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Using Person-First Language across the Continuum of Care for Substance Use Disorders & other Addictions: Words Matter to Reduce Stigma

Substance misuse, abuse and use disorders (SUDs) and other addictions like gambling are chronic medical conditions, but the general public associate people with addiction/SUDs with poor choices and moral failings. As a result, many people who suffer from addiction are not treated the same way as people with a chronic physical health condition. This paper looks at this issue across the continuum of care and proposes person-first language designed to help people by de-stigmatizing addiction/SUD care and related issues.



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Words Matter to Reduce Stigma

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Using Person-First Language across the Continuum of Care for Substance Use Disorders & other Addictions: Words Matter to Reduce Stigma

To begin this discussion, we should acknowledge that the childhood adage, “sticks and stones can break my bones, but names can never hurt me,” is patently untrue. Words, and the meanings with which they are imbued can achieve accuracy and relevance or they can transmit dangerous stereotypes and half-truths. They can empower or disempower, humanize or objectify, engender compassion or elicit malignant fear and hatred. Words can inspire us or deflate us, comfort us or wound us. They can bring us together or render us enemies. Put simply, our lives are profoundly shaped by the words we apply to ourselves and those that come to us from others. The shaping/transforming/deforming power of labels is particularly compelling: Educators have long noted the self-fulfilling power of labeling children (White, 2001).

Overview

Substance misuse, abuse and use disorders (SUDs) and other addictions like gambling are chronic medical conditions. In Ohio, 6.7% of the population reported an alcohol use disorder in the past year, and 2.8% reported dependence or abuse of an illicit drug (SAMHSA, 2015). However, many people who suffer from SUDs and other addictions are not treated the same way as people with chronic physical health conditions due to the heavy stigmatization of SUDs (Smith, 2016). Using alcohol and other drugs outside of what is socially acceptable has been viewed as a moral failing. The amount of stigma toward people with addiction disorders reflects an attitude that the users' choices were the reasons that they have SUDs/addiction (Room, 2005). What exactly is an addiction and why do they occur?

- Addiction (including SUDs) is defined as a chronic, relapsing brain disease characterized by compulsive drug seeking and use, despite harmful consequences.
- Addictions are frequently chronic and relapsing.
- Addictions are moderately to highly inheritable.
- Addictions are characterized by craving, excessive use and withdrawal/negative effects.
- Addictive drugs change the brain's reward regions, leading to tolerance of higher and higher doses and habit formation due to craving responses and withdrawal symptoms.
- The negative effects (withdrawal symptoms and craving) last long after use of the drug ceases, but eventually the symptoms diminish.
- The initial decision to take drugs is typically voluntary. People think they can control their use of drugs, but drugs can quickly take over their lives.
- Early use of drugs, heredity and having other risk factors in one's life are all factors that increase the potential for addiction/SUDs.
- No single factor determines whether a person will become addicted to drugs, and addiction can happen to anyone (NIDA 2014).

The stigma felt by many people with addiction/SUDs contributes to marginalization of people suffering from SUDs, creating many barriers to accessing treatment and other healthcare. However, since SUDs are a medical condition and not a moral failing, those who work in SUD prevention, treatment and recovery must do all they can to eliminate stigma.

One of the main factors that practitioners can address to decrease stigma is the language they use in their work to describe people with SUDs. The use of pejorative language creates more stigmatization among people with SUDs. Providers across the Institute of Medicine's Continuum of Care have the responsibility to use language that does not stigmatize SUDs or people with SUDs, which includes professionals in prevention work, in the treatment field and those furthering recovery.

Prevention

Special attention needs to be paid to language use in prevention as it can help to create a tone for community norms and sets a foundation for the continuum of care. Professionals who specialize in SUD prevention follow the Substance Abuse and Mental Health Service Administration's Center for Substance Abuse Prevention (SAMHSA/CSAP) six strategies. These six strategies include (1) information dissemination, (2) prevention education, (3) alternative activities, (4) community-based processes, (5) environmental approaches and (6) problem identification and referral. Using person-centered language that does not stigmatize SUDs in each of these strategies can lessen the stigmatization around substance use disorders. It is important to understand how these strategies can be used to reduce stigma at a community level.

In information dissemination, the messaging is one-way. One-way messaging includes publicly displayed billboards, brochures and signs (Hogan et al, 2003). The agencies and systems creating these messages should pay special attention to not re-stigmatize people with SUDs. Information dissemination is also an effective way to distribute information about the services provided in an area to potential consumers or those who need help with SUDs. Creating messaging with inclusive language may help to reduce community stigma. Prevention education involves two-way messaging. There is an interaction between the person receiving the information and the educator. The most effective prevention education strategies include education about the risks of substance use and modeling of skills that promote protective factors such as self-regulation and enhanced coping skills (Hogan et al, 2003). Those who write and deliver curricula must be mindful of the language they use when talking about substance abuse and those who have the condition.

Community-based process is an integral prevention strategy. This strategy recognizes that communities are best able to plan, organize, and execute prevention strategies in their own communities. Coordinating among community agencies to leverage more funding for prevention is just one of the many ways community-based strategies play out (Hogan et al, 2003). It is imperative for the participants to understand the stigma that people with SUDs may face. Considerations should be made around the language in their action plans and other community mobilization efforts. Environmental approaches can affect a large number of people (Hogan, 2003). When environmental strategies are implemented, policies and procedures need to be

consistent with language that does not stigmatize people who have SUDs. The policies need to avoid stigmatizing language and have inclusive language across the continuum of care.

Finally, problem identification and referral is a strategy where people who have already started using substances in a harmful way are screened and referred for further assessments (Hogan, 2003). Those practitioners who are using various screening tools or delivering activities designed to screen individuals need to be mindful about terminology used.

Treatment

Stigmatization of SUDs not only has implications for the language we use to describe prevention messaging, but it also has widespread consequences for persons in need of treatment. By creating a limited picture of what constitutes substance abuse (i.e., use so pervasive it leads to the person losing everything valuable in his/her life), as well as the perceived value of people who abuse substances (i.e., no value), stigma encourages persons in need of treatment to deny the problems caused by substances in their lives. To recognize someone's problematic substance abuse pattern means identifying with someone who society has deemed unreliable, untrustworthy or worthless (Kelly & Westerhoff, 2009). In this way, stigma undermines the initiation of treatment. Even to those who are in recovery, stigma leads to constant reminders of the shame induced by society as a result of SUD.

Members of the helping community are not immune to the impact of stigma on attitudes toward persons with substance abuse problems. According to Meltzer et al. (2013), primary care physicians were more likely to treat patients with SUDs more negatively than patients displaying other medical symptoms. Moreover, educational sessions intended to break down stigma for physicians resulted in improved attitudes as physicians experienced increased understanding of chemical dependency, its causes and the conditions necessary for treatment. This led to more positive attitudes among doctors.

If stigma is communicated by stigmatizing language, then non-stigmatizing language is needed to combat stigma and take the place of stigmatizing language in the substance abuse lexicon. To that effect, experts in the substance abuse field (Kelly et al., 2016; American Society of Addiction Medicine, 2013) have recommended the use of person-centered language when discussing substance abuse and chemical dependency. Although person-centered language originated in the developmental disability community, the focus on the person, rather than his/her condition, is a benefit that has led to the adoption of person-centered language in other fields, including substance abuse treatment and prevention (Meltzer et al., 2013).

By keeping personhood at the forefront of one's description, helpers and non-helpers alike are conditioned to think of someone as a person first, and their disability or chemical dependency status second. That distinction leads to a superior level of care between caregivers and patients, facilitating communication and the ability of persons in need of treatment to describe their symptoms and the help they need (Meltzer et al., 2013). Moreover, person-centered language changes society's perception of substance abuse by refocusing attention on chemical dependency as a medical condition rather than a personal, easily mutable choice (American Society of Addiction Medicine, 2013).

Recovery

Individuals in long-term recovery from substance use disorder have a number of challenges to face. In the early stages of recovery, maintaining sobriety, having a safe place to live, getting or keeping a job, restoring physical health and mending relationships among family and friends all require work and commitment. As early recovery becomes long-term recovery, further challenges might include having one's record expunged, completing an education, establishing or owning a residence and paying the bills. The force of stigma toward people with SUDs pushes back on every step forward made (Ahern, et al, 2007).

Active addiction exacts a toll on the person trying to live with the addiction, as well as on his/her friends and family members. SUDs drain everything of value from a person; the addiction causes extensive negative consequences that can lead to criminal records, poor health, unemployment, shame and social exclusion.

To demonstrate the negative impact caused by stigma on people with addictions and other behavioral health diagnoses, the Ohio Department of Mental Health and Addiction Services Ohio Substance Abuse Monitoring (OSAM) Network recently conducted a survey. A total of 299 clients involved in state-certified substance abuse, mental health, and/or criminal justice services agencies responded to the questions below, among others:

1. Have you ever felt bad about the way media or other people talk about people with substance use disorders or mental illness?

69% of respondents said, "Yes." 31% said, "No."

2. What consequences have you experienced from the "stigma" of being a person with mental illness and/or addiction?

A majority (over 50%) of participants responded that they have experienced the consequences of shame, blame, anger, social isolation, being a 'black sheep of the family,' a loss of self-worth and hopelessness."

Participants had the opportunity to state other consequences of stigma they had experienced. The relevant answers were categorized, and the most frequent reference was summed up as "emotional consequences." The number in parentheses is the number of responses that make up the category.

- Emotional consequences: "guilt, worthlessness, numb, defeated, demoralized" (10)

3. What words make you feel bad? Most common responses were:

- Junkie (38)
- Addict/ Drug addict (23)
- Fiend/ Dope fiend/ Pill fiend/ 'Phene' (19)
- Crackhead (16)

Some participants feel bad about words having to do with substance use as an illness or disease:

- Disease/ Brain disease/ Mental disease (12)

Maintaining the behavioral changes necessary for a long-term recovery takes commitment and strength, along with a supportive community. A cultural shift to non-stigmatizing person-centered language would provide a framework for viewing behavioral health conditions in the same light as physical health conditions, with an expectation of healthy lifestyles for the individual and community as a whole.

"...In discussing substance use disorders, words can be powerful when used to inform, clarify, encourage, support, enlighten, and unify. On the other hand, stigmatizing words often discourage, isolate, misinform, shame, and embarrass. Recognizing the power of words, this guide is designed to raise awareness around language and offer alternatives to stigmatizing terminology associated with substance use disorders. It is offered primarily as a resource to those who work within the field of prevention, treatment, and recovery support...(SAMHSA, 2004)."

Focusing on the subtle meaning of words--rejecting some while embracing others--is far more than a matter of shallow political correctness. It is about changing the way addicted and recovering people see themselves and are seen by others. It is about changing the language that affects social policies and is in turn affected by those policies. Changing language is a way to personally and culturally close one chapter in history and open another (White, 2001).

Why Does Language Matter?

Stigma remains the biggest barrier to addiction treatment faced by patients. The terminology used to describe addiction has contributed to the stigma. Many derogatory, stigmatizing terms were championed throughout the "War on Drugs" in an effort to dissuade people from misusing substances. Education took a backseat, mainly because little was known about the science of addiction. That has changed, and the language of addiction medicine should be changed to reflect today's greater understanding. By choosing language that is not stigmatizing, we can begin to dismantle the negative stereotype associated with addiction. Changing attitudes of stigma will benefit everyone. It will allow patients to more easily regain their self-esteem, allow lawmakers to appropriate funding, allow doctors to treat without disapproval of their peers, allow insurers to cover treatment, and help the public understand this is a medical condition as real as any other. Choosing the words we use more carefully is one way we can all make a difference and help decrease the stigma.

The following terms are considered effective in furthering public understanding of addictive disorders as a medical issue, which, in turn, provides impact in reducing stigma and stereotyping.

Addiction. *Why it works:* This widely understood term describes "uncontrollable, compulsive drug seeking and use or behavior, even in the face of negative health and social consequences."¹ There is a distinction between addiction and physical dependence, although the words are often incorrectly used interchangeably. Addiction involves both social and health problems, whereas physical dependence only involves health.

Addiction Free. *Why it works:* Indicates the patient is free from the dangerous compulsive behaviors of addiction. Less stigmatizing than "clean" or "sober" yet shows the person is no longer in active addiction.

Addiction Survivor. *Why it works:* This terminology is in line with other life-threatening diseases. (i.e. cancer survivor) It is a positive indication of a person's disease status. It is less

stigmatizing than “recovering addict,” especially to people unfamiliar with recovery language. It also indicates that a person’s treatment has triumphed over active addiction and shows that the person is substantially past the initial phases of recovery, unlike “in recovery” which doesn’t differentiate between days or decades of addiction-free life.

Addictive Disorder, Addictive Disease. *Why it works:* By incorporating disorder or disease, these terms reinforce the medical nature of the condition.

Medication-Assisted Treatment. *Why it works:* This is a practical, accurate, and non-stigmatizing term to describe addiction treatment with medically monitored pharmacological medications such as methadone, naltrexone, buprenorphine and other medications.

Misuse. *Why it works:* It offers the same intended meaning as what has traditionally been termed as abuse, but without the stigma and judgmental overtones that abuse carries. *Caveat:* Some say that technically speaking, one does not misuse a substance when it is used as intended. Example, marijuana is purchased with the intention of being smoked, so technically it is not misused when people smoke it. For this reason, some prefer the terms risky use or problem use.

Patient. *Why it works:* As with other illnesses, the word accurately refers to a person who is being medically treated for an addictive disorder. It reinforces the fact that addictive disorders are indeed health issues. It replaces stigmatizing labels like addict.

Person(s) or People with... *Why it works:* Used in terms such as person(s) or people with addictive disorders, with addictions, or with addictive disease, these modifiers give identity to individuals as people, rather than labeling them by their illness.

Remission. *Why it works:* It is medical terminology that describes a period in which the signs and symptoms of the illness have disappeared. It emphasizes that addiction is indeed a medical condition. *Caveat:* Prior to this, remission was seldom used in conjunction with addictive disorders.

“Words are important. If you want to care for something, you call it a ‘flower’; if you want to kill something, you call it a ‘weed’ (Don Coyhis).”

Words to Avoid and Alternatives:

Following are stigmatizing words and phrases which could be replaced with the suggested “preferred terminology” as a start in reducing the stigma associated with addiction.

Addict, Abuser, Junkie, Degenerate Gambler. *Problem with the terms:* These terms are demeaning because they label a person by his/her illness. By making no distinction between the person and the disease, they deny the dignity and humanity of the individual. In addition, these labels imply a permanency to the condition, leaving no room for a change in status.

Preferred terminology: Person in active addiction, person with a substance misuse disorder, person experiencing an alcohol/drug/gambling problem, patient (if referring to an individual receiving treatment services).

Abuse. *Problem with the term:* Although “abuse” is a clinical diagnosis in the DSMIV and ICD10, it is stigmatizing because: (1) it negates the fact that addictive disorders are a medical condition; (2) it blames the illness solely on the individual with the illness, ignoring environmental and genetic factors, as well as the ability of substances to alter brain chemistry; (3) it absolves those selling and promoting addictive substances of any wrong doing; and (4) it feeds into the stigma experienced not only by individuals with addictive disorders, but also family members and the addiction treatment field.

Preferred terminology: Misuse, harmful use, inappropriate use, hazardous use, problem use, risky use.

Clean, Dirty. (when referring to drug test results) *Problem with the terms:* Commonly used to describe drug test results, these terms are stigmatizing because they associate illness symptoms (i.e. positive drug tests) with filth.

Preferred terminology: Substance-free.

Habit or Drug Habit. *Problem with the terms:* Calling addictive disorders a habit denies the medical nature of the condition and implies that resolution of the problem is simply a matter of willpower in being able to stop the habitual behavior.

Preferred terminology: Substance use disorder, alcohol and drug disorder, active addiction, gambling disorder.

Replacement or Substitution Therapy. *Problem with the terms:* This implies that treatment medications such as buprenorphine are equal to street drugs like heroin. The term suggests a lateral move from illegal addiction to legal addiction, and this does not accurately characterize the true nature of the treatment. The essence of addiction is uncontrollable compulsive behavior. The first goal of addiction treatment is to stop this dangerous addictive behavior. With successful buprenorphine therapy, as part of a comprehensive treatment plan, the dangerous addictive behavior is stopped not replaced.

Preferred terminology: Treatment, medication-assisted treatment, medication.

User. *Problem with the term:* The term is stigmatizing because it labels a person by his/her behavior. It is also misleading because the term “user” has come to refer to one who is engaged in risky misuse of substances, but “use” alone is not necessarily problematic.

Preferred terminology: Referring to misuse: person who misuses alcohol/ drugs or person engaged in risky use of substances.

See companion web page at www.naabt.org/language.

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