highest percentage population (8.6 million) in the U.S compared to other Asian American subgroups. Acknowledging the distribution of ethnicities of Asian Americans is crucial to understanding how current aggregated data concerning Asian American substance use has created biases and oversight of substance use prevention and treatment for Asian American subgroups that need them the most.

TABLE 1

ETHNICITIES UNDER THE ASIAN AMERICAN UMBRELLA



Source: U.S. Census Bureau, 2019 American Community Survey as cited in Jin’s (2021) article.

The 2013 U.S. National Survey on Drug Use and Health (NSDUH) reveals that Asian American youth have the lowest prevalence of past-month alcohol use and binge drinking compared to other races or ethnic groups (Substance Abuse and Mental Health Services Administration, 2013). However, data which combine all Asian American sub ethnicities under one category hide and ignore the reality of high-risk groups. A 2017 study found prevalence estimates of alcohol use among Korean, Japanese, and Filipino American adolescents were in fact very similar to other racial groups (i.e. white and Black populations) that experience a high risk of alcohol use (Kane et al., 2017). Another study by Cook et al. (2015) found the culture of drinking in the country of origin, namely Korea, Japan, and the Philippines, predicted heavy episodic drinking among these young adults. Low levels of alcohol use among Chinese Americans and Asian Indian Americans–the two largest Asian American subgroups in the United States, skew the data when evaluating alcohol use among Asian Americans as a whole (Saraiya et al., 2019; U.S. Census Bureau, 2021). Collectively, these findings accentuate the existing alcohol use amongst Asian American youth and the importance of disaggregating this data by ethnicity.

There is limited research on illicit substance use (e.g. cannabis, opioids, and illicit stimulants) among Asian Americans. The existing small body of research depicts Japanese and Korean ethnicities reporting higher use of illicit substances compared to other Asian American ethnicities (Ryabov, 2015; Saraiya et al., 2019 as cited in Ahmmad & Adkins, 2021).

CHINESE AMERICANS & TAIWANESE AMERICANS

Although Chinese Americans comprise over half of the East Asian population in the U.S., this group consistently reports low alcohol use prevalence compared to other Asian American subgroups (Chang et al., 2008). However, this does not mean alcohol and substance use is non-existent among Chinese American youth.

This phenomenon requires examining the process of acculturation–how closely one adheres to cultural norms in the U.S–which appears to be a strong predictor of substance use for other ethnicities. For instance, one study highlights how Chinese Americans are more influenced by specific cultural values (i.e., family obligation and expectations of autonomy). This means that Chinese American youth with a higher internalized sense of these values engaged in less misconduct (Juang & Nguyen, 2009). Although family values are a strong predictor of substance use in Chinese American youth, it is important to note that substance use is part of Chinese culture. Moreover, Chinese and Taiwanese American youth are greatly impacted by the recent history of immigration in their families. Immigration can greatly alter family dynamics and values and affect how these values contribute to substance use.

In existing research on substance use in Taiwanese Americans, this group is often combined with Chinese Americans, perhaps due to the very similar culture and the comparatively lower population of Taiwanese Americans. A study on smoking behavior among Chinese American and Taiwanese American college students found personal meanings associated with smoking are powerful predictors of smoking for this population (Spruijt-Metz & Hsia, 2003). Specifically, participants of this study reported that personal feelings about smoking are closely related to culture and smoking customs in some regions in China and Taiwan where smoking is socially accepted and even encouraged among men. In comparison, the personal feelings about smoking in female participants are more influenced by family education and parental attitudes compared to social customs.

KOREAN AMERICANS

On the other hand, Korean American college students are found to be drinking alcohol more frequently and in higher amounts compared to Chinese American students. Particularly, Korean Americans are more likely than Chinese American students to view drinking as a socially acceptable practice and a way to facilitate social interactions (Chang et al., 2008). The two most common environments where Korean Americans drank alcohol were drinking at night with friends or at parties (Nakashima & Wong, 2000). Drinking behavior among Korean

American students is closely associated with the drinking behaviors of their parents and friends. They are more likely to drink frequently when they have more spending money and are more likely to engage in substance misuse if their parents or friends use alcohol or tobacco (Chang et al., 2008). Similarly, along with their Chinese American counterparts, acculturation is not a significant predictor of drinking for Korean American teenagers. Peer influence, scholastic achievement or aspirations, and current smoking habits are stronger predictors (Cook et al., 2009). Contrary to their Chinese American counterparts, gender difference does not significantly change the measure of alcohol use among Korean American teenagers.

Regarding smoking, a 2002 study (Price et al.) found that 33.5% of Korean Americans use cigarettes, which is higher than the percentage of Caucasian Americans who do so (30%). Moreover, from 2010 to 2013, the prevalence of cigarette use among Korean Americans was 20%, a number that is almost twice the average of the aggregate Asian American population (10.9%) in the same period. This means the risk of cigarette smoking among Korean Americans is comparable to other higher-risk U.S. demographic groups (Martell, Garrett, and Caraballo, 2016 as cited in Ahmmad & Adkins, 2021).

JAPANESE AMERICANS

As discussed above, the use of alcohol among Japanese American youth is prevalent (Kane et al., 2017). The influence of acculturation to U.S. cultural norms is especially significant for Japanese Americans and their relationship with alcohol and substance use (Ahmmad & Adkins, 2021). The drinking culture of their country of origin is also a significant determining factor (Cook et al., 2015). These findings are unsurprising since Japan is to this day known for its drinking culture. The drinking culture in Japan has become so normalized that the Japanese government encouraged its younger generation to drink more to support the alcohol industry during the COVID-19 pandemic, exacerbating the existing prolific drinking culture (Hida & Yoon, 2022).

A separate study in Hawaii indicates that the onset of smoking and drinking among Japanese American students is closely associated with Japanese culture. The findings emphasize that although acculturation is an influential factor, nationality and level of education have stronger associations with smoking, and education is a stronger predictor of alcohol use (Tomioka & Maddock, 2007). This research shows that social workers are needed to ensure a quality of education which centers the experiences of East Asian Americans, namely concerning their experience in American public education.

MULTIETHNICITY ASIAN AMERICANS & PART-ASIAN AMERICANS

Literature (cited in Ahmmad & Adkins, 2021) shows that marriages between two Asian ethnicities and between Asians and other racial or ethnic groups are increasing, resulting in more youth identifying as multiple Asian ethnicities (e.g. Vietnamese and Chinese).

These individuals often identify as multiracial (e.g. Japanese and white); however, there is no research exploring the prevalence and patterns of substance use among these groups. The failure to consider Asian identities beyond mono-ethnic and mono-racial studies will increasingly create confusion and misinterpretations regarding the relationships between race, ethnicity, and substance use.

TREATMENT CHALLENGES AND RECOMMENDED TREATMENT APPROACHES

Unfortunately, research on treatment approaches for Asian Americans, including East Asian Americans and particularly EAA youth, is limited. Regardless, available studies do show that Asian Americans have certain preferences for substance use treatment (Wang & Kim, 2010). Most studies group East Asian Americans with other Asian American subgroups. Regardless, there is a common denominator showing Asian Americans require culturally appropriate care and approaches that take into consideration discrimination based on race and ethnicity.

CULTURALLY-APPROPRIATE CARE

Research shows that when Asian Americans participate in therapy services, they are more likely to drop out than their white counterparts (Wang & Kim, 2010 as cited in Ong, 2023). One potential explanation for this may be the cultural practice of shaming substance use and mental illness and the pressure to maintain the family's image. These tendencies may cause families to encourage their youth to avoid going to professionals and choose to address these issues in private or deny their existence altogether (Gateway Foundation, n.d.; Gemme, 2023). Hence, the Asian American population as a whole can benefit from family support for people who misuse substances, open discussion of the cultural stigma of substance-use problems, and culturally appropriate localized knowledge of drug misuse (Lee et al., 2004).

Due to the aforementioned reasons, Asian Americans are less likely to seek help and treatment services compared to other racial groups (Guarnotta, 2023; Spencer et al., 2010). In fact, only 3.3% of Asian Americans needing substance abuse treatment receive such treatment (SAMHSA, 2019). Compared to the rest of the country, Asian Americans are three times less likely to seek and receive treatment compared to the general population (SAMHSA, 2014 as cited in Kaliszewski, 2022). Therefore, more outreach efforts regarding treatment options and processes are needed in the communities of EAA youth.

As such, Asian Americans would benefit from shame and stigma reduction programs. Two studies in 2007 and 2013 on Japanese American youth highlight the need for culturally specific interventions for Japanese, Japanese American, and part-Japanese American teenagers and youth. Culturally appropriate care requires therapy providers to better understand the influences and effects that culture, ethnicity, and regional customs have on alcohol and substance use among adolescents (Tomioka & Maddock, 2007; Williams et al., 2013).

As treatment adherence is also associated with how much the client can relate to and understand the treatment provider's explanation of symptoms and illnesses, treatment providers should be trained in acknowledging and understanding the existence, prevalence, manifestation, and treatment of Asian culture-specific syndromes. Examples of these include:

> "hwa-byung" (Korean syndrome similar to, yet different from DSM-IV major depression), "taijin kyofyusho" (Japanese disorder similar to, yet different from DSM-IV social phobia), and "koro" (Southeast Asian syndrome now referred to as genital retraction syndrome in the global mental health literature) [which] are all psychological disorders that have been documented in Asian-Americans/Pacific Islanders. Clinicians unaware of such disorders are at higher risk for misdiagnosing such problems and, thus, implementing culturally inappropriate interventions. (Iwamasa, 2012, Inadequacies section)

Additionally, American treatments and methodologies may be dismissive of culturally specific healing practices that are unknown or unfamiliar in the U.S. Treatment providers must not only be aware of culturally specific practice, but also understand how Asian healing practices have been ignored and looked down upon. Asian American youth who grow up in the U.S. may have complicated feelings regarding these practices. All in all, providers can use this as an opportunity to explore the complexities of discrimination and healing instead of ignoring them.

OPPRESSION AND DISCRIMINATION

Due to the myth of the model minority, oppression and racism can also be the causes of mental health issues and substance use among Asian Americans. Asian Americans and Pacific Islanders often experience discrimination in their places of employment, where they may experience the "glass ceiling effect:"

> Although trained and competent, in many companies, Asian Americans and Pacific Islanders find it difficult to move beyond mid-level positions. Stereotypes of Asian-American/Pacific

> Islander employees as being smart, hardworking, and reliable, yet passive and quiet, result in many individuals being passed over for much-deserved promotions and recognition. Implications for negative effects on self-worth are clear. (Iwamasa, 2012, Oppression section)

Accordingly, the American Psychological Association recommends treatment providers serving the Asian American population be aware of inaccurate historical stereotypes and myths of Asian Americans (e.g. the Model Minority Myth). Treatment providers should gain knowledge of the diversity in educational and occupational achievement, socioeconomic status, and the frequent need for family members to have multiple jobs to make ends meet among Asian Americans (Iwamasa, 2012). As in treatments with any other racial group, treatment providers should not make assumptions regarding a client's experiences and how much an Asian American individual adheres to their cultural values and practices. Thus, recruiting treatment providers who identify as East Asian American and have lived experiences similar to EAA youth is extremely beneficial–although not always required. Additionally, hiring treatment providers who speak East Asian languages is important. Although language barriers can generally be a challenge for Asian Americans who are recent immigrants as well as first-generation EAA youth, it may not be a challenge for second and third-generation EAA youth.

Lastly, treatment providers should be aware of the common substances used by EAA youth. For instance, between 2000 and 2010, methamphetamine and marijuana were the two most commonly reported illicit drugs among Asian Americans (SAMHSA, 2014 as cited in Guarnotta, 2023). Part of exercising due diligence in providing the best support for Asian American youth includes recognizing the common causes of substance misuse among different EAA ethnicities as outlined in this paper. For example, alcohol misuse among Korean American youth is mostly a peer-reinforced phenomenon (Nakashima & Wong, 2000). Hence, strategies and goals have to be set accordingly depending on the tendencies of each population.

PREFERENCES FOR PREVENTION APPROACHES

RESILIENCY-FOCUSED PREVENTION PROGRAMS

A 2004 study on perceptions of substance use in Asian American communities, namely the Chinese, Indian, Korean, and Vietnamese populations, shows that these populations lack interest in using support groups such as Alcoholics Anonymous or Narcotics Anonymous because of their cultural preferences to confide in family and friends (Lee et al., 2004). The study recommends drug-prevention programs for the Asian American population to focus on a range of other available treatment options as well as the pros, cons, and feasibility of using personal resources to address substance-use problems. Also, Asian American populations tend to respond favorably to topics such as wellness, health promotion, and resiliency (Fang & Schinke, 2013). As such, family-based prevention programs focusing on strength and resiliency rather than pathology and deficits may be particularly relevant to East Asian Americans.

Asian American participants in another study reported they would be more attracted to programs made specifically for Asian Americans, but very few such programs exist. Schools and community centers (e.g., health clinics, YMCA, etc.) were the most frequently mentioned locations to hold such a program. Some participants felt an online program that targeted the Asian community would be appropriate, and some also showed preferences for family-based programs (Fang et al., 2011). However, other participants noted that Asian parents' "ordering" communication style tends to create a negative atmosphere and tense relationships with their children even in treatment settings. Many also mentioned that Asian American parents are generally more focused on their children's academic performance than other supplemental or extracurricular activities, so parents may overlook the need for a family-based prevention program.

FURTHER RESEARCH

Generally, there needs to be more research on the preferences of Asian American individuals for prevention approaches. One consistent finding among most Asian American subgroups is the importance of considering the perspectives of the family. Consequently, ensuring that treatment approaches are aligned with an individual's family preferences and culture is crucial. There is a lack of research on prevention among Taiwanese Americans and other ethnicities with smaller populations such as Hong Kong Americans, Macau Americans, and Mongolian Americans. Moreover, due to the minute population of North Korean Americans, the term Korean Americans generally refers to South Korean Americans, although North Korean Americans have distinctly different alcohol and substance use behaviors in their country of origin.

There is minimal research and data on effective treatments for East Asian Americans, much less EAA youth. More and updated research, as well as disaggregated data alongside studies on appropriate treatment approaches, specifically on EAA youth, is needed for public health professionals, social workers, and treatment providers to create appropriate policies and programs to help EAA youth who require support. Future research must look into separate Asian American subgroups/ethnicities and consider the distinct cultural differences among these groups. Research must also include South and Southeast Asian subgroups, especially groups with a high population in the U.S. (i.e. Filipino Americans and Vietnamese Americans). Ultimately, efforts for further research are increasingly needed as these populations continue to grow.

CONCLUSION

There are clear differences in substance use between ethnicities that fall under the East Asian American term or identity, notwithstanding the similarities among Chinese American, Taiwanese American, Korean American, and Japanese American youth, which include less likelihood to seek help and a higher likelihood to drop out of therapy services compared to their white counterparts. Differences such as drinking habits and social norms are influential determinants for higher-risk ethnicities such as Korean Americans and Japanese Americans. Due to the history of systemic racism against Asian Americans, more advocacy and cultural representation in treatment, such as understanding culture-specific explanations of certain symptoms and illnesses, is necessary (Gemme, 2023). On a macro level, efforts to dismantle stereotypes and the Model Minority Myth are also necessary as these can lead to mental health issues and substance use among Asian Americans. Lastly, the familiarity of providers with the treatment preferences of the Asian American population may improve treatment adherence and willingness to continue treatment. Consideration of family perspectives on treatment approaches and acknowledging the pressure from stigmatization of mental health among Asian Americans is crucial to the well-being of this community.

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