Maximally Supportive Care: Creating SUD Systems to Improve Engagement and Retention

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ASAM April 6, 2024

Disclosure Information (Required)

- Presenter 1: Eowyn Rieke MD MPH FASAM
  - – No Disclosures

Motivation for this talk

We have worked so hard to reduce barriers to care

Still:

- 48.7 million people in the US have a substance use disorder 40% of the moderate or severe

- 94% of people with a substance use disorder do not receive treatment

- retention in buprenorphine care at 6 months averages 35-45%, as low as 21% among unhoused people

- more and more people are losing hope: they think it is impossible to get on buprenorphine, or impossible to stay on

Fine (2021), Krawcyk (2021), SAMHSA (2021) SAMHSA (2022)

Learning Objectives

Using buprenorphine services as our primary example, you will

- Understand opportunities and challenges to providing substance care that is highly accessible and flexible: “minimally disruptive”, “low threshold”, “low- or no-barrier”
- Appreciate the importance of proactive connection, kindness and understanding in SUD care: “maximally supportive”
- Appreciate the important role of voices of people using drugs in all components of substance use care, from research to program design and implementation
- Select 1 strategy to improve engagement and retention in your current care setting, explore implementation challenges and determine next steps

What is medical care like NOW for people who use drugs??

- Survey
  - 22 residential patients
- Describe their experiences of health care: pick 3-5 words from a list of 15 pairs of opposites
  - e.g. comfortable and uncomfortable, easy and difficult

What is medical care like NOW for people who use drugs??

Care that is Minimally Disruptive, including Low Barrier, No Barrier, Low Threshold

Definitions

- Minimally disruptive medicine (MDM) is a framework that focuses on achieving patient goals while imposing the smallest possible burden on patients' lives
- Low Threshold characteristics: same-day treatment entry, flexible scheduling, multiple appointment modes (telehealth, video, in person), harm-reduction approach, and wide availability in places where people with opioid use disorder go
  - Increased patient retention and satisfaction
  - Flexibility and informal structure not for everyone

Carlberg-Racich 2022, Englander 2023, Gertner 2022, Hassan 2022, Hsu 2023, Jakubowski 2013, Lowenstein 2023, Sue 2022

Location of care

Co-locate with Traditional Health Services

- Proximity < 5 miles
- Primary care
  - “anonymous normalcy”
- Infectious disease clinics, prenatal care, other medical services
- Mental health services
- Emergency Rooms
- Bridge Clinics

Cioe 2020 Falade-Nwulia 2023, Incze 2023, Jegede 2023, Lynch 2022, Sullivan 2021, Tofighi 2022, Villamil 2024, Willis 2023

Co-location and Integration Challenges

- Patient concern about stigma and desire for siloed care
- Staff stigma and negative attitudes about buprenorphine
- Different belief systems among staff and community partners
- Lack of knowledge about substance use care
- Inadequate admin support
- Challenges of ongoing patient engagement with
- Lack of flexibility, especially prescribing and scheduling

Every time I see my GI doc he asks me when I'm going to get off of bupe. Every time. I'm so tired of feeling like I have to educate him

BHC

Austin 2023, Kapadia 2021, Kapadia 2022, Lindenfield 2023, Poulsen 2023, Taylor 2021, Weinstein 2020

Integration into Less Traditional Sites

- Mobile outreach
  - Medical vans
  - Street Medicine
- Harm Reduction Programs
  - Syringe Service Programs
- Overdose Prevention Clinics/Safe Consumption Sites
- Emergency Medical Services
  - 3/76, 36/year

Hood 2020, Jakubowski 2022, Stewart 2023

Challenges to Mobile Services

- Publicizing: word of mouth limits access, consider peer
- Logistics: inclement weather and lack of privacy, lack of anonymity
- Importance of maintaining consistent staff and scheduling to maintain engagement and foster trust
- Need brick and mortar back up?
- Resource investment: van driver, maintenance, parking, overnight parking

Grieb 2022, Lowenstein 2023

Telehealth

- Video or audio only
- High patient satisfaction
- Retention similar or increased compared to in person
  - Telehealth 180 days 69.1% compared to 27-31%
  - Risk of discontinuation 71% lower for remote telemedicine, 51% onsite telemedicine
- Improved initial access and retention especially for marginalized and minoritized, compared to in person visits:
  - African Americans
  - Unhoused
  - Rural
- Overdose/poisoning rate reduced

A visit every week? 2 weeks? No way can I keep my job and do that. So I love phone visits because now I can do them during my work breaks. *AJ*

Frost 2022, Ghosh 2022, Guille 2022, Krawczyk 2023, Lin 2022, Nguyen 2023, Tomlinson 2022, Ward 2022, Weintraub 2021, Williams 2022

Telehealth Challenges

- Impact on empathy/relationship
- Privacy
  - Impact on disclosure, depending on patient location
- Technology challenges
  - Access to phone/tablet, minutes, charger, internet, cell service
  - Answering blocked calls
  - Understanding of technology
- Missed appointments

Janie at Plaid Pantry totally hooked me up with a phone for my appointments. Until she got another job, then I didn't have any way to get the calls. DW

Ghosh 2022, Kang 2022

Other factors in low-threshold care

Logistics: Time, Transportation

- Same Day
  - 6.9x more likely to attend same-day appointment, 1.7x next day
- Night and Weekend Services
- On Demand
  - Bridge Clinic via hotline
- Transportation
  - Esp for unhoused, rural, poor public transportation, underresourced

Fine 2024, Roy 2020

Medication Flexibility

- Buprenorphine monoproduct
  - What is impact of adverse effects from naloxone?
- Tablets or films
- Doses > 24 mg
- Readily available injectable buprenorphine
- Careful attention to transition on to buprenorphine
  - “Low and Slow”, adjunctive meds, social situation
- Medications for Post Acute Withdrawal Syndrome

Grande 2022, Grande 2023, Gregg 2023

Urine Toxicology Requirements

- Patients report they are highly stigmatizing and traumatizing
- Minimal data on impact of UDS testing on treatment
  - Canada Opioid Agonist Therapy Clinic: increased retention at 1 year with weekly testing
- Before requiring consider:
  - Are they necessary?
  - How will results impact treatment plan?
  - Is the trauma to patients worth the impact on treatment plan?
- If requiring
  - Be clear about expectations and how results will be used

Khatri 2021, McEachern 2019, Morin 2022

Pharmacies

- Stigma, supply, refusal to dispense, insurance issues
  - 1/3 patients had trouble filling. OR of use with med challenges: 8.9
  - Secret Shopper Suboxone available for pick up 31%
  - High overdose counties: 20% pharmacies would NOT fill
- Onsite pharmacies
- Medical-pharmacy collaborations
- Pharmacist education
- DEA and HHS have made “adequate and uninterrupted supply of MOUD” a priority

Carpenter 2024, DEA 2024, DiPaula 2015, DiPaula 2023, Green 2023, Kazerouni 2021, Muzyk 2019, Noel 2023, Tutag 2023, Winstanley 2022, Wu 2021

Technology Assisted Treatment

- Apps
  - Peer support
  - Med reminders
  - Motivational messages
  - Contingency Management

All this innovation is still not enough

- Desperate fear of precip: people losing hope
- Buprenorphine harder to initiate, not as effective in reducing cravings and may not block euphoric effect of high potency synthetic opioids
- Characteristics of fentanyl and analogs make abstinence especially challenging
  - Very inexpensive, readily available
  - Profound anxiety with cessation

"It sends me into precipitated withdrawals every fucking time that I try to get off of fentanyl. I keep trying but sometimes I feel like I should just give up on bupe and accept the inevitable.
LR

Dasgupta 2018, Pilarinos 2023, Shearer 2021, Silverstein 2019, Sue 2022

“It's long past time we recognize the meaningful role we play in one another's lives. The scientifically proven positive influence of kindness, inclusion, and compassion (versus the negative effects of stigma, rejection, and isolation) cannot be ignored.

Barbara Lodge

The Chocolate Chip Cookie Theory: Maximally Supportive Care

AKA

How can we make care so good that people want to engage and want to stay?

Lodge 2022

What do people want in care?

- Informal Survey
  - 22 residential patients

What do people want in care?

- Trauma Informed Care + Harm Reduction + Common Humanity
  - Safety, Autonomy and Collaboration
  - Appreciation and Understanding
  - Connection, Authenticity and Spirituality

Safety

- People feel neither physical or emotional safety in SUD care
  - Historical alienation
    - 5x positive for each negative
  - Unpredictability of buprenorphine transitions
  - Stigma
- Expressing support for harm reduction principles increases patient trust

> *When I go to the ER I feel like they are thinking 'Kindly fuck off and go die in the street.'*
> *RS*

O'Brien 2022

Autonomy

- People self-treat out of desire for autonomy
  - Use of non-prescribed more common when autonomy is a priority
    - May lead poor outcomes and patient unwillingness to try medication again
- Many programs, especially higher levels of care, have inflexible rules and requirements that can be especially challenging for people with a history of trauma or institutionalization

Hayes 2021, McLean 2019

Collaboration

- Patient Centered Care
- Collaborative Care
- Shared Decision Making
  - Improve drug use decision-making and psychiatric problems
- Goal setting
  - Prioritizing patient-identified needs builds trust and increases engagement
    - emotional well-being, decreased drug use, and attendance to basic functioning
    - Being happy, having hopes, dreams, and goals for the future, having self-worth

Austin 2024, Joosten 2009, Marchand 2019, Reed 2023, Watkins 2017

Appreciation and Understanding

- Focusing on strengths and achievements
  - Praise and recognition. Acknowledge every positive thing you can
  - Fun activities, joy
  - “You are a superhero. You inspire me.”

- Knowing people as individuals
- Understanding circumstances
  - Incentives/Contingency Management
    - “justify the effort needed to sustain term abstinence”
    - “Where’s the book guy?”

> *I would like to think that given the opportunity that people [medical providers] would see that we are human and they just haven’t had the chance yet. EG* long-

Holtyn 2021, Lodge 2022, McKay 2017, Winograd 2023

Connection, Authenticity and Spirituality

- “Treated like a human being”
- Respectful, encouraging interactions with staff facilitate engagement.
- Peer involvement
- Spiritual well-being
  - Higher spiritual well-being and social connectedness associated with less frequent substance use

Most of the time they treat us like shit. But those times when someone makes even the littlest effort to understand what I’m going through, that makes all the difference. *FT*

Kapadia 2023, Kane 2023, Lowenstein 2023, Lodge 2022

Challenges to Maximally Supportive Care

> *How do you beat 50c a blue? You have to reach into people's hearts People have to feel that they are worth it. That takes time. It is an investment.* *AC*

- Time and money
- Organizational philosophy
- Staff training
  - Countertransference can lead to a host of negative feelings including anger, shame, hopelessness.
    - *"Degrading and dehumanizing attitudes toward people with substance use disorders could stem from internalized negative societal constructs against disenfranchised, minoritized, and stigmatized persons.*
- Staff burnout
- External partners who do not share philosophy

Alfonso 2023, Lindenfield 2023

How can we build systems that are responsive, flexible and loving when we are so busy managing the day to day of the changing drug supply, staff shortages, financial challenges and so much more?

Centering the voices of people with lived and livING experience in all aspects of SUD care

Satisfaction Surveys: Not Enough

- Not always accurate
  - May not ask about unmet needs
  - Low expectations: “not awful”
  - Fear of losing access to care
  - Social etiquette
- Satisfaction surveys often do not reflect the values, needs and experiences of people in SUD services
- Models of inclusive satisfaction surveys: Vancouver and Alberta Canada

Currie 2020, Lowenstein 2023, Olding 2018, van der Sterren 2023

Research

- Community Based Participatory Research gives us a chance to elevate voices of people using drugs, address equity concerns and increase power of vulnerable people
- People using drugs often have more insight in to the current drug market, effects of different substances and best ways to engage people who use drugs in services
- Researchers with previous or current substance use can provide unique insight

Afifi 2020, Damon 2017, Salazar 2021, Souleymanov 2016

Service Codesign

- Codesign: an innovative process that ideally integrates equal input from both care providers and service recipients, who jointly identify issues and then collaboratively design an improved approach to care
- From tokenism to empowerment
- Compassion, Inclusion and Empowerment Initiative
  - Vancouver BC effort to involve people with lived experience in planning, design implementation, and evaluation of services

If I can help one person by talking about all my mistakes, I guess that makes it les awful. It gives me some hope to help make things better.
EG

Bosak 2023, Hussey 2019, Larkin 2015, Maguet 2023, Ocloo 2016

Consumer Advisory Board

- For an organization, a service or a region
- Great resources are available!
- May need to provide education and training to members
- Must be a board that has influence and power, not just performative

Danforth 2023, Drug User Health Advisory Group 2017

Consumers as Organizational Leaders

- Build organizational positions and priorities
- Similar to DEI movement
- Inherently challenging to existing hierarchies and decision-making structures

Principles for Consumer Involvement

- Be clear about expectations and how information will be used
- Pay for time and expertise, ideally with cash
  - Pay for transportation
  - Be clear about payment requirements and logistics
- Promise only what you can deliver
- Maintain strict confidentiality
- Provide information in multiple formats: verbal, written with close attention to literacy levels

Draus 2005, Festinger 2008, Seddon 2005, Souleymanov 2016, Striley 2011

Principles for Consumer Involvement

- Locate in place that is familiar and comfortable to consumers
- Provide food and drink
- Build multiple ways to engage
  - One-off
  - Short-term
- Be clear about participant expectations including attendance, input, substance use before and during events
- Provide extra support to facilitate engagement and communication
  - How To Be In The Room guidebook
- Share results/report with participants before making public
  - Legacy of exploitation

Balian 2010, Canadian Association of People who Use Drugs (2021), Draus 2005, Festinger 2008, Seddon 2005, Souleymanov 2016, Striley 2011

Participant Recruitment Considerations

- What is your goal? Who should you recruit?
  - People currently enrolled in your organization's services
  - Previous patients
  - People not accessing services at all
- Be aware of power dynamics
- Diversity
- Safety: participants may
  - Use on-site
  - Be substance affected
  - Be re-traumatized

Shoot the Sh*t, March 2024

- Gathering of people using community harm reduction services and medical leaders
- The Everly Project and Portland People's Outreach Project co-sponsored with recruitment, space and food
- ORSAM co-sponsored with recruitment, organizing, $$ for food, stipends, space
  - $50/participant CASH
- 2 hours pizza and beverages for informal conversation and relationship building

Shoot the Sh*t, March 2024

- Let go of expectations
- Be flexible
- Have a sense of humor!

Participant Recruitment

- Community organizations
  - Harm Reduction
  - Social Service
- Peer networks
- Drug User Unions

What change could you make?

- What change could you make in your setting?
  - Reduce barriers to care
  - Increase comfort and connection
  - Elevate patient voices
- Start simple, manageable, achievable
- See worksheets on tables

Small Group: 20 min

- What change do you want to make?
- What impact will this have?
- Who will help you make this change?
- What are the first few steps?
- Which of these steps can you do NOW? (call, text, email, schedule meeting)

- 5 – 10 min solo work
- 10 – 15 min discuss with people at your table

Activities

Visual settings

Edit

When poll is active respond at **PollEv.com /eowynrieke980**

Send **eowynrieke980** and your message to **22333**

Maximally Supportive Care: Practice and Program Changes

Nobody has responded yet.

Hang tight! Responses are coming in.

Final Takeaways

- There are many strategies to create low-threshold substance use care: each has significant pros, cons and strategies for success.
- We need to go beyond services that are easy to access: we must make care Maximally Supportive or so good that people look forward to it. Key principles include safety, autonomy, collaboration, connection and authenticity
- We must amplify and center the voices of people using drugs in all components of substance use care, from research to program design and implementation
- Ultimately, we heal together. When we are authentic, humble and caring with patients we will all be more successful.

Thank you!!!!

- Coauthors: Andy Cho, Andrea Chiavarini, Elona Dellabough-Gormley, Alice Mollo-Christensen, Brandy Simmons-Fishback, Annie Demotta and Brandy Benedict
- Everly Project
- Portland People's Outreach Program (PPOP)
- Patients at Fora Health
- People who use drugs for teaching me so much!

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