

Human Rights, Stigma, and Substance Use

JENIFER WOGEN AND MARIA TERESA RESTREPO

Abstract

The primary purpose of political, civil, socioeconomic, and cultural rights is to protect the dignity of all human beings. Good mental health and well-being is defined by the “social, psychosocial, economic, and physical environment that enables individuals and populations to live a life of dignity, with full enjoyment of their rights and in the equitable pursuit of their potential.”¹ Stigmatization, discrimination, and negative stereotypes are barriers to mental health and well-being.² Individuals with mental health problems, including those with drug dependence, suffer stigmatization, which is a direct affront to dignity and may have enduring health impacts. This paper discusses the implications of stigma for a human-rights based approach to improving mental health among those with drug dependence, with a focus on the opioid epidemic now ravaging the United States. It explores the public health burden of stigma related to substance misuse, including stigma in the context of treatment and health care. It also discusses the role of policy initiatives—including decriminalization—in addressing stigma related to substance misuse.

JENIFER WOGEN, MS, is a PhD student and Graduate Assistant at the Department of Public Health Sciences, University of Connecticut School of Medicine, Farmington, USA.

MARIA TERESA RESTREPO, MPH, MA, is a PhD candidate and Research Associate at the Department of Public Health Sciences, University of Connecticut School of Medicine, Farmington, USA.

Please address correspondence to Jenifer Wogen. Email: wogen@uchc.edu.

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We begin by emphasizing the need to consider the impact of stigma and discrimination for persons who experience substance use problems as a violation of their human rights and dignity. Although the literature on mental health stigma has grown significantly in recent years, it is critical to apply what we have learned on stigma specifically to substance use. In 2016, a report by the National Academies of Sciences, Engineering and Medicine concluded that the body of research on stigma related to substance use is sparse compared to the much larger evidence base that has amassed for mental illness.³ In 2017, a series of papers evaluated the status of the current evidence base for stigma related to mental illness and drug dependence. The authors identified four systematic reviews of substance use-related stigma in the published literature representing approximately 200 published studies, compared to 49 systematic reviews of mental illness-related stigma representing more than 1,000 empirical studies.⁴ In the United States specifically, given the opioid-driven overdose crisis, low rates of treatment among populations with opioid dependence, and the lack of a robust evidence base related to the impact of stigma, there is an urgent need to identify strategies to reduce the stigma associated with both self-identification of opioid dependence and use of medication-assisted treatment for opioid dependence. Effective strategies to reduce stigma could foster increased access to treatment for substance use problems.

In this paper, we explore some of the connections around human dignity, human rights, language, and stigma. Recognizing that there is extensive work being done around the concept of human dignity and its relationship to human rights from different perspectives, we embrace in this paper the notion of human dignity as the ethical core value and justification for human rights, and the idea that human rights are the means to realizing human dignity.⁵ In the international human rights context, human dignity is considered inherent to every person and the basis for equal and inalienable rights. In its first article, the Universal Declaration of Human Rights declares that “all human beings are born free and equal in dignity and rights.”⁶ Sim-

ilar references to human dignity are inscribed in several other international legal instruments. This notion of human dignity emphasizes an egalitarian belief in the sense that all persons are guaranteed dignity by virtue of their intrinsic value or worth as human beings, or “inherent dignity.”⁷ The foundation of this notion relies on Kantian ideas of human beings as autonomous entities with the capability of making their own decisions and determining their destinies. Human dignity defined as egalitarian and inherent necessarily implies that every person should be treated with respect and have their rights respected, protected, and fulfilled. To make this possible, societies need to ensure that every person has the opportunity to exercise their rights.

Along these lines, we need to be critical of the language used to refer to individuals who use substances. The growing body of literature on this subject shows us that language frames what the public thinks about substance misuse and dependence, and treatment and recovery, and it can affect how individuals think about themselves and their own ability to recover.⁸ Language is one of the key mechanisms for reinforcing beliefs about persons with substance use problems that impair their dignity as human beings and interfere with the protection of their human rights. For example, the use of pejorative or condemnatory language (such as “junkie” and “addict”) to refer to an individual with substance use problems may foster or perpetuate stigma. This is not simply about “political correctness”—it is about taking into consideration scientific evidence showing that certain terminology commonly used in the addiction field is associated with implicative cognition biases against the human dignity of persons with substance use problems.⁹ Person-first language emphasizes the person instead of her condition (for example, a person who uses drugs or a person with a substance use problem or condition, as opposed to an “addict” or “drug abuser”). The use of person-first language is a way to deter the use of language that undermines human dignity and to protect the rights of individuals who use substances; thus, health care providers in particular have an obligation to use person-first language when referring to individuals with sub-

stance use problems.¹⁰ Stigmatizing language in a health care setting may influence medical care and provider perceptions of individuals with drug dependence.¹¹

Mental health and substance use problems

Since both mental distress and substance use problems are prevalent conditions and frequently co-occur, strategies to understand and address stigma have implications for the mental health of populations. In the United States, an estimated one in four individuals will experience mental or substance use problems during their lifetime.¹² In 2017, approximately 47 million US adults reported a mental illness, while 20 million persons aged 12 and older reported having a substance dependence problem; furthermore, almost one-fourth of adults (23%) with serious mental illness report past-year substance use problems.¹³ About half of persons with serious mental illness report discrimination due to mental health status, physical disability, substance use, and ethnic or sexual minority status.¹⁴ These figures likely represent underestimates, as stigmatization may contribute, in part, to underreporting in population-based surveys.¹⁵ Worldwide, alcohol and illicit drug use is a leading cause of death. In 2017, approximately three million persons died from alcohol use, indirectly or directly, while the number of people deceased due to illicit drug use was approximately 800,000.¹⁶ Additionally, mental health and substance use problems combined are the leading cause of years lost to disability, and the associated global burden of disease continues to grow, as evidenced by an increase of 37.6% between 1990 and 2010.¹⁷

What is stigma?

We can trace the term “stigma” to the ancient Greeks, who used this word to refer to the skin mark they left on the bodies of criminals, slaves, and traitors to identify them as immoral—“a blemished person, ritually polluted, to be avoided, especially in public places.”¹⁸ According to Erving Goffman in

his seminal text on stigma, stigma embodies tribal identities (for example, race, ethnicity, religion), physical characteristics or conditions (for example, obesity, disability), and “blemishes of individual character.” In this sense, stigma relates to personal characteristics, or cues, that are socially considered shameful. Goffman’s discussion of stigma helps us understand that when we stigmatize others whom we perceive as different from ourselves, we assume that they are bad, dangerous, or weak. In addition, by stigmatizing an individual who is different, we are invalidating her whole personhood and diminishing her to a lesser status. Consequently, a person who is being stigmatized may perceive that she is not accepted or considered equal, engendering feelings of inferiority, shame, and self-loathing.¹⁹

Persons with mental health and substance use problems are exposed to an array of stigma components that interact to endanger their mental health. These components include stereotypes, prejudice, and discrimination.²⁰ Stereotypes are the over-generalized social beliefs we have about groups of people. For instance, persons with substance use problems may be perceived as untrustworthy, weak, and unwilling to stop using substances. Prejudice is an emotional response (for example, anger, irritation, pity, fear) among those who agree with the stereotype. Discrimination refers to behavior resulting from stereotypes and prejudices; for example, a person with drug dependence may be denied housing on the basis of these characteristics.

Types of stigma

To understand the mental health impact that stigma can have on people with substance use problems broadly, it is important to distinguish how stigma works at different levels of society and the individual. Furthermore, the use of different types of substances may be associated with the level at which stigma manifests and the intensity of that stigma. We will discuss five types of stigma: public, courtesy, structural, self, and multiple stigma. Each type of stigma entails specific challenges and responses in the protection of rights for persons with

substance use problems.

Public stigma refers to the collective public's prejudice and discrimination toward a specific group of individuals—in this case, individuals with substance use problems. These prejudices and discriminatory actions are founded on cognitive representations that “perceivers” have about persons with the stigmatized condition (“targets”), which elicit negative emotional and behavioral responses.²¹ Mental health conditions, including substance use problems, are more highly stigmatized than physical health conditions, regardless of the specific condition or severity.²² High levels of perceived personal responsibility for a condition may elicit public anger and stigmatizing behavior, while low levels may induce sympathy and willingness to assist; higher levels of severity of the condition may evoke more public sympathy.²³ Among people with mental health conditions, those with substance use problems tend to experience more stigma because of the perceived personal responsibility often associated with this condition. Cognitive representations explain, in part, the greater public stigma associated with substance use as compared to mental illness, as substance use may be viewed as more controllable and a more egregious norm violation.²⁴ Despite research suggesting widespread understanding of the neurobiology of both mental illness and substance use problems, public beliefs related to substance use problems tend to blame the individual.²⁵ Research has demonstrated less willingness to socially include people with substance use problems than those with mental health conditions and more unfavorable reactions to persons with substance use problems.²⁶ Thus, public stigma creates obstacles for persons with substance use problems when other members of the community prevent their access to basic needs such as housing, food, education, and employment. In addition, stigma does not affect all individuals with mental illness or problematic substance use equally. For instance, individuals with psychosis are more stigmatized than those with depression or anxiety.²⁷ In addition, people who use intravenous drugs and crack cocaine are more highly stigmatized than those who use other substances by both the general

public and people who use drugs.²⁸

Within the realm of public stigma is the stigma experienced by associates of stigmatized groups, including treatment professionals, family, and friends, labeled as *courtesy stigma*.²⁹ This type of stigma may serve to further isolate stigmatized individuals, since associates may distance themselves from the individual to avoid such stigma. Family stigma may involve societal blame for some conditions.

Structural stigma refers to policies or institutional actions that restrict—whether intentionally or not—the opportunities of targeted groups.³⁰ Examples of structural stigma include discriminatory behaviors or overtly negative attitudes manifested by individuals acting as institutional representatives, such as those working in health care or within the criminal justice system.³¹ Unintentional structural stigma encompasses both public and private sector policies, with consequences that restrict opportunities for those with drug dependence in unintended ways and may restrict access to and diminish the quality of care.³² For instance, a review of legislation found some degree of legal restrictions for persons with mental illness in all 50 US states related to rights to serve on a jury, vote, hold political office, have parental custody, and engage in marriage.³³ One of the more serious issues with this type of legislation is the broad language used—which refers to people with any diagnosis of mental illness—instead of specific metrics of functional impairment; this reflects the stigma associated with persons with mental illness and substance use problems as dangerous and untrustworthy.³⁴ Consequently, persons with mental health and substance use problems may experience limitations and the infringement of their civil and political rights.

Another critical violation of the human rights of persons with mental health and substance use problems arises from policies established by the United States' war against drugs. It has been estimated that 65% of the US prison population has an active substance use diagnosis, while an additional 20% have been incarcerated for a crime involving drugs, including drug use.³⁵ The disproportionate representation of people with substance use prob-

lems in the criminal system may be an indication that the laws have been designed with the implicit intention of targeting such people. As a society, we have preferred a punitive approach to deal with persons with substance use problems instead of responding from a more humanistic perspective that considers drug dependence as a chronic mental health and medical condition that needs to be treated as such. Decriminalization could play an important role in reframing substance use problems as chronic health conditions rather than criminal activities. Within society, the illegal status of specific substances engenders structural stigma, and individuals who use illegal substances may thus experience greater effects of stigma than those who use licit substances.

Self-stigma occurs when a member of a targeted group internalizes a public stereotype or prejudice. Much of stigma's impact is a consequence of self-stigma, as it encompasses low self-esteem and alienation of self and has been associated with recovery orientation, empowerment, and perceived devaluation.³⁶ It has been suggested that self-stigma may mediate the relationship between structural stigma and poor health.³⁷ Self-stigma may result in lower self-efficacy, decreased motivation, and reduced quality of life, and it has been associated with increased depression risk.³⁸ Related to the impact of self-stigma on mental health is *label avoidance*, which occurs when a person avoids activities that reveal his or her condition or mental distress.³⁹ Label avoidance may manifest in a reluctance to seek care, as persons may avoid entering treatment or taking medication to avoid a stigmatic label. In general, individuals with mental health conditions, including those with substance use problems, may be more likely to conceal their diagnosis than those with a physical one. Because of label avoidance, persons with substance use problems may experience isolation and a reduction of social support, which may prevent them from the self-identification needed to benefit from protections afforded by anti-discrimination legislation.⁴⁰ Self-stigma and label avoidance may prevent persons with substance use problems from obtaining the health care services needed to attain complete physical,

mental, and social well-being.

Public stigma, courtesy stigma, structural stigma, and self-stigma work together in an inter-related multilevel system, and public stigma, as a societally shared idea that a specific condition is devalued, is at the core of the interrelated domains.⁴¹ However, other stigma domains may serve to increase (or decrease) effects of other domains. This systems understanding of stigma takes into account reciprocal relationships between individuals, their social networks, and larger social structures.⁴² For example, higher levels of structural stigma related to substance use may result in higher levels of public stigma, courtesy stigma, and self-stigma; higher levels of public stigma may work to foster more structural stigma, as public opinion is incorporated into policy. Thus, the potential for stigma to infringe on individuals' human rights is not limited to the socioeconomic and cultural rights of persons with substance use problems and can also affect their political and civil rights. This framework also suggests that researchers should consider that stigma interventions at one level may have additive, enduring effects across the entire system.⁴³

The concept of *multiple stigma* is particularly relevant to understanding the additive impact of stigma for many individuals with substance use problems. Among individuals who identify with multiple stigmatized groups, the accumulative distress of multiple stigma may result in more severe manifestations of mental distress and thus make discriminatory treatment by others more likely.⁴⁴ The tendency of substance use and mental illness to co-occur, and to also be associated with other stigmatized states (such as homelessness and poverty), is thus critically important from the perspective of multiple stigma.

The burden of stigma related to substance use

Understanding the burden of stigma related to problematic substance use must guide effective approaches to improve population health and individual health outcomes, which are intimately related to the protection and promotion of people's

human rights; this, in turn, may foster the realization of certain human rights, such as the right to the highest attainable health. In a nationally representative survey of the US general adult population, which evaluated public stigma associated with specific mental health conditions (such as major depressive disorder and schizophrenia) and alcohol dependence, more than 80% believed that treatment for mental illness and alcohol dependence is effective, and this proportion increased over time, as did the proportion who attributed mental health disorders to neurobiological causes.⁴⁵ However, measures of social distance and perceived danger associated with individuals with mental illness and alcohol dependence did not decrease over the time period studied. Furthermore, 62% of respondents were unwilling to work closely with, and 52% were unwilling to socialize with, individuals with schizophrenia; 47% and 74% were unwilling to work closely with individuals with major depressive or alcohol dependence, respectively. Despite endorsing treatment overall, one in two adult respondents said that treatment for a mental health disorder would result in discrimination and, among children with mental health disorders who are treated, long-term harm to a child's future. These findings highlight the pervasiveness of public stigma within the United States that is associated with mental health conditions and substance misuse, as well as a continued resistance to change despite increased knowledge; they also suggest that understanding the neurobiological component of drug dependence may not be sufficient to preclude or address stigma or discrimination. Research has also highlighted the pervasive effects of internalized self-stigma and its impact on individual well-being across multiple domains among those experiencing mental distress. For example, research conducted among a population with serious mental illness demonstrated that expectations of discrimination prevented 64% from applying for employment or educational opportunities and 55% from entering into interpersonal relationships, and about one-third reported anticipating discrimination in situations where no discrimination was subsequently experienced.⁴⁶

Stigma and treatment for substance use problems

Stigma influences the entire continuum of care for individuals with substance use problems—including treatment seeking, choice of treatment, treatment retention, and treatment adherence—which results in poorer individual and population health. The majority of individuals with drug dependence do not receive treatment. Fewer than 1 in 10 who need treatment for substance misuse or dependence receive any treatment.⁴⁷ Furthermore, less than half of individuals who meet diagnostic criteria for opioid misuse or dependence engage in treatment.⁴⁸ Stigma is a barrier to seeking treatment among affected individuals and may exacerbate preexisting health disparities by deterring health-seeking among affected persons.⁴⁹ Stigma prevents individuals from seeking the care needed to obtain a diagnosis, as those with a condition may be motivated to hide the condition to avoid public stigma (label avoidance).

Stigma is also a barrier to treatment seeking among individuals with alcohol or drug dependence. For example, among a nationally representative sample of adults with alcohol dependence, those who perceived higher stigma toward individuals with this disorder had lower odds of treatment utilization.⁵⁰ Among those with drug dependence who do enter treatment, the effects of stigma on their treatment (including treatment choice, adherence, and retention) may negatively affect treatment outcomes. For example, medication-assisted treatment (MAT) with buprenorphine or methadone is considered the current gold standard for treatment for opioid dependence, since its use is associated with reduced risk of relapse and mortality, yet stigma may present a barrier to its use, including stigma associated with MAT use within sectors of the treatment community. Stigma has been identified as a factor associated with individuals' desire to use a lower dose of methadone than may be necessary to prevent opioid cravings.⁵¹ Further, self-stigma has been implicated in early MAT discontinuation, thus increasing individuals' risk of relapse and overdose.⁵² Some peer-led support groups and 12-step recovery support programs

may not support MAT use, and consequently individuals in recovery who are being treated with MAT may experience stigma from peers or group facilitators or, perhaps unintentionally, be persuaded to discontinue MAT use.⁵³

Within the health care and substance use treatment systems, the use of pejorative diagnostic labels such as “addict,” “drug abuser,” and “psychotic” may perpetuate stigma. Health care systems may provide inferior care and reduced access to care for individuals with stigmatized conditions. A recent literature review identified 28 studies between 2000 and 2011 that assessed health care professionals’ attitudes toward patients with substance use problems and concluded that providers’ negative attitudes directed at such patients contribute to suboptimal care.⁵⁴ In addition, this review highlighted that surveyed providers lacked education, training, and support that specifically addressed substance misuse or drug dependence.

Structural stigma, ethics, and implications for policy and public health

Structural stigma encompasses policies within corporations, the judicial system, government, professional groups (including health care), schools and universities, and social service agencies, which may affect health care, employment, and educational opportunities.⁵⁵ Structural stigma may endorse discrimination and foster self-stigma and public stigma. An example of structural stigma is the lack of mental health parity in the United States, as historically mental health treatment infrastructure, workforce capacity, and insurance coverage has been less comprehensive than physical health.⁵⁶ Both the Mental Health Parity Act (2008) and Affordable Care Act (2010) represent policy responses to structural stigma that expand insurance coverage for mental health services; however, disparities persist, and not all persons and mental health conditions have equal access. Multiple components of the stigma process are unable to be directly addressed by policy; legislation cannot directly alter public attitudes toward those with mental health conditions, including substance use problems, but

it can address the discrimination component of stigma, and the legislative protection of stigmatized groups may help change cultural norms.⁵⁷ Anti-discrimination policies may indirectly improve components of public and self-stigma (stereotype and prejudice) by upholding the standard that persons with mental health conditions should not be subject to discrimination, and they represent a mechanism for addressing stigma-related outcomes in arenas such as health care, education, and employment; however, legislative reform to combat discrimination must be accompanied by anti-stigma programs (for example, media campaigns) that directly address other components of stigma to improve such outcomes.⁵⁸

Ethical consideration of structural stigma related to mental health conditions should contemplate whether society has an obligation to arrange social institutions to ensure that all citizens are equally protected from disease as much as possible.⁵⁹ Universal, equal access of all persons to appropriate health care and educational opportunities is an imperative for distributive justice and for the protection and fulfillment of the right to the highest attainable standard of health. Self-respect requires the respect of others, which is undermined by stigma, and in a just society, institutions respect every individual equally; structural stigma opposes these principles. Policy considerations differ for mental and substance use disorders, in large part due to the widespread criminalization of substance use. In the United States, federal legislation generally protects the rights of individuals with mental illness, while anti-discrimination protection for persons with substance use disorders is more tenuous. This differentiation, from an ethical perspective, is contrary to the principle of distributive justice, since fewer health care resources and legal protections are available to persons suffering from substance use problems than other mental health conditions.⁶⁰

The decriminalization of drug use and possession has been proposed as a public health strategy for the United States’ current overdose crisis. It is also a strategy to protect the human rights of those with substance use problems. Related to the

use of illegal substances, the Joint United Nations Programme on HIV/AIDS (UNAIDS) asserts that “decriminalization of drug use and possession for personal use reduces the stigma and discrimination that hampers access to health care, harm reduction and legal services ... people who use drugs need support, not incarceration.”⁶¹ UNAIDS maintains that states should “[p]rotect and promote the human rights of people who use drugs by treating them with dignity, providing equal access to health and social services, and by decriminalizing drug use/consumption and the possession, purchase and cultivation of drugs for personal use,” and that taking action to end stigma and discrimination experienced by individuals who use drugs, including as related to health, legal, education, employment, and social protection services, is of paramount importance. There is some evidence that Portugal’s decriminalization of all illicit drugs in 2001 may have resulted in reduced stigma around substance use, with downstream public health benefits.⁶² Subsequent to decriminalization, drug-related incarceration plummeted, and significant reductions were observed in drug-related morbidity and mortality; the role of reduced stigma in increased treatment entry and service seeking may have played a role. Decriminalization could pave the way for expanded harm reduction and evidence-based public health approaches used in other countries, such as supervised injection facilities, that could curb the United States’ current overdose crisis.

While this paper has adopted a US focus to specifically address the opioid overdose crisis, addressing substance use-related stigma in all societies is important regardless of geographic boundaries. Indeed, addressing stigma may be more imperative in low- and middle-income countries, where individuals with substance use problems may be forcibly institutionalized or otherwise involuntarily restrained and where pharmacological treatments may be unavailable.

Conclusion

Stigma related to substance use problems is a direct affront to the dignity and human rights of affected

individuals, and it presents a barrier to individuals’ attainment of the highest possible standard of physical and mental health. Stigma influences the entire continuum of care for individuals with substance use problems, including treatment seeking, choice of treatment, treatment retention, and treatment adherence, negatively influencing individual and population health. Public stigma, structural stigma, courtesy stigma, and self-stigma are interrelated in a multi-level system, which must be considered as a whole, and interventions or other changes specific to one component of substance use-related stigma may affect the entire system. Policy initiatives, including the decriminalization of substance use, could play a significant role in reducing discrimination and stigma associated with drug misuse and dependence. Such targeted anti-stigma initiatives could play a critical role as part of an armamentarium of policy and other initiatives to address the United States’ opioid overdose crisis.

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