Drugs, Stigma, and Policy: How and Why Words Matter

John F. Kelly, PhD, ABPP

Sponsored by the Florida Alcohol and Drug Abuse Association, a subsidiary of the Florida Behavioral Health Association, and the State of Florida, Department of Children and Families
Personal Introduction John F. Kelly, PhD, ABPP

- Elizabeth R. Spallin Professor of Psychiatry in Addiction Medicine, Harvard Medical School
- Founder and Director of the Recovery Research Institute at Massachusetts General Hospital (MGH)
- Associate Director of the Center for Addiction Medicine (CAM) at MGH, and the Program Director of the Addiction Recovery Management Service (ARMS).
- Former President of the American Psychological Association's (APA) Society of Addiction Psychology; Fellow of the APA and a Diplomate of the American Board of Professional Psychology.
- Consultant to U.S. federal agencies and non-federal institutions, as well as foreign governments and the United Nations.
- I’ve published over 200 peer-reviewed articles, reviews, chapters, and books in the field of addiction medicine, and author on the U.S. Surgeon General's Report on Alcohol, Drugs, and Health.
- His clinical and research work has focused on addiction treatment and the recovery process, mechanisms of behavior change, and reducing stigma and discrimination among individuals suffering from addiction.
Disclosures and Objectives

• Dr. Kelly is a full-time faculty member in the department of Psychiatry at Harvard Medical School and Massachusetts General Hospital

• I have received an honorarium for this presentation.

• Dr. Kelly has received funding from NIAAA, NIDA, NIMH, SAMHSA, Department of Veterans Affairs, and state agencies to conduct research on addiction, treatment, and recovery.

• Dr. Kelly has no conflicts of interest

Learning Objectives:
By the end of this presentation, participants will:

• Understand the importance of how we conceptualize and describe substance use disorders (SUD) and related phenomena.

• Examine the evidence demonstrating the impact of stigmatizing language on the provision, quality, and allocation of resources for SUD prevention and care.

• Identify strategies for addressing stigma in policy and practice settings using non-stigmatizing language and other strategies.
50 years....
1970-2020
Etiology: Genetics, Genomics, Pharmacogenetics
But, SUD is multifactorial, complex, heterogeneous...

**RISK FACTORS**

**Biology/Genes**
- Genetics
- Gender
- Mental Health
- Route of administration
- Effect of drug itself

**Environment**
- Chaotic home and abuse
- Parent’s use and attitudes
- Peer influence
- Community attitudes
- Poor school achievement
- Early use
- Availability
- Cost

**Drug**

**Brain Mechanisms**

**AUD**

*Figure 1. A depiction of the complex nature of substance use disorder.*
Nature of Impact: Neuroscience - Neural plasticity
Epidemiology
Prevalence and pathways of recovery from drug and alcohol problems in the United States population: Implications for practice, research, and policy

John F. Kelly, Brandon Bergman, Bettina B. Hoeppner, Corrie Vilsaint, William L. White

ARTICLE INFO

Keywords: Drug and alcohol dependence, recovery, treatment, prevalence

ABSTRACT

Background: Alcohol and other drug (AOD) problems cause a global, prodigious burden of disease, disability, and premature mortality. Despite widespread acknowledgment of the need to reduce the adverse effects of AOD problems, little is known about the extent to which individuals in the United States are able to recover. This study examined the prevalence and pathways of recovery from AOD problems in the U.S. population.

Methods: A cross-sectional survey of 50,860 adults was conducted using the National Survey of Drug Use and Health, from 2010 to 2015. Recovery was assessed using a validated measure of recovery status.

Results: The prevalence of recovery from AOD problems was 9.8%, with 46% of individuals identifying as "in recovery." The majority of individuals in recovery were male (55.5%) and white (67.0%). The most common pathways to recovery were through treatment (22.6%), support from family and friends (22.4%), and self-help (11.8%). The most common barriers to recovery were financial (31.8%), legal (22.6%), and social (16.1%).

Conclusions: The prevalence of recovery from AOD problems is lower than previously reported. The most common pathways to recovery were through treatment, support from family and friends, and self-help. The most common barriers to recovery were financial, legal, and social. These findings have important implications for policy, practice, and research.
9.1% or 22.35 million Americans have resolved an alcohol or other drug problem.
RECOGNITION OF MULTIPLE PATHWAYS TO POSITIVE CHANGE...

Acknowledges myriad ways in which individuals can recover:

Clinical pathways (provided by a clinician or other medical professional – both medication and psychosocial interventions)

Non-clinical pathways (services not involving clinicians like AA)

Self-management pathways (recovery change processes that involve no formal services, sometimes referred to as “natural recovery”).
### Clinical Course

<table>
<thead>
<tr>
<th>Stages of Change</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Precontemplative</strong></td>
<td>In this stage, individuals are not even thinking about changing their behavior. They do not see their addiction as a problem; they often think others who point out the problem are exaggerating.</td>
</tr>
<tr>
<td><strong>Contemplative</strong></td>
<td>In this stage people are more aware of the personal consequences of their addiction &amp; spend time thinking about their problem. Although they are able to consider the possibility of changing, they tend to be ambivalent about it.</td>
</tr>
<tr>
<td><strong>Preparation</strong></td>
<td>In this stage, people have made a commitment to make a change. This stage involves information gathering about what they will need to change their behavior.</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td>In this stage, individuals believe they have the ability to change their behavior &amp; actively take steps to change their behavior.</td>
</tr>
<tr>
<td><strong>Maintenance</strong></td>
<td>In this stage, individuals maintain their sobriety, successfully avoiding temptations &amp; relapse.</td>
</tr>
</tbody>
</table>
What people really need is a good listening to...
“Quitting smoking is easy, I’ve done it dozens of times” –Mark Twain
Swift, certain, modest, consequences can help shape behavioral choices...
The power and cost-effectiveness of clinical-peer linkages and peer support...

Effective Medications
Harm Reduction Strategies

- Anti-craving/anti-relapse medications ("MAT")
- Overdose reversal medications (Narcan)
- Needle exchange programs
- Heroin prescribing
- Overdose prevention facilities (safe Injection facilities)
Continuing care and recovery management
During the past 50 yrs since “War on Drugs” declared, our LANGUAGE and TERMINOLOGY also has changed... we have moved from “Public Enemy No. 1” to “Public Health Problem No. 1”
The Last 50 Years in U.S. Addiction Laws

1965
- Reorganizational Plan No. 2
  Creation of the Drug Enforcement Agency (DEA), consolidating a number of different entities to form a single federal agency to enforce government drug control policy.

1967
- Charitable Choice
  Charitable choice allows direct U.S. government funding of religious organizations to provide substance use prevention & treatment.

1973
- Sober Truth on Preventing Underage Drinking Act (STOP Act)
  Passed in 2006, the STOP act created a grant program to target underage drinking within communities & established the federal Interagency Coordinating Committee on the Prevention of Underage Drinking (ICCPUD) with high-level leadership from across 15 federal agencies to coordinate government efforts to address underage drinking.

1996
- Comprehensive Addiction & Recovery Act (CARA)
  Passed in 2016, CARA increased access to overdose treatment, naloxone (overdose reversal medication), & medication assisted treatments (MAT), reauthorized an opioid treatment program for pregnant & postpartum women, & allocated money for creation of opioid epidemic response plans on the state level.

2006
- Fair Sentencing Act
  Passed in 2010, the act reduces the sentencing disparity between crack & powder cocaine from 100:1 to an 18:1 ratio.

2010
- Mental Health Parity & Addiction Equity Act (MHPAEA)
  Enacted in 2008, the MHPAEA closed loopholes in the Mental Health Parity Act of 1996 by requiring insurance companies to offer coverage for mental & substance use disorders that is equal to the coverage or benefits offered for other medical or surgical care (e.g. deductibles, co-pays, out-of-pocket maximums, treatment limitations).

2017
- The Patient Protection & Affordable Care Act (ACA)
  Healthcare legislation enacted in 2010, declared substance use disorders 1 of the 10 elements of essential health benefits in the U.S., requiring that Medicaid & all insurance plans sold on the Health Insurance Exchange provide services for addiction treatment equal to other medical procedures (closing insurance exemption gaps of the 2008 MHPAEA). Commonly referred to as the Affordable Care Act or "Obamacare".

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Laws passed in the past 50 yrs have moved from more punitive ones to public health oriented ones.... increasing availability, accessibility and affordability of treatment.

Criminal justice approaches have began to shift and embrace clinical and public health emphases....
Public Health Approaches to Addressing Drug-Related Crime: Drug Courts
Public Health Approaches to Law Enforcement

- Chief Campanello
  - Angel Program
    - “Help not Handcuffs”
The clinical course of addiction and achievement of stable recovery can take a long time. **A major reason for this long clinical course is stigma/discrimination...**
WHAT IS STIGMA?

An attribute, behavior, or condition, that is socially discrediting
WHAT IS DISCRIMINATION?

The unfair treatment of individuals with the stigmatized condition/problem
Stigma Consequences: Public and Personal

• Public:
  • Public stigma can lead to:
    • Differential public and political support for treatment policies
    • Differential public and political support for criminal justice preferences
    • Barriers to employment/education/training
    • Reduced housing and social support
    • Increased social distance (social isolation)

• Personal:
  • Internalization of public stigma can lead to:
    • Shame/guilt
    • Lowered self-esteem
    • Rationalization/minimization; lack of problem acknowledgment
    • Delays in help-seeking
    • Less treatment engagement/retention; lowered chance of remission/recovery
## Commonly Studied Dimensions of Stigma

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Blame</strong></td>
<td>are they responsible for causing their problem/disorder?</td>
</tr>
<tr>
<td><strong>Prognostic pessimism/optimism</strong></td>
<td>will they ever recover “be normal”, “trustworthy”?</td>
</tr>
<tr>
<td><strong>Dangerousness</strong></td>
<td>are they unpredictably volatile, a threat to my/others’ safety?</td>
</tr>
<tr>
<td><strong>Social distance</strong></td>
<td>would I have them marry into my family, share an apartment with them, have them as a babysitter?</td>
</tr>
</tbody>
</table>
**Addiction may be most stigmatized condition in the US and around the world:**

Cross-cultural views on stigma

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illicit drug addiction</td>
<td>1st</td>
</tr>
<tr>
<td>Alcohol addiction</td>
<td>4th</td>
</tr>
</tbody>
</table>

**Stigma, social inequality and alcohol and drug use**

**ROBIN ROOM**

Centre for Social Research on Alcohol and Drugs, Stockholm University, Stockholm, Sweden

**Sample:** Informants from 14 countries

**Design:** Cross-sectional survey

**Outcome:** Reaction to people with different health conditions

Studies have shown that...

- **SUD is more stigmatized** compared to other psychiatric disorders.
- Compared to other psychiatric disorders, people with SUD are perceived as more to blame for their disorder.
- Describing SUD as treatable helps.
- Individual’s themselves who hold more stigmatizing beliefs about SUD less likely to seek treatment; discontinue sooner.
- Physicians/clinicians shown to hold stigmatizing biases against those with SUD; view SUD individual’s as unmotivated, manipulative, dishonest; **SUD-specific education/training helps**.

SO, WHY IS ADDICTION SO STIGMATIZED COMPARED TO OTHER SOCIAL PROBLEMS AND HEALTH CONDITIONS, AND OTHER MENTAL ILLNESSES?
# What Factors Influence Stigma?

<table>
<thead>
<tr>
<th>Cause</th>
<th>Controllability</th>
<th>Stigma</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It’s not their fault”</td>
<td>“They can’t help it”</td>
<td>Decreases</td>
</tr>
<tr>
<td>“It is their fault”</td>
<td>“They really can help it”</td>
<td>Increases</td>
</tr>
</tbody>
</table>
Relation between Cause and Controllability in producing Stigma

Figure 3.
If Drugs Are so Pleasurable, Why Aren’t We All Addicted?

Genetics substantially influence addiction risk

- Genetics
- Genetic differences affect subjective preference and degree of reward from different substances/activities

In terms of cause... Biogenetics

Neural Circuits Involved in Substance Use Disorders

In terms of controllability...

...all of these brain regions must be considered in developing strategies to effectively treat addiction

What can we do about stigma and discrimination in addiction?

**Education** about essential nature of these conditions

**Personal witness** *(putting a face and voice on recovery)*

**Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
What can we do about stigma and discrimination in addiction?

- **Education** about essential nature of these conditions
- **Personal witness** (putting a face and voice on recovery)
- **Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
MIGHT GREATER BIOMEDICAL EMPHASIS AND EXPLANATIONS (E.G., BIOGENETIC AND/OR NEUROBIOLOGICAL) HELP REDUCE STIGMA?
Biogenetic explanations as ways to reduce stigma...

- Meta-analysis of 28 experimental studies found biogenetic explanations:
  - Reduced blame, but increased...
  - Social distance
  - Dangerousness
  - Prognostic Pessimism

Neurobiological explanations as ways to reduce stigma...

Neurobiological explanation studies found they increased:

- Social distance
- Dangerousness
- Prognostic pessimism
- had no effect on reducing blame

What about ways of describing drug-related impairment, specifically?

A Randomized Study on Different Addiction Terminology in a Nationally Representative sample of the U.S. Adult Population

Terminology:
What’s the best way to describe drug-related impairment to reduce stigma/discrimination?

- Chronically relapsing brain disease
- Brain disease
- Disease
- Illness
- Disorder
- Problem

Design

- N=3,635
- Randomly assigned to receive one of 12 vignettes which described someone with opioid-related impairment in one of six different ways, as a(n):
  - Chronically relapsing brain disease
  - Brain disease
  - Disease
  - Illness
  - Disorder
  - Problem

“Alex was having serious trouble at home and work because of (his/her) increasing opioid use. (He/She) is now in a treatment program where (he/she) is learning from staff that (his/her) drug use is best understood as a (TERM) that often impacts multiple areas of one’s life. Alex is committed to doing all that (he/she) can to ensure success following treatment. In the meantime, (he/she) has been asked by (his/her) counselor to think about what (he/she) has learned with regard to understanding (his/her) opioid use as a (TERM).”

Paradoxical nuanced findings on biological explanations of stigmatized disorders

Reviews of the research suggest that biogenetic and neurobiologic explanations, while reducing attributions of blame - increase perceived dangerousness, social distance, and prognostic pessimism.

Meta-analytic review with 28 experimental studies found that biogenetic explanations reduce blame (Hedges g=-0.324) but induce pessimism (Hedges g=0.263). Also found biogenetic explanations increase endorsement of the stereotype that people with psychological problems are dangerous (Hedges g=0.198).

Promoting biogenetic or neurobiologic explanations to alleviate blame may induce pessimism and set the stage for self-fulfilling prophecies that could hamper recovery. Highlights need to emphasize most people recover, lead normal productive lives, but it can take time…


Emphasizing that SUD is highly treatable and most people will recover although it can take time… (?)
What can we do about stigma and discrimination in addiction?

- **Education** about essential nature of these conditions

- **Personal witness** (putting a face and voice on recovery)

- **Change our language/terminology** to be consistent with the nature of the condition and the policies we wish to implement to address it
TERMINOLOGY
Confusing array of terms Describing the Construct and Spectrum of Substance-Related Problems
Array of Terms Describing the Person using or suffering from compulsive substance use

- Addict
- Substance Abuser
- Crackhead
- Substance Misuser
- Junkie
- Drunk
- Problem User
- Alkie
- Smackhead
- Alcoholic
People with eating-related conditions are always referred to as “having an eating disorder”, never as “food abusers”.

So why are people with substance-related conditions referred to as “substance abusers” and not as “having a substance use disorder”?

Question...
Does it matter?

Much ado about nothing?

“Political correctness”?

Mere “semantics”? 
Two Commonly Used Terms…

- Referring to someone as…
  - “a substance abuser” – implies willful misconduct (it is their fault and they can help it)
  - “having a substance use disorder” – implies a medical malfunction (it’s not their fault and they cannot help it)
  - But, does it really matter how we refer to people with these (highly stigmatized) conditions?
  - Can’t we just dismiss this as a well-meaning point, but merely “semantics” and “political correctness”?
Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms

John F. Kelly, Cassandra M. Westerhoff

*International Journal of Drug Policy*

How we talk and write about these conditions and individuals suffering them does matter
“Substance Abuser”

Mr. Williams is a substance abuser and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs...

“Substance Use Disorder”

Mr. Williams has a substance use disorder and is attending a treatment program through the court. As part of the program Mr. Williams is required to remain abstinent from alcohol and other drugs...

Compared to those in “substance use disorder” condition, those in “substance abuser” condition agreed more with idea that individual was personally culpable, needed punishment

Substance-related terminology is often a contentious topic because terms may convey meanings that have stigmatizing consequences and present a barrier to treatment. Chief among these are the labels, “abuse” and “abuser.”
Implications

➢ Even well-trained clinicians judged same individual differently and more punitively depending on which term exposed to

➢ Use of “abuser” term may activate implicit cognitive bias perpetuating stigmatizing attitudes—could have broad effects (e.g., treatment/funding)

➢ Let’s learn from allied disorders: people with “eating-related conditions” uniformly described as “having an eating disorder” NEVER as “food abusers”

➢ Referring to individuals as having “substance use disorder” may reduce stigma, may enhance treatment and recovery

Stop Talking ‘Dirty’: Clinicians, Language, and Quality of Care for the Leading Cause of Preventable Death in the United States

A patient with diabetes has “an elevated glucose” level. A patient with cardiovascular disease has “a positive exercise tolerance test” result. A clinician within the health care setting addresses the results. An “addict” is not “clean”—he has been “abusing” drugs and has a “dirty” urine sample. Someone outside the system that cares for all other health conditions addresses the results. In the worst case, the drug use is addressed by incarceration.

• Avoid “dirty,” “clean,” “abuser” language

• Negative urine test for drugs

http://www.amjmed.com/article/S0002-9343(14)00770-0/abstract
ADDICTIONARY

IF WE WANT ADDICTION DESTIGMATIZED, WE NEED A LANGUAGE THAT'S UNIFIED.

www.recoveryanswers.org

The words we use matter. Caution needs to be taken, especially when the disorders concerned are heavily stigmatized as in substance use disorders.
Together, recovery is possible.
g.co/recovertogtherer
Anyone can support the recovery movement

With your words

The leaders of the modern recovery movement ask us all to be thoughtful with the words we use around addiction and recovery. Some common terms, even those historically used by those in recovery, can reinforce stigma and even discourage people struggling with addiction from seeking treatment. Here are some that label people or inadvertently pass judgment, with advice on how to replace them with objective descriptions of symptoms or behaviors.

<table>
<thead>
<tr>
<th>Old Term</th>
<th>Replace with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addict/Alcoholic/Junkie</td>
<td>a person with, or suffering from, addiction or substance use disorder.</td>
</tr>
<tr>
<td>Lapse/Relapse/Slip</td>
<td>neutral terms such as “resumed,” or experienced a “recurrence” of symptoms.</td>
</tr>
<tr>
<td>Clean</td>
<td>terms like “in remission or recovery”</td>
</tr>
<tr>
<td>Dirty</td>
<td>a person having positive test results or exhibiting symptoms of substance use disorder</td>
</tr>
</tbody>
</table>

Visit the Addictionary from the Recovery Research Institute for more terminology and guidance.
February 08, 2019

Addictionary

The Recovery Research Institute at Massachusetts General Hospital and Harvard Medical School has developed the Addictionary, a very useful tool when writing or discussing addiction and people with addiction and in recovery. According to the site, “The words we use matter. Caution needs to be taken, especially when the disorders concerned are heavily stigmatized as in substance use disorders.”
ISAJE editors adopted consensus statement advocating against use of stigmatizing language like “abuse” “abuser” “dirty,” “clean” in addiction science in 2015

http://www.parint.org/isajewebsite/terminology.htm
Impact around the U.S. and world…

- ONDCP – White House Office of National Drug Control Policy - efforts to change SUD terminology to reduce stigma
- NIH, SAMHSA, website/literature changes; SGR (2016)
- U.S. Associated Press (AP) style guide update on SUD
- World Federation for the Treatment of Opioid Dependence
- The European Pain Federation EFIC
- International Association for Hospice and Palliative Care
- International Doctors for Healthier Drug Policies
- Swiss Romany College for Addiction Medicine
- Swiss Society of Addiction Medicine

…Also, called on medical journals to ensure that authors always use terminology that is neutral, precise, and respectful in relation to the use of psychoactive substances.
Our national institutes on addiction have “abuse” embedded in their names... This needs to change
Change the Name: End the Stigma

SENATOR PATTY MURRAY, SENATOR LAMAR ALEXANDER, REPRESENTATIVE FRANK PALLONE JR., AND REPRESENTATIVE GREG WALDEN

Change the Names, Remove "Abuse"

The term "Abuse" is embedded in the names of our national institutes on addiction, and gives rise to the term "drug abuser." Saying someone is a "drug abuser" causes others to see them as needing punishment instead of treatment, compared to describing them as having a substance use disorder.

Research shows this to be true among both the general population AND clinicians. "Abuse" has no place in the names of our national addiction institutes:

- National Institute on Drug Abuse
- National Institute on Alcohol Abuse and Alcoholism
- Substance Abuse and Mental Health Services Administration

FACES & VOICES OF RECOVERY

#Changethenames; #Endthestigma

The words that we use matter. Stigma has been identified as a barrier to treatment and recovery among individuals with addiction. Research shows that the commonly used term, "abuse," increases stigma.

Now is the time to tell Congress that national government agencies with words like "abuse" must undergo a NAME CHANGE (e.g., National Institute on Drug Abuse [NIDA], National Institute on Alcohol Abuse and Alcoholism [NIAAA], and Substance Abuse and Mental Health Services Administration [SAMHSA]).

Abuse is a disease. Using words such as "abuse" or "abuser" implies that addiction is a character flaw. It takes an act of Congress to change a government agency name, so support is needed at all levels.

This petition was prompted by the recent brief authored by Dr. John Kelly and Valerie Earnhardt, PhD and published by the Society of Behavioral Medicine. The brief, entitled "End the Stigma: Change the Names of Our Federal Institutes on Addiction," (attached).

https://actionnetwork.org/petitions/change-the-name-end-the-stigma
Recommended language examples…

Don’t say…

• “drug abuser”
• “alcoholic”
• “dirty urine”
• “heroin addict”

Instead, say…

• “Person/individual/patient with a substance use disorder”
• “Person/individual/patient with an alcohol use disorder”
• “The urine was positive/negative for….”
• “Person/individual/patient with an opioid use disorder”
References


References

Resources

- Google’s Recover Together resources page (https://recovertogether.withgoogle.com/)
- MOAR assorted Resources page (https://www.moar-recovery.org/resources)
- NIDA News & Events (https://www.drugabuse.gov/news-events)
- recoveryanswers.org from the Recovery Research Institute (https://www.recoveryanswers.org)
- Addictionary® from the Recovery Research Institute (https://www.recoveryanswers.org/addiction-ary/)
- Multimedia and Infographics from the Recovery Research Institute (https://www.recoveryanswers.org/media/)
Thank you for your attention!

Enhancing Recovery Through Science

recoveryanswers.org

Recovery Research Institute

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