Words Matter

Language in Perinatal Substance Use and Mental Health
Language and Mental Health
3 Types of Stigma

PUBLIC
Discrimination and Devaluation by Others

SYSTEMIC
Reduced Access to Care and Resources Due to Policies

SELF
Internalization of Negative Stereotypes
Why does it matter?

- Stigmatizing language significantly contributes to **negative health outcomes** and **increases barriers to seeking care**
- Provider stigma can lead to internalized self-stigma and shame which increases obstacles to care and can impede healing
  - Shame increases risk of suicide and increases avoidant coping

ND Volkow, JA Gordon, and GF Koob. *Choosing Appropriate Language to Reduce the Stigma Around Mental Illness and Substance Use Disorders*.

Yanos PT, DeLuca JS, Roe D, Lysaker PH. The impact of illness identity on recovery from severe mental illness: a review of the evidence.
Why do words really matter?

We react and respond to words without even realizing it.

- **System 1**: Feeling brain (limbic system)
  - Associative Action
- **System 2**: Thinking brain (neocortex)

https://www.mentalhealth.org.uk/blog/why-language-we-use-describe-mental-health-matter
Why do words really matter?

- **Litigation**
  - Most lawsuits filed when breakdown in physician-patient communication
  - Trusting and mutual-respective relationship
- **Reduce moral injury and compassion fatigue**
Everyone on the Same Page

New U.S. federal law gives everyone the right to read clinicians’ notes in their electronic medical records. OpenNotes is the international movement that advocates for transparent communication in healthcare and studies the effects of shared notes in patients’ records. We call these open notes.
Words have a magical power. They can either bring the greatest happiness or the deepest despair.

Sigmund Freud
Further Considerations

- Your community
  - As there are not always shared consistencies in person-first language among groups, it is important to engage with the community you serve to understand preferences
- Our own Implicit bias and intersection with racism
- Cultural & individual Family lived experiences and expectations of mental health treatment
Stigma and Perinatal Mental Health
Perinatal mental illness = “Bad parent”

Providers can reinforce unachievable and unrealistic expectations of parenthood

Reduced self-stigma with non-judgemental treatment environment
  ○ Reduced perinatal depression/reduced severity
  ○ Increased parental confidence
  ○ Increase in help-seeking and leaning into supports
Postpartum Psychosis

St. Cloud Woman Charged With Murdering Baby, Throwing Body In Dumpster

By WCCO-TV Staff November 30, 2021 at 3:14 pm Filed Under: Local TV, Murders, St. Cloud News

Los Angeles Times

Mom Accused of Tossing Sons Into River Charged
Her sentence complete, Naomi Gaines-Young wants to talk about mental illness

“I want people to know my story,” she said. “It’s important to do that. I want people to know about serious mental illness and what can happen if it isn't treated.”

By Andy Steiner | Contributing Writer
<table>
<thead>
<tr>
<th>Language with Negative Connotation</th>
<th>Person-Centered</th>
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<tbody>
<tr>
<td>Committed suicide</td>
<td>Died by suicide</td>
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<tr>
<td>Successful or Failed suicide attempt</td>
<td>Survived or did not survive suicide</td>
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<tr>
<td>Self-mutilation</td>
<td>Nonsuicidal self-injury</td>
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<tr>
<td>Manipulation</td>
<td>Patient sought to meet their needs of...</td>
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<tr>
<td>Refused medications or ____</td>
<td>Declined or chose not to accept ____</td>
</tr>
<tr>
<td>Trigger</td>
<td>Prompt</td>
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<tr>
<td>Demanding</td>
<td>Made repeated requests</td>
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<tr>
<td>Non-compliant</td>
<td>Did not adhere to treatment plan</td>
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<tr>
<td>Hysterical, dysfunctional</td>
<td>Dysregulated</td>
</tr>
<tr>
<td>Needy</td>
<td>Sought reassurance</td>
</tr>
<tr>
<td>Failed trial (of meds or other tx)</td>
<td>Treatment not associated with improvement or non-beneficial trial</td>
</tr>
<tr>
<td>Patient Complaint/Chief Complaint</td>
<td>Patient/Presenting Concern</td>
</tr>
<tr>
<td>Schizophrenic, Psychotic</td>
<td>Patient with schizophrenia, psychosis, etc.</td>
</tr>
<tr>
<td>Unfit Parent</td>
<td>Experiencing barriers to successful parenting</td>
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</table>
Language and substance use disorders
The Real Stigma of Substance Use Disorders

In a study by the Recovery Research Institute, participants were asked how they felt about two people “actively using drugs and alcohol.”

One person was referred to as a “substance abuser”

The other person as “having a substance use disorder”

No further information was given about these hypothetical individuals.

THE STUDY DISCOVERED THAT PARTICIPANTS FELT THE "SUBSTANCE ABUSER" WAS:

- less likely to benefit from treatment
- more likely to benefit from punishment
- more likely to be socially threatening
- more likely to be blamed for their substance related difficulties and less likely that their problem was the result of an innate dysfunction over which they had no control
- they were more able to control their substance use without help

https://www.mghpcs.org/eed/SUD/SUD-stigmatizing-lang.shtml
Need for secrecy in treatment due to stigma of identity as “addict”
May disengage with treatment if identify conflicts arise
Seeking help from primary care provider to avoid stigma of “addiction treatment”
Stigma one of top 3 reasons provided for not accessing care
Stigma consciousness as predictor of treatment utilization for women
The association between perceived stigma and substance use disorder treatment outcomes: a review

Crapanzano et al 2018

- Stigmatizing aspects of treatment, negative emotions associated with stigma - interfere with engagement in treatment
- Social exclusion and marginalization interfere with treatment
- Negative views of “replacement therapy” - decreased retention in treatment
- Lack of judgement and stigma by staff - increased retention in treatment
- Understanding behavior from staff - stronger effect that social and self-stigma
- Examples cited lack of perceived stigma in OTPs (“methadone clinics”)
Stigma and perinatal substance use

Pregnant and postpartum people with substance use disorders are less likely to:

- Seek treatment for substance use disorders
- Access prenatal care
- Breastfeed their babies
Online survey platform, 1227 respondents

Clinical scenario described using more or less stigma-associated language

- Majority supporting engagement in recovery and parenting support
- \textit{While also} agreeing with:
  - Punitive-blaming views - mandated treatment
  - Personal responsibility for disease of addiction
 Hundreds of babies born addicted to drugs and alcohol

Babies born with neonatal abstinence syndrome may suffer from uncontrollable trembling and hyperactivity, have blotchy skin and high-pitch crying.

1 in 12 Maine babies is born drug addicted, report says

Babies born addicted to opioids cost U.S. more than half a billion dollars a year

'Heartbreaking': At least 852 babies born addicted in Scotland since 2017
“Patient realizes that she needs to get sober for this baby.”

“Understands that her baby has a chance of being born addicted that cannot be avoided if she is on medication-assisted treatment.”

“Patient refuses to initiate buprenorphine treatment and therefore has been placed on a 72 hour hold.”

“Wants to stop using.....recognizes that her baby doesn’t have a choice in this and she needs to do better”
What is your emotional response?

You are consulted on a baby born addicted to opioids. Her mother has a history of injection heroin use. Medication was recommended to help her stop using heroin during the pregnancy, but the patient refused to start treatment until halfway through her pregnancy, and when she finally did, she couldn’t stay clean for more than a month. Child welfare services are now deciding if she can keep custody of this addicted baby when she is discharged from the hospital.
What is your emotional response?

You are consulted to see McKenna J, a three day old baby with prenatal opioid exposure. Her mother has a history of opioid use disorder. Medication for opioid use disorder was started during the pregnancy. The patient initiated methadone during her pregnancy but had to relocate to a new play to stay with friends and was unable to get her to treatment, and therefore consistent treatment was challenging for her. Child welfare services are now deciding if they provide her with sufficient support to care for a newborn with substance exposure when she is discharged from the hospital.
A comparison case

- 32 year old sugar abuser ("diabetes") calls your clinic to establish care
- Very high glucose levels at appointment, so medication started
- 3 month follow-up - improved blood sugars, continue same regimen
- 5 month follow-up - blood sugars very elevated again, level in clinic 397
  - Discharged from clinic - non-compliant with recommended medication
- 5 months later, the patient come to the ED with chest pain, found to have a myocardial infarction
  - Told it's the patient's fault - asked if they took their medications and followed the right diet
  - Advised to call a list of cardiologists and cath labs on their own - list handed to them at discharge
  - Warned if develops chest pain again, they may be discharged from the clinic again for failing treatment

@DrSarahWakeman, @HannanBraun
“Protest any labels that turn people into things. 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.’”
We must lead the change in language

➢ Clinic and hospital staff
➢ Patients and their families
➢ Learners - students, residents, fellows
➢ Our communities
➢ Our elected officials
Person-first language

*Person-first language maintains the integrity of individuals as whole human beings by removing language that equates people to their condition or has negative connotations.¹ For example, “person with a substance use disorder” has a neutral tone and distinguishes the person from his or her diagnosis.²
<table>
<thead>
<tr>
<th><strong>Avoid</strong></th>
<th><strong>Prefer</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuse¹⁻⁵</td>
<td>Use (or specify low-risk or unhealthy use; the latter includes at-risk/hazardous use, harmful use, substance use disorder, and addiction)</td>
</tr>
<tr>
<td>Addicted baby</td>
<td>Baby experiencing substance withdrawal</td>
</tr>
<tr>
<td>Addict, user, abuser, alcoholic, crack head, pot head, dope fiend, junkie</td>
<td>Person with (the disease of) addiction, a substance use disorder, or gambling disorder</td>
</tr>
<tr>
<td>Dirty vs clean urine²⁴</td>
<td>Positive or negative, detected or not detected</td>
</tr>
<tr>
<td>Drunk, smashed, bombed, messed up, strung out Meth</td>
<td>Intoxicated Methamphetamine, methadone, methylphenidate</td>
</tr>
<tr>
<td>Medical marijuana</td>
<td>Consider using instead “cannabis as medicine”⁹</td>
</tr>
<tr>
<td>Misuse, problem ‡</td>
<td>More accurate terms include at-risk or risky use, hazardous use, unhealthy use to describe the spectrum from risky/at-risk/hazardous use through disorder</td>
</tr>
<tr>
<td>Inappropriate use</td>
<td>More accurate terms should specify what is meant</td>
</tr>
<tr>
<td>Fix</td>
<td>Dose, use</td>
</tr>
<tr>
<td>Binge ‡</td>
<td>Heavy drinking episode</td>
</tr>
<tr>
<td>Relapse ³,²⁰</td>
<td>Use, return to use, recurrence (of symptoms) or disorder vs remission specifiers (early or sustained) as defined by DSM-5</td>
</tr>
<tr>
<td>Substitution, replacement, medication assisted treatment</td>
<td>Opioid agonist treatment, medication treatment, psychosocially assisted pharmacologic treatment, treatment</td>
</tr>
<tr>
<td>Smoking cessation</td>
<td></td>
</tr>
<tr>
<td>Moderate drinking (or drug use)</td>
<td>Low- or lower-risk use</td>
</tr>
<tr>
<td>Detoxification</td>
<td>Withdrawal management, withdrawal</td>
</tr>
</tbody>
</table>

*Currently marijuana (the plant leaf, stems, and seeds) is not typically sold as medicinal grade or conclusively researched as having more benefits than risks, nor is it FDA approved. Moreover, cannabis is the term more internationally used and is more descriptive relating to compounds being researched to explore medical value—such as cannabidiol.*

‡Could be used if clearly defined and most useful for prescription drug (misuse) when the nature or severity of the condition is unknown. Avoid calling the person a problem or their use a problem.

§Can be useful for public health messaging but needs to be clearly defined as it is sometimes used to mean a heavy drinking episode but also used to mean several days of long episode of heavy drinking or other drug use (e.g., cocaine).

$This term will likely continue to be used, but it should not imply a binary process (abstinence vs relapse) that does not reflect real typical clinical course (that can include lapses or in-between states).

||A similar term is not typically used for other drugs with addiction liability. This term seems to place tobacco in a category different than other drugs, which may not be helpful considering its high addiction risk and high morbidity and mortality. More favored terms for “smoking” include “tobacco” (or “nicotine”). Further, “cessation” (or abstinence) while highly desired should not be the only goal. Smoking reduction may have limited health benefits related to smoking and may also reduce relapse rates with other substances used by the patient. However, the evidence for smoking reduction having health benefits related to smoking is low, and these results are small compared to complete abstinence.

Saitz et al 2021
<table>
<thead>
<tr>
<th>Stigmatizing language</th>
<th>Proposed terminology</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abuser; addict; street addict; former or reformed addict; alcoholic, booser; crackhead, cokehead; pothead, weed user; dope addict; narco; junkie; druggy; tweaker; dope fiend; alkie; lush</td>
<td>Person with [substance] use or [substance use or behavior] disorder or addiction involving [substance use or behavior]. Person in remission from a [substance use or behavior] disorder. Person with [substance use or behavior] disorder who is homeless.</td>
<td>Some of these terms can refer to a person with or without an substance use or behavior disorder. A disorder is diagnosed if the DSM-5 criteria for use or behavior disorder are met. See Editorial for guidance on the diagnosis-related terminology.[1]</td>
</tr>
<tr>
<td>Having a drug habit or bad habit; having a drug of choice, drug of abuse</td>
<td>Having a [substance use or behavior] disorder or addiction involving [substance use or behavior].</td>
<td>Addiction is a chronic disease, not a habit; the term ‘habit’ or ‘choice’ implies that it is merely a problematic behavior and something that a person can ‘fix’ by simply desiring a change. “Cigarette habit” and “heroin habit” are examples of such problematic terms.</td>
</tr>
<tr>
<td>Smoker</td>
<td>Person with cannabis and/or tobacco or nicotine use disorder, or addiction involving cannabis / tobacco / nicotine use.</td>
<td>With the increasing use of vaping and e-cigarettes, it is suggested to use the term ‘nicotine’ rather than ‘tobacco’ as it encompasses both tobacco chewing and smoking, and the use of non-combustible nicotine delivery systems.</td>
</tr>
<tr>
<td>Addicted baby; crack baby; meth baby</td>
<td>Neonate (or newborn, child) with [substance] withdrawal; or with neonatal withdrawal syndrome; or with in utero exposure to [named substance]</td>
<td>Children can be exposed in utero to substances. They can develop a physical or physiological dependence with prolonged in utero exposure to certain substances that can lead to a withdrawal syndrome post-birth. They are not born with addiction -- they do not meet the diagnostic criteria for SUD.</td>
</tr>
<tr>
<td>Being clean or sober</td>
<td>Being substance-free. Being abstinent. Being in remission. Toxicology test testing “negative” for a [substance].</td>
<td>Remission occurs when the symptoms of a disease subside. Recovery extends beyond the remission phase. See Editorial for guidance on the remission related terminology.[1]</td>
</tr>
<tr>
<td>Being dirty</td>
<td>Using [substances]. Toxicology test testing “positive” for a [substance].</td>
<td>“Dirty urine” implies that the person is a “dirty” person.</td>
</tr>
<tr>
<td>Getting/being high; stoned; wasted</td>
<td>Being intoxicated; being under the influence of [substance]</td>
<td></td>
</tr>
<tr>
<td>Shooting up, jacking up, slamming, banging, pinning</td>
<td>Intravenous drug use; injection drug use</td>
<td>Intravenous drug use refers to substance use and does not automatically mean that the individual has addiction.</td>
</tr>
<tr>
<td>Kicking the habit</td>
<td>Initiate abstinence; receive/start treatment; enter remission, etc.</td>
<td>The commonly used phrase ‘kick the habit’ implies that it is a habit not a disease, and that the ‘treatment’ occurs simply based on sufficient ‘willpower’ to stop the behaviors.</td>
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<tr>
<td>Being in detox</td>
<td>Undergoing a detoxification treatment; withdrawal management/treatment; tapering off medications</td>
<td></td>
</tr>
<tr>
<td>Being in rehab</td>
<td>Undergoing intensive addiction treatment or management; intensive pain rehabilitation or restoration program</td>
<td></td>
</tr>
<tr>
<td>Replacement or substitution treatment for OUD; Medication-Assisted Treatment (MAT)</td>
<td>Medication treatment; pharmacotherapy</td>
<td>Misconceptions about agonist medications, buprenorphine and methadone (such as “they replace one addiction for another”), imply that this evidence-based treatment for OUD is a continuation of drug use; statements that people treated with agonist medications are not in remission because they are not “drug free” convey a similar message. Using the term Medication-Assisted Treatment can imply that medication per se is not a treatment. Because the acronym MAT has now deep cultural roots, the change to “Medications for Addiction Treatment” could preserve the commonly-used acronym while changing its full name to a non-stigmatizing one.</td>
</tr>
<tr>
<td>Having dirty / clean urine</td>
<td>Toxicology test testing positive / negative for a substance. Results are unexpected / expected; inconsistent / consistent with the prescribing record.</td>
<td></td>
</tr>
<tr>
<td>Recidivism</td>
<td>Remission</td>
<td>See Editorial for guidance on the remission-related terminology.</td>
</tr>
</tbody>
</table>

Zgierska et al 2021
● SUD (DSM) vs. addiction vs. dependence (ICD-10)
● MAT - meds do not assist treatment, they *are* treatment
  ○ Use medication for addiction treatment OR medication for opioid use disorder (MOUD)
● Patients do not “use” buprenorphine, they “take” buprenorphine
● Substance testing - positive vs. negative OR detected vs. not detected

*We do not make recommendations on what terms patients/clients should use.*

*But changing the narrative in clinical and scientific speaking is the beginning of an important process!*
Words Matter - Terms to Use and Avoid When Talking About Addiction

Your Words Matter – Language Showing Compassion and Care for Women, Infants, Families, and Communities Impacted by Substance Use Disorder

References - stigma and mental illness

- [https://practicetransformation.umn.edu/clinical-tools/person-centered-language/](https://practicetransformation.umn.edu/clinical-tools/person-centered-language/)
- [https://www.psychiatry.org/patients-families/stigma-and-discrimination](https://www.psychiatry.org/patients-families/stigma-and-discrimination)
- [https://www.tn.gov/behavioral-health/stigma.html](https://www.tn.gov/behavioral-health/stigma.html)
References - stigma and SUD


