Radical Accompaniment:

Caring for Seriously Ill Patients Who Use Substances

Mountain West AIDS Education and Training Center
Addiction Medicine Webinar
September 20th, 2023

Emma Wonsil, LICSW-A, MHP
Behavioral Health Social Worker
Adult Behavioral Health
Catholic Community Services

Michael A. Light, LICSW, MPH, APHSW-C
Palliative Care Social Worker
Harborview Medical Center
Co-Director
UW Palliative Care Training Center

Positionality Acknowledgement

Emma

- White
- Cis Woman
- Lesbian (she/they)
- Born in USA
- Family language: English
- Highly educated, middle class family of origin
- “12-step” family
- No experience of active, chaotic substance use
- Experience of mental illness/neurodivergence
- Independently housed
- No experience of homelessness
- No military service
- Roman Catholic tradition
- Full Code/Longevity Goal

Michael

- White
- Cis Male
- Queer (he/they)
- Born in USA
- Family Language: English
- No Experience of Disability
- No History of Substance Use Disorder
- History of Mental Illness
- Independently Housed
- History of Homelessness
- No Military Service
- Middle Income Family
- Unitarian Universalist; Raised Christian
- Full Code/Longevity Goal

- These identities shape our experiences, worldview, beliefs and access to resources
- We come from social positions that have experienced and caused harm
- People with oppressed and marginalized identities disproportionately experience harm and lack access to equitable care
- We have “outsider status” to many of the identities and experiences of our patients

Learning Objectives

1. Explore issues at the intersection of substance use and end-of-life.

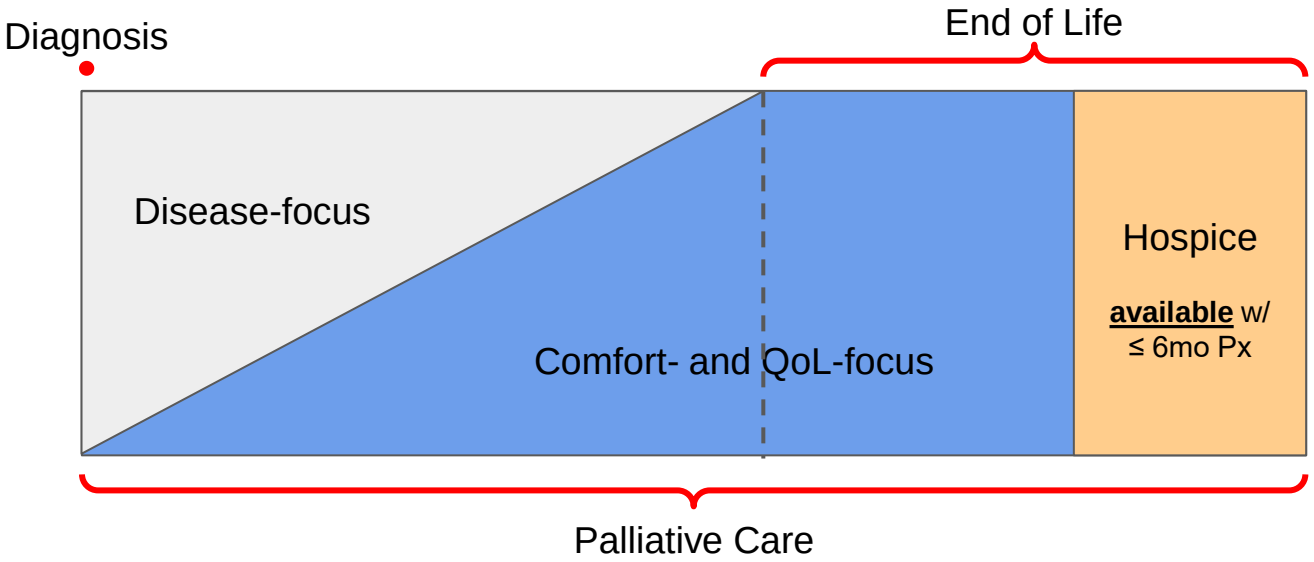
2. Identify the role of moral distress and moral injury in patient care.

3. Implement skills to communicate about patients' substance use and providers' commitment to non-abandonment and radical accompaniment.

What is your learning goal?

Who Are We Talking About?

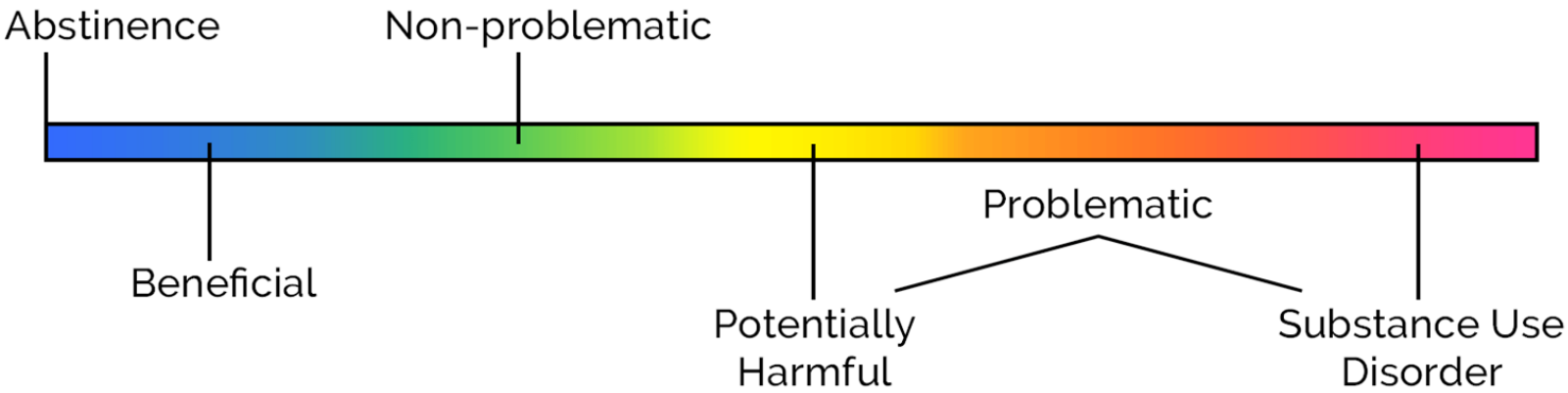
Serious illness: “a health condition that carries a high risk of mortality and either negatively impacts a person's daily functioning or quality of life or excessively strains… caregivers,” (CAPC, 2019).



Who Are We Talking About?

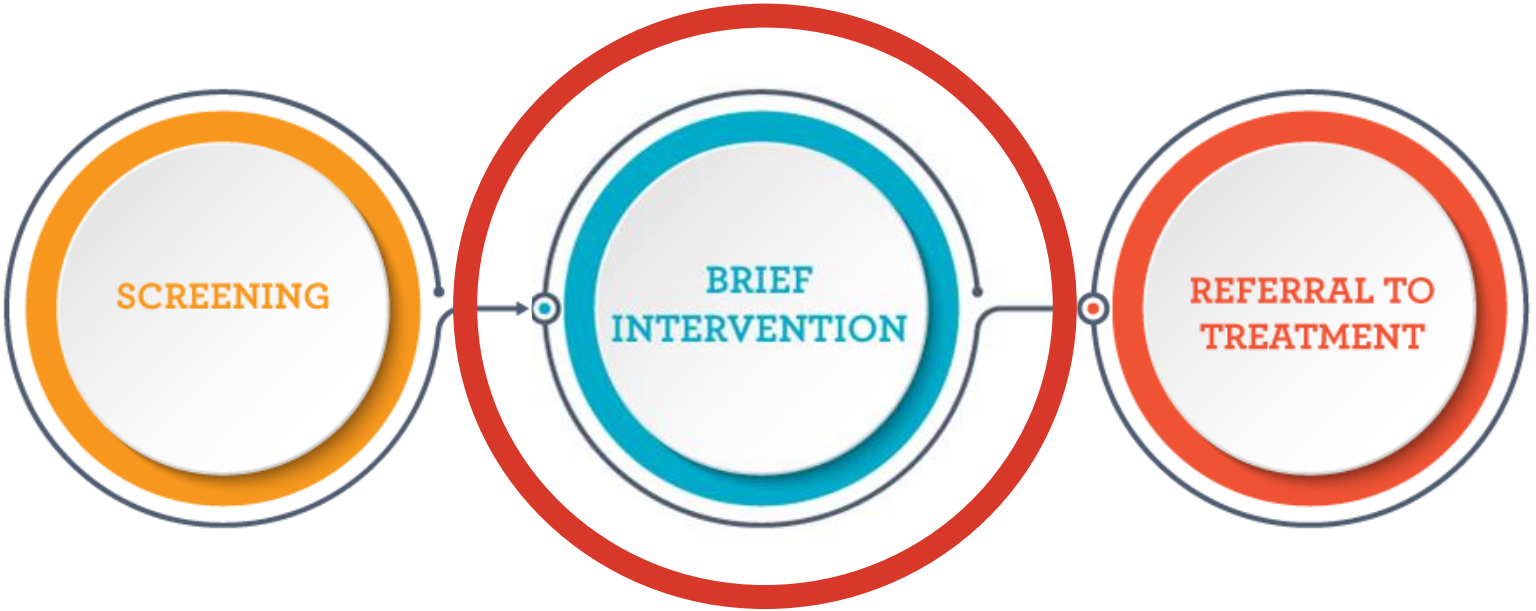
People Who Use Substances (PWUS)

Note: some people who use drugs may use different terms to self-identify



First Nations Health Authority (2013). A path forward: A provincial approach to facilitate regional and local planning and action. /www.fnha.ca/documents/fnha_mwsu.pdf

Who Are We Talking About?



Bring It In

Think of a patient you cared for who was experiencing serious illness and a significant substance use disorder

Patient Name/Pseudonym: _____

Write 2-4 sentences about their health situation and course of care.

What is/was most challenging in providing care for them?

People Who Use Substances & HIV

Transmission	• Data focuses on people who inject drugs (PWID)[1] • PWID accounted for 10% new HIV Dx in 2018[1]
Serious Illness Trajectory	• Less likely adherent to take life-saving HIV medication[2] • Use may increase viral load & accelerate disease progression[2,3] • Risk for other disease and infections[2]
Mortality	• Moderate & excessive EtOH use increased mortality by 25-35%[4] • PWID account for nearly 1/3 of HIV deaths in 2018[5]

1. CDC, 2020 2. NIDA, 2020 3. Dash et al., 2015 4. Petoumenos & Law, 2016 5. CDC, 2022

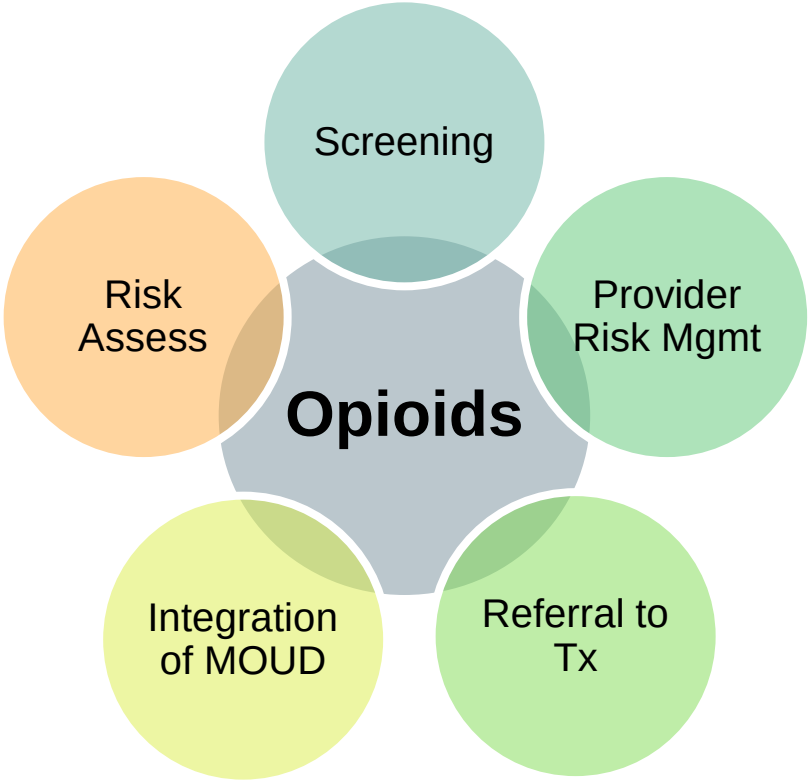
Systemic Factors & PWID with HIV

Selected Characteristics Among PWID With HIV in 23 US Cities, 2018

Social and economic factors may limit access to HIV treatment services among PWID with HIV.

Source: CDC. HIV infection risk, prevention, and testing behaviors among persons who inject drugs–National HIV Behavioral Surveillance: injection drug use – 23 U.S. Cities, 2018. *HIV Surveillance Special Report* 2020; 24.

Current Literature



Substances other than opioids

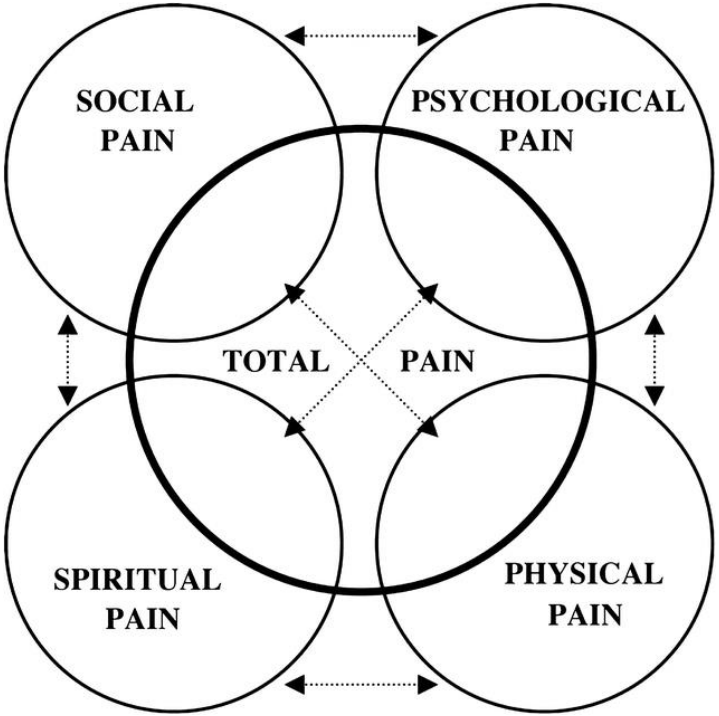
Psychosocial aspects of patient care

Patients not pursuing abstinence/change in use

(Groniger & Knapik, 2019; Wells-Di Gregorio, 2022)

Patient “Complexity”

Complex Expressions of Distress



- **Cumulative Loss**
- **Historical & Generational trauma**
- **Institutional Oppression & Structural Violence**
- **Complex Guilt & Shame**

Bring It In

Think of a patient you cared for who was experiencing serious illness and a significant substance use disorder

Patient Name/Pseudonym: _____

Write 2-4 sentences about their health situation and course of care.

What is/was most challenging in providing care for them?

How does/did the experience of proving care feel for you?

Moral Injury

Moral injury is the “lasting psychological, biological, spiritual, behavioral, and social **impact** of **perpetrating, failing to prevent, or bearing witness** to acts that **transgress deeply held moral beliefs** and expectations,” (Litz et al, 2009)

Moral Distress vs Moral Injury

	Moral Distress	Moral Injury
Definition	Making a moral judgement and desired plan but obstructed by an organization or more powerful agent	Perpetrating, failing to prevent, or bearing witness to acts that transgress deeply held moral beliefs and expectations
Responsible Actor	The organization or more powerful agent impeding the moral action	The individual PROVIDER of care taking an action
Impact on individual	Psychological/emotional distress (guilt, blame, anguish, sorrow) that can lead to functional impairment.	Psychological/emotional distress that can lead to functional impairment; Emotional wounding resulting in internal dissonance.

Underlying Moral Injury

Friction with “deeply held moral beliefs & expectations.”

In the chat…

What informs the values, beliefs, and expectations that guide our care?

- **Our identity as care providers, healers, or workers?**
- **Our professional guidelines and values?**
- **Our feeling of competency in providing care & solving problems?**
- **Our own experiences with substances in our lives?**
- **Our positionality?**
- **Our bias?**

Impacts on Our Care

FEELING OVERWHELMED?	**SO IS YOUR PATIENT!**
Moral Injury = Empathy Killer	**Lean Into Empathy**

Health Behavior Change

Write a health behavior goal for yourself?

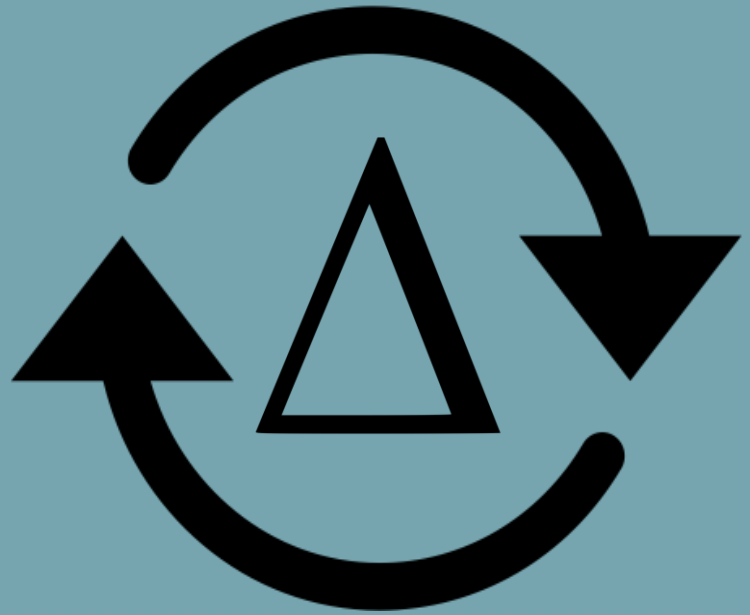
E.g. more exercise, cutting caffeine, sleeping earlier

In the chat…

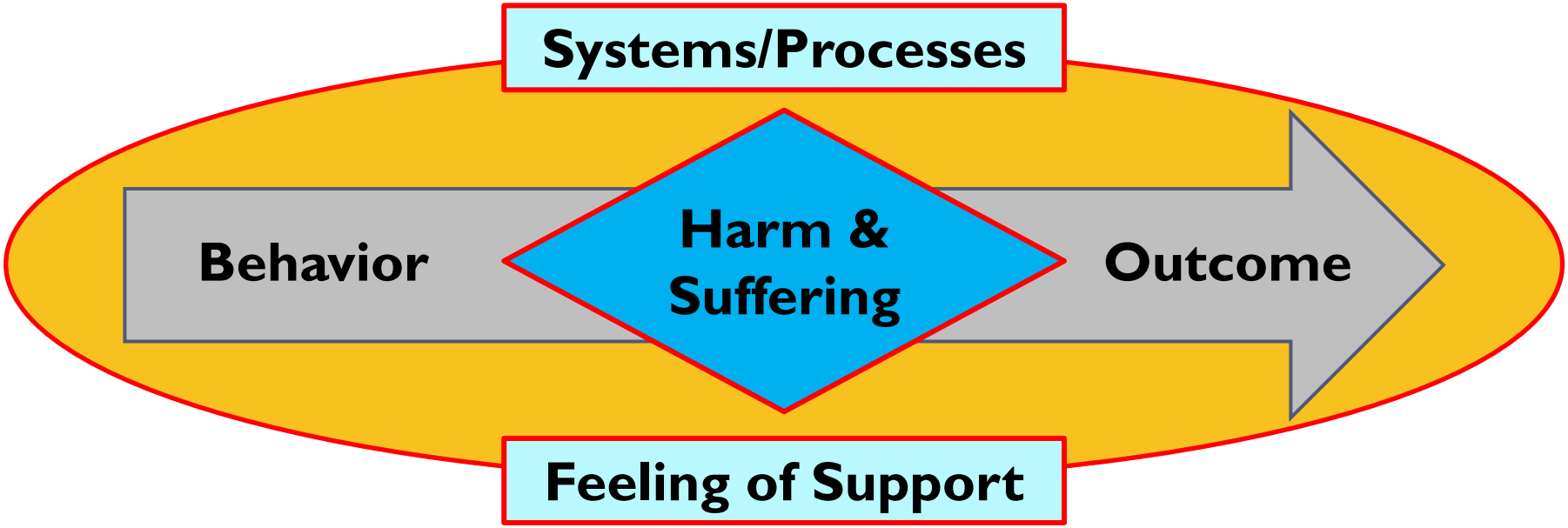
TWO reasons this change is hard

In the chat…

ONE benefit of **NOT** changing

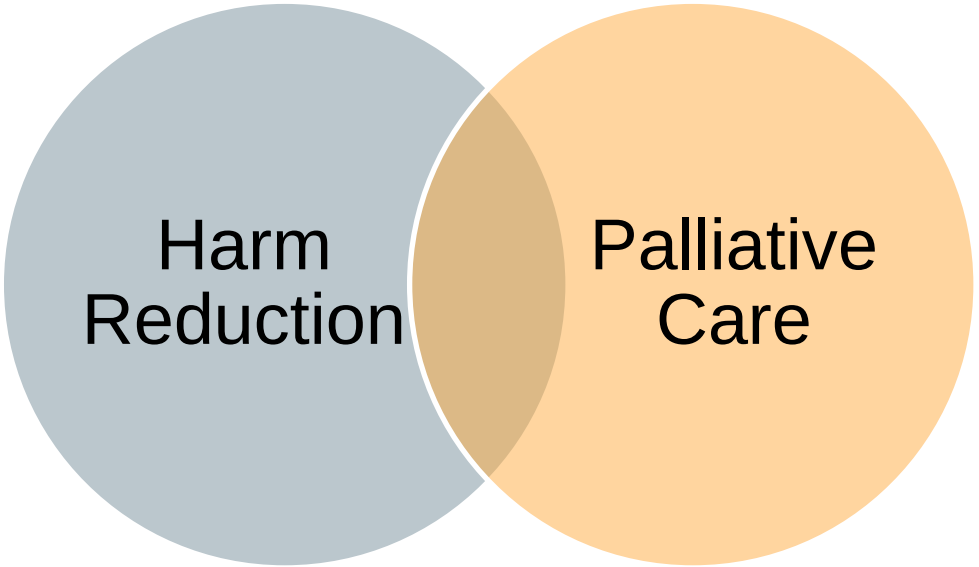


Reorienting Change Strategy



Principles for Approaching Care

- Reduce suffering, not condition
- Focus on quality of life and wellbeing
- Patient voice & autonomy
- Values-aligned, goal-concordant care



National Harm Reduction Coalition, 2020. Principles of Harm Reduction

Shifting Toward Radical Accompaniment

Stance of Nonabandonment

Sagers and Childers (2019) describe utilizing a **stance of nonabandonment** in conversations with seriously ill patients and nonmedical opioid use.

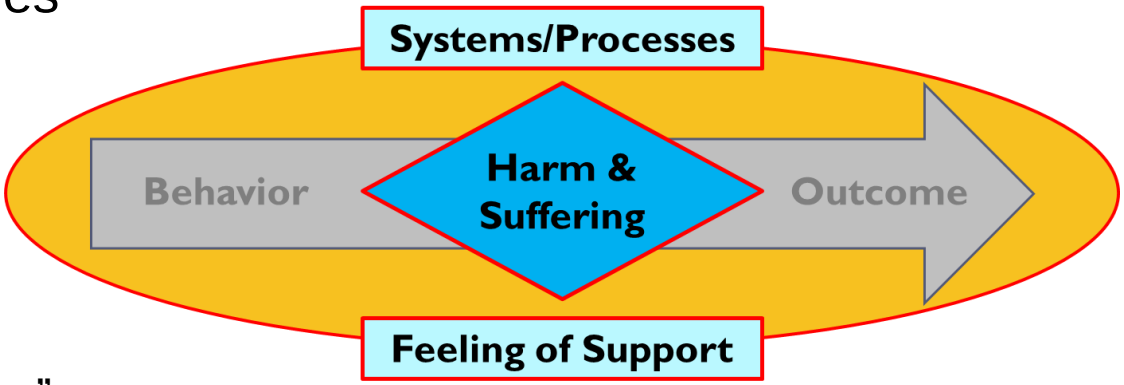
Nonabandonment = “Open-ended, long-term, caring commitment to joint problem solving”

Towards Radical Accompaniment

Nonabanonment: focus on problem-solving and outcomes

Radical Accompaniment: focus on **process** and **relationship.**

- “Sit in the suck”
- From “How do I provide care” to “How do I show care?”



“If they're 49 years old, have an ejection fraction of 15 and they're still using meth - I have to let go of the goal of this person's going to stop meth. **So what do I do to help them? … I try to hear them.** There's something that they're trying to say, and no one's been listening to them and so we just try and understand. I think you have to go in there and have to let it all go. Because they are not able to meet your goals anymore. So what are theirs?”

-Palliative Care Physician

“He got this terminal cancer diagnosis and… his substance use goals aren’t really his focus now—and maybe they shouldn’t be. I feel like now I’m focused on **having a relationship with him until he dies.**”

- Addiction Social Worker

Bring It In

Think of a patient you cared for who was experiencing serious illness and a significant substance use disorder

Patient Name/Pseudonym: _____

Write 2-4 sentences about their health situation and course of care.

What is/was most challenging in providing care for them?

How does/did the experience of proving care feel for you?

What do/did you admire, respect, or love about this patient?

Trauma-Informed Communication Guide to Demonstrate Radical Accompaniment

1. Ask Permission to Discuss Use
2. Start with Perspective Taking
3. Validate Emotions & Experiences
4. Express Concern with Permission
5. Articulate Radical Accompaniment

Adapted from Sagers and Childers (2019)

Skill #1: Ask Permission to Discuss Use

Why We Do It	Example Phrase
● Introduce the discussion ● Share power and respect agency	**“Would it be OK** if we talked together about your substance use?”

What if a patient says no?

Skill #2: Start with Perspective Taking

Why We Do It	**Example Phrases**
● Develop patient-centered narrative about their use, relationship with substances, and goals ● Challenge our projected narrative ● Informs patient-specific responses	“To start, **I’d like to hear from you**. Could you tell me about your **current use and anything you’re concerned about**.”

Skill #3: Validate Emotions & Experiences

Why We Do It	**Example Phrases**
● Explicitly demonstrate listening and empathy ● Affirm and confirm our understanding ● Build alliance and trust in patient/provider relationship	**“I can hear** how much you’re struggling lately.” **"I heard you say** that you’re using more methamphetamine lately and you believe it makes your symptoms worse but you’re not ready to stop using it right now. **Is that right?**”

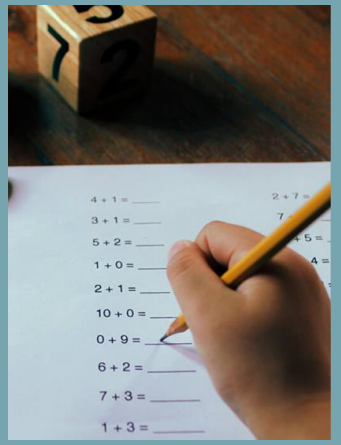
Skill #4: Express Concern with Permission

Why We Do It	Example Phrase
● Reinforce power sharing and agency by asking for permission to share your concern ● Be honest about the deep worry that we have…. Leaning into empathy… ● **TIP:** be succinct and specific	**“Would it be ok** if I share what concerns me?**”** **“I’m worried that** your alcohol use is making your symptoms worse and making it hard for you to tolerate the medication.”

Skill #5: Articulate Radical Accompaniment

Why We Do It	**Example Phrase**
● Communicate investment in patient's inherent dignity and value, regardless of outcome ● Focus on patient experience of a relationship rooted in trust and consistency ● Take action that aligns with our moral beliefs	"I want you to know that whether your substance use changes or stays the same, I'm going to be **here for you.**"

Communication Skills Practice

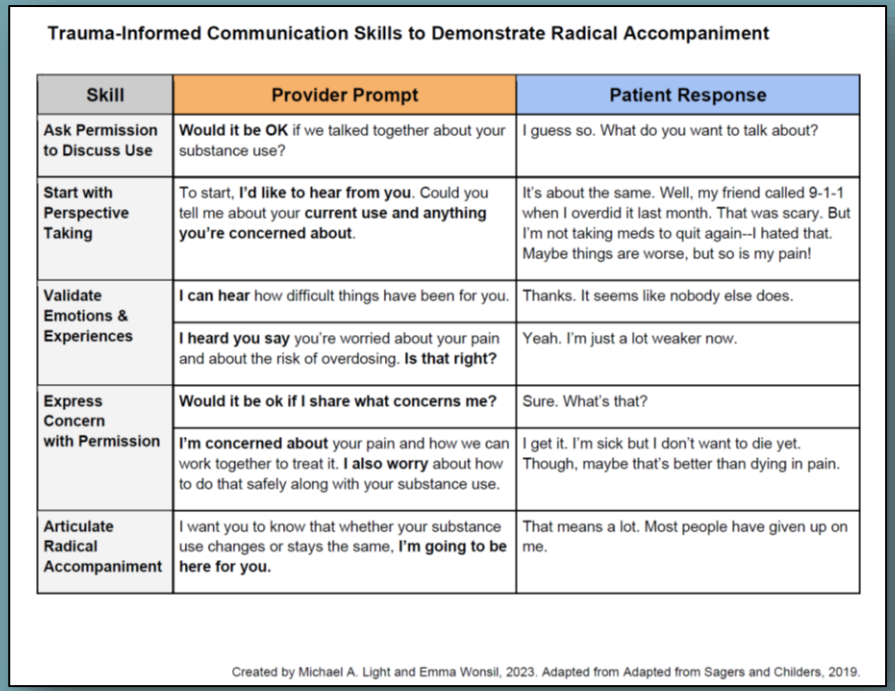


Communication Skills Practice

7 min breakout rooms of 3 people

1. **Share your name and location.**
2. **One person reads Provider role; one person reads Patient role; One person observes. Read the script, then rotate.**
3. **Discuss your experience practicing these skills and words.**

Download document in Zoom chat



Trauma-Informed Communication Skills to Demonstrate Radical Accompaniment

Skill	Provider Prompt	Patient Response
Ask Permission to Discuss Use	**Would it be OK** if we talked together about your substance use?	I guess so. What do you want to talk about?
Start with Perspective Taking	To start, **I'd like to hear from you**. Could you tell me about your **current use and anything you're concerned about**.	It's about the same. Well, my friend called 9-1-1 when I overdid it last month. That was scary. But I'm not taking meds to quit again--I hated that. Maybe things are worse, but so is my pain!
Validate Emotions & Experiences	**I can hear** how difficult things have been for you.	Thanks. It seems like nobody else does.
	I heard you say you're worried about your pain and about the risk of overdosing. **Is that right?**	Yeah. I'm just a lot weaker now.
Express Concern with Permission	**Would it be ok if I share what concerns me?**	Sure. What's that?
	I'm concerned about your pain and how we can work together to treat it. **I also worry** about how to do that safely along with your substance use.	I get it. I'm sick but I don't want to die yet. Though, maybe that's better than dying in pain.
Articulate Radical Accompaniment	I want you to know that whether your substance use changes or stays the same, **I'm going to be here for you.**	That means a lot. Most people have given up on me.

Created by Michael A. Light and Emma Wonsil, 2023. Adapted from Adapted from Sagers and Childers, 2019.

Bring It In

Think of a patient you cared for who was experiencing serious illness and a significant substance use disorder

Patient Name/Pseudonym: _____

Write 2-4 sentences about their health situation and course of care.

What is/was most challenging in providing care for them?

How does/did the experience of proving care feel for you?

What do/did you admire, respect, or love about this patient?

List one thing from today you can use in your practice this week?

Resources

Articles

- Navigating Challenging Conversations About Nonmedical Opioid Use in the Context of Oncology (Sagers & Childers, 2019)
- Adapting Palliative Care Skills to Provide Substance Use Disorder Treatment to Patients With Serious Illness
- Aging, multimorbidity, and substance use disorders: The growing case for integrating the principles of geriatric care and harm reduction

Center to Advance Palliative Care Trainings

- Balancing Pain Treatment with Risks of Comorbid Substance Use Disorder for Patients with Serious Illness; https://www.capc.org/blog/palliative-pulse-the-palliative-pulse-december-2018-balancing-pain-treatment-with-risks-of-comorbid-substance-use-disorder-for-patients-with-serious-illness/
- Course 4: Assessing Risk for Opioid Substance Use Disorder; https://www.capc.org/training/pain-management/course-4-assessing-risk-for-opioid-substance-use-disorder/
- DEA 8-Hour Opioid and Substance Use Disorder Training; https://www.capc.org/training/learning-pathways/opioid-and-substance-use-disorder-training-for-dea-registered-clinicians/
- Course 13: Managing Pain in Patients At Risk for Substance Use Disorder; https://www.capc.org/training/pain-management/course-13-managing-pain-in-patients-at-risk-for-substance-use-disorder/

National Harm Reduction Coalition Training

- Engaging People who Use Drugs - (not a free training)