Findings & Recommendations from the NYS Buprenorphine Consumer Listening Sessions

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Purpose of Buprenorphine Consumer Listening Sessions

• Gather qualitative data from people with buprenorphine consumption and/or treatment experience

• Report back to NYS Buprenorphine Working Group (BWG) to incorporate the experiences of people directly impacted into developed recommendations

• Assess the interest of potential members of a Buprenorphine Consumer Advisory Group (BCAC)
Participant Sample

• 51 people interviewed
• Buffalo, Albany, Rochester, Long Island, NYC, Batavia
• Taken buprenorphine at one time
  • Current or former experience
  • Prescribed or non-prescribed
• Interviews conducted in-person, over the phone, or email correspondence (within a group setting or individual)
• Each participant received $25 Visa gift card and transportation stipend
First Experiences with Bupe

First learned/heard about bupe
  • Within drug using community, family, or friends
  • Helps to medicate withdrawal symptoms

First time taking bupe
  • Non-prescribed (through diversion)
    • Precipitated withdrawal was common
    • No knowledge of precipitated withdrawals until experienced
  • Prescribed
    • Feelings of immense relief
    • “Miracle drug”
Benefits of Taking Bupe

- Helps with cravings and withdrawal
- Preferred over methadone
- Helps with pain management
- Provides stability
- Helps other mental health issues (i.e. depression, anxiety)
- Boosts motivation and energy throughout the day

“I feel great, I run 3 miles every morning, lost 30 lbs, and I’m starting to lift weights now.”
Barriers to Treatment

- Waiting list
- Stigma seeking a provider
- Visits prior to induction (3 initial visits or a psych eval)
- Required negative urine tox screens (for opioids and/or benzos)
- Travel distance to prescribers (driving 2 hours each day for a week of in-office inductions)

“I know some people who died because they couldn’t get treatment.”
Reasons for Discontinued Treatment

- Suicidal ideations
- Missed counseling sessions
- Positive urine toxs (zero tolerance for any drug)
  - Several claims of false positives
- Finding out about diversion (sharing among partners)
- Tapering was rare
- Some referrals to other prescribers but not taking more patients
- Discontinued treatment always resulted in diversion or return to other opioid use

“No one would believe me it was a false dirty. I went into labor the next day and I was 8 months pregnant.”
Community-based Diversion

• No one reported buying bupe ‘off the street’ or within the community for recreational purposes
• Experiences of incarceration were the only noted experiences of people buying bupe for recreation
• Often bought bupe from a friend or family member to self medicate their own withdrawal
• Bupe was generally reported to be more expensive on the street than heroin (depending on location prices ranges but roughly $10 more)

“It is easier to get heroin than buprenorphine.”
Consequences of Precipitated Withdrawals

• If taken non-prescribed, most had no knowledge of precipitated withdrawals

• Learned from adverse experiences

• Expressed thoughts of suicide or homicide

• Many were fearful to take bupe again but wanted to
  • Currently on methadone or using non-prescribed opioids

“I took bupe after an hour of taking methadone and thought I was going to die. I went into convulsions and woke up in the hospital. That is when I learned you can’t mix [methadone and buprenorphine]. If someone, would have told me, I would have never done that.”
Women and Pregnancy

- Most were unplanned pregnancies
- Denial of pain medicine during labor
- Stigma among hospital staff
- Preferred buprenorphine mono-product
- Desire to split dosing
- Difficulty finding OBGYN prescribers
- Child welfare stressors
- All reported healthy babies/children

“I was told [by a prescriber] that I was in no position to care for myself let alone another human being. I wanted to switch my doctor but I was 8 month pregnant on Subutex. I couldn’t go anywhere while 8 months pregnant, no one would take me [on as a patient].”
Incarceration

• Not provided in jails (except Rikers) or prisons even if already prescribed
• Did not keep it properly
• Only noted experiences of people buying bupe for recreation
• Diverted to treat withdrawal symptoms (roughly $80 for 8mg)
• Guards making fun of inmates in withdrawal
• Suicides or suicide attempts while in withdrawal (few reports of hanging)

“I knew a girl in withdrawal who jumped off the top tier.”
Additional Key Themes

• Denial of pain medicine due to buprenorphine prescription
  • Even in reports of being shot, broken bones, dental work

• Other forms of consumption
  • Injection common with most severe precipitated withdrawal symptoms
  • Injection associated with problems with intense, permanent swelling in arms and legs

• Partners sharing one prescription

• Going to the ED specifically for withdrawal symptoms

• Observed urines or strip searches at every appointment
Recommendations

• Education!
  • Community-based (i.e. harm reduction programs, pharmacies, drug using communities, general public)
  • What to expect from a prescriber or navigating medical procedures (i.e. induction procedures, stabilization, maintenance, length of treatment plan)

• Anti-stigma campaigns in community and medical settings

• Availability in corrections

• Greater leniency for urine tox screens

• Formulation changes—easier switch from methadone, less physical dependence, taste changes
Recommendations Continued

• Eliminate consequences of diversion
• Increase availability in EDs
• Provide support for stable housing and transportation
• Focus on aging population—patients on Medicare
• Financial support for prescription co-payments
• Eliminate patient capacity
• Additional training for prescribers
• Video of real-life experiences and case scenarios
• If treatment is discontinued, prescribers should be required to taper patient
Takeaways

- Clear structured recommendations seemed challenging
- A lot of interest in future bupe consumer group involvement
- Very much appreciated listening sessions
- Future champions already identified
Questions?

For full transcripts email Medley@harmreduction.org