### Grief and Loss Within LGBTQ Communities

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Our commitment to you is that we take this stance seriously and invite you to do the same. We ask that if you find something offensive, off-putting, or inaccurate to please let us know.

We continue to grow and evolve and welcome you on our journey.

*"When we know better we do better."* –Dr. Maya Angelou



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# Grief and Loss Within LGBTQ Communities

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# Hello! I'm Annie (she/her)

Annie Handley, LCSW, LSCSW Therapist. Trainer. Too Many Lemons, LLC



### Acknowledgements

# Community

Research

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# Our Objectives:



Understand the psychosocial phenomenon of disenfranchised grief among LGBTQ communities.



Articulate best practices for counseling bereaved LGBTQ clients and tools for strengthening coping skills to support them through the experience of loss.



Identify three ways bereavement can look different within LGBTQ communities.



### What Are We Talking About Today?

- Grief and Loss
- Prolonged Grief Disorder
- End of Life Care
- Disenfranchised Grief/Stigma
- Best Practices



# Grief and Loss

What do we think about when we think about grief and loss?





Rage N Panicked	umb	Depression	Anxious Lonely Guilt Exhausted	Lonely
S	hame	Sadness		Exhausted
Preoccupie	<sup>ed</sup> Th	e Emotio	ns and	
Guard	ded Fe	elings of	Grief	Afraid
Remorsef		nd Loss	Overwhel	Denial med
Sho	cked	Anger	Lo	onging
	F	Relief Co	onfusion	Sorrow

### **Grief and Loss**

- Grief and Loss is not one thing:
  - ▶ Has different components: psychological, physiological, and social
  - Different for every person, but there are commonalities
  - Everyone grieves in their own way
  - Changes and evolves over time
  - Different for different losses

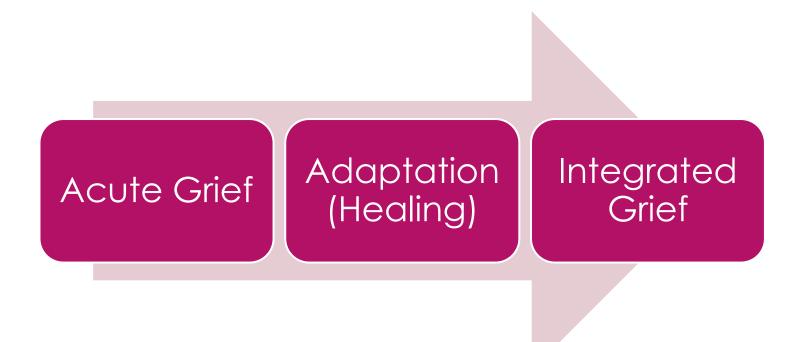


### **Grief and Loss**

- The most common trajectory is one where the grief symptoms largely resolve by 18 months post-loss
- As many as 20% of the grieving population experiences that their grieving difficulties persist and even grow, rather than diminish, over time

- Often these individuals suffer from Prolonged Grief Disorder (PGD) also known as Complicated Grief
- Grief evolves over time. In the beginning, it is ACUTE, gradually it becomes INTEGRATED unless it becomes COMPLICATED
  - More common in a sudden or violent death
  - More common with the loss of a spouse/child

### Grief and Loss: Adaptation and Integration



### Grief and Loss: Acute Grief

- Acute or Initial Grief:
  - The initial response to bereavement
  - Intense yearning, longing, sorrow, emotional pain where it is difficult to focus on anything else
  - Feelings of anxiety, bitterness, anger, remorse, guilt and shame are also common
  - Feeling disconnected from others and life
  - Feelings of disbelief, difficulty comprehending the reality
  - This grief dominates a person's life
  - Weeks to months



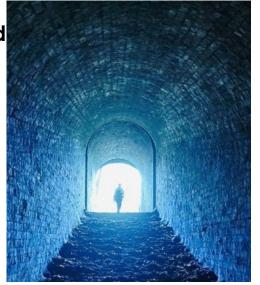
### Grief and Loss: Adaptation and Integration

- Acceptance of the reality of the death
  - ► The finality
  - What the loss means to the bereaved person
- Envisioning a future with possibilities for joy and satisfaction
  - Sense of mattering and belonging
- Continuing bonds with the deceased
  - A changed relationship with the person who has died
  - They are no longer present in the physical world



### Grief and Loss: Adaptation and Integration

- As we adapt to a loss, grief is gradually integrated into ongoing life:
  - Reality to the death is assimilated
  - Bereaved person is able to engage once again with the world and other people
  - There is a meaningful sense of connection with the deceased
  - Sorrow, yearning and thoughts of the deceased no longer dominate the mind



Prolonged Grief Disorder

What is PGD? How is it different from grief?



### Prolonged Grief Disorder- DSM-5-TR

- Prolonged Grief Disorder is new to the DSM-5-TR
- It is considered a Trauma and Stressor Related Disorder
- The death, at least 12 months ago, of a person who was close to the bereaved individual
- Since the death, the development of a persistent grief response (one or both):
  - Intense yearning/longing for the deceased
  - Preoccupation with thoughts or memories of the deceased person

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS FIFTH EDITION TEXT REVISION DSM-5-TR™

### Prolonged Grief Disorder- DSM-5-TR

#### Since the death, three of the following:

- Identity disruption (feeling as though part of oneself has died) since the death
- Marked sense of disbelief about the death
- Avoidance of reminders that the person is dead
- Intense emotional pain related to the death
- Difficulty reintegrating into one's relationship and activities after the death
- Emotional numbress as a result of the death
- Feeling that life is meaningless as a result of the death
- Intense loneliness as a result of the death

### Prolonged Grief Disorder- DSM-5-TR

- Causes clinically significant distress or impairment in functioning
- Duration and severity of the bereavement reaction clearly exceed expected social, cultural or religious norms for the individual's culture and context
- Symptoms not better explained by another mental disorder or are not attributable to the physiological effects of a substance or another medical condition



### Prolonged Grief Disorder

- What happens when there are complications?
- Adaptation is blocked by complications (ineffective emotional regulation, excessive avoidance or compulsive proximity seeking, rumination [if only])
- Thoughts: Second guessing, blaming, catastrophizing thoughts
- Feelings: Intense negative, low positive emotions
- Behavior: Avoidance behavior, compulsive proximity seeking (safety)

# Prolonged Grief Disorder

#### Effects of Losing a Love Relationship:

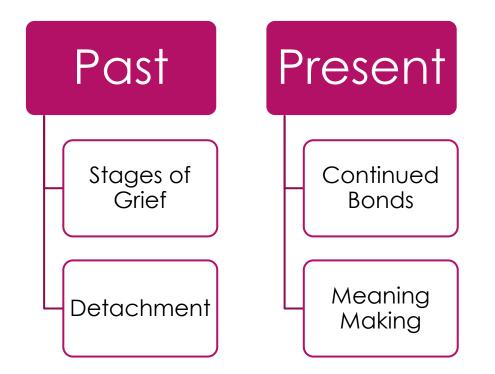
- Disrupts core biologically motivated behavioral systems: attachment, caregiving and exploration
- We get a safe haven/secure base from our loved ones and we give them one in return

- Alters regulatory psychological and physiological functions
- Bereavement is like an earthquake
- Can be loss of sense of self
- The closer and more rewarding the relationship is, the more we define ourselves by it

# Prolonged Grief Disorder vs. MDD

Major Depressive Disorder	Acute Grief	
Pervasive loss of interest or pleasure	Loss of interest or pleasure related to missing loved one	
Pervasive dysphoric mood across situations	Pangs of emotion triggered by reminders of loss	
Preoccupation with low self-esteem; general sense of guilt or shame	Preoccupation with the deceased; guilt and self- blame	
General withdrawal from activities and people	Avoidance of activities, situations and people because of the death	
Intrusive images are not prominent	Intrusive images of the deceased are common	
Yearning and longing not usually seen	Yearning and longing are frequent	

### Prolonged Grief Disorder: Treatment



### Prolonged Grief Disorder: Treatment

"And what J've had to learn is that moving forward, with every moment of joy, there's also going to be overwhelming sadness that accompanies it."

- This is Us



### Prolonged Grief Disorder: Treatment

- Core principles in Prolonged Grief Disorder treatment:
  - **Everyone has a natural inborn capacity to adapt to loss.**
  - We adapt best by dealing with loss and restoration in tandem- acceptance of loss, restoration of meaningful engagement in ongoing life.
  - Adaptation does not mean grief is gone: Grief needs to find a place in our lives, softened by a sense of continuing bonds and feelings of self-compassion.



### Prolonged Grief Disorder: Treatment

#### Encouraging Adaptation (Healing):

- Keep grief center stage
  - Accepting reality of the loss
  - Grief monitoring
  - Revisiting the story of the death



### Prolonged Grief Disorder: Treatment

#### Encouraging Adaptation (Healing):

- Honor the person who died
  - Continuing bonds
  - Revisiting the story of the death
  - Memories and pictures
  - Imaginal conversations



### Prolonged Grief Disorder: Treatment

#### **Encouraging Adaptation (Healing):**

- Envision a future with possibilities for happiness
  - Aspirational goals
  - Revisiting the world
  - Rebuilding connections



### Prolonged Grief Disorder: Treatment

#### Restorative Retelling Prompts:

- What do you think your loved one was thinking/feeling?
- Where would you place yourself at this moment?
- If you could be there, what would you say?
- What do you think your loved one would say back?
- How would he/she want to be remembered?
- What was this like for you?



### Prolonged Grief Disorder: Treatment

- Working with Guilt: Normalize the Guilt!
  - It is essential in grief
  - Guilt does not go away; it is something we release
  - It can feel like if we let go of the guilt, we let go of the person
  - Validate
  - When will you know you're forgiven?
  - What do you have to do to forgive yourself?



### Prolonged Grief Disorder: Treatment

- Revise your assumptions about the grieving process and the role of the clinician
  - Sit with the pain without needing to fix it
  - Grief integration, not resolution
  - Be prepared for the intensity
- Goal: To provide a safe and sheltered place for doing grief work and learning coping skills
- Attend to trauma
  - How much are you reliving this?



End of Life Care

What are the options? How does being LGBTQ impact care?



### Terminology

#### Ally- Actively supportive of LGBTQ+ people

Asexual- Often called "ace" for short; refers to a complete or partial lack of sexual attraction or lack of interest in sexual activity with others

- Bisexual- Emotionally, romantically or sexually attracted to more than one sex, gender or gender identity though not necessarily simultaneously
  - Sometimes this is used interchangeably with pansexual
- Cisgender- Describes a person whose gender identity aligns with those typically associated with the sex assigned to them at birth
- Sex assigned at birth (AFAB/AMAB)- The sex, male, female or intersex, that a doctor or midwife uses to describe a child at birth based on their external anatomy

# Terminology

- Transgender- An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth
  - Gender is different from sex
  - Transgender people can be gay/straight/pan/etc.
- Transitioning- A series of processes that some transgender people may undergo in order to live more fully as their true gender.
  - Social transition
  - Medical transition (hormones or surgery)
  - Legal transition
  - Trans folks can choose to go through all, none or some of these processes



# What Does End of Life Care Look Like?

- Practical care and assistance
  - Bathing, feeding, dressing
- Comfort and dignity
  - Ease pain and discomfort
  - Providing time for meaningful connections
  - Emotional and spiritual comfort



# What is Hospice Care?

- People have learned that they are not expected to recover from their condition
- There are no longer curative options, or the person has chosen not to pursue treatment
- Two physicians must certify that the person has six months to live or less
- Typically happens at home
- Medicare pays for all hospice associated costs
- Medicaid varies state by state



# What is Palliative Care?

- Specialized care for persons living with a serious illness
- Focus of care is on providing relief from symptoms and stress
- Based on the need of the person, not the diagnosis/prognosis
- Palliative care typically happens where the person is receiving care (hospital, outpatient clinic, etc.)
- Holistic approach
- Person can move in and out of palliative care



# Unique Considerations For LGBTQ

- 3 times more likely to be single (2015)
- Significantly less likely to have children
- Possibly estranged from their birth families
- Experienced multiple losses within LGBTQ community due to AIDS, suicide, addictions, marginalization, etc.
- Increased risk of mental health problems resulting from lifetime of marginalization & oppression
- All these mean lower chance of stable, ongoing informal care



- Black patients are significantly less likely to access hospice or palliative care in the final six months of life compared to their white peers, regardless of cause of death
  - Cultural and spiritual differences may play an important role in choosing to forgo life-sustaining procedures
  - Black patients may also have less access to higher-quality end-of-life care, including engagement in advanced care planning
  - Black patients disproportionately have higher rates of cancer and heart disease



- Racial/ethnic minority patients are less likely to report finding pain specialists available to them compared to non-Hispanic white patients
- Geriatric researchers at Duke University concluded that Black Americans are more likely to experience untreated pain at the end of life
- \* "Among African Americans, there's a legacy of distrust with health care. Older folks who are now the age to enter hospice know about the Tuskegee experiments and other such mistreatment. They've experienced discrimination and have a lifetime of interacting with white doctors who didn't listen and take time with them. They've been talked down to and they missed having compassionate experiences with American medicine" Dr. Dennis Cross, Hospice Physician, St. Paul



- LGBTQ people with cancer are less likely than heterosexual people with cancer to be given written information about the type of cancer they have
- 43% of respondents of a 2018 survey of hospice professionals reported having directly observed discriminatory behavior toward LGBTQ patients
- LGBTQ patients with cancer are significantly more likely to say that their pain was not adequately managed than their heterosexual peers



- Discriminatory care to the family and friends of LGBTQ patients included:
  - Having visiting hours limited
  - Being denied or having limited access to patient in the intensive care unit (ICU) or emergency department
  - Having their treatment decisions disregarded or minimized
  - Being denied private time with the patient
  - Being treated disrespectfully or abusively



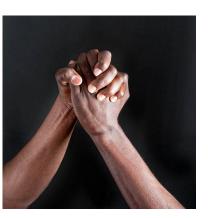
Health Organization Barrier	Potential Consequences
Heterosexist assumptions of patient's sexual and gender identity	Lack of inclusion of families of choice in decision making
Lack of culturally competent caregiver support and bereavement groups	Higher levels of caregiver strain and disenfranchised grief
Estrangement from family of origin	Incorrect assumptions in regard to surrogate decision making
Higher rates of mistrust of health care systems	Delayed uptake of medical care
Lack of comprehensive legal protections	Child custody not formalized; burial rights for transgender individuals not observed
Isolation and lack of social support	Greater levels of disease-associated distress

#### Anticipating Discrimination

- 3 in 5 older LGBTQ are not confident that services will meet their specific needs (Stonewall Survey)
- Systems are heteronormative
- Older LGBTQ have lived through times when living openly could mean being arrested, being defined as mentally ill or losing a job/children, etc.
- A 2015 Stonewall study found 57% of health care providers didn't consider someone's sexual orientation to be relevant to their health needs
- A 2020 study showed that 30% of transgender patients reported postponing or avoiding medical treatment due to discrimination
- These are fears based on their real life experiences



- Anticipating Discrimination
- Lack of choice/control
  - Loss of dignity
  - "You've created spaces for yourself where you're comfortable then suddenly... somebody is gonna put you in the closet. I don't wanna live in a closet, I don't need to live in a closet, I'm not interested in a closet...."
  - There was a colleague of mine who fought for their parents so that they could be together in the same room at the [long term care facility] and so she fought bureaucracy and got that changed."



# Barriers to End of Life Care

#### Anticipating Discrimination

- Many LGBTQ people are delaying or refusing access to health and social care support at the end of life
  - Relying heavily on friends and family to provide informal care without support of health professionals
- Best Practices
  - Health and social care support specifically for LGBTQ
  - Services run by LGBTQ
  - Images of inclusion



#### Religion and LGBTQ Care

- Many end of life care systems (hospices, hospitals, etc.) have a religious affiliation
- Early trauma can be reignited at end of life
- Trauma related to their sexual orientation/gender identity may leave them distrusting of institutions they need at end of life
- Best Practices
  - ► Hold their story in confidence
  - Never call in a religious support without their permission
  - Coach staff on LGBTQ and religious trauma



#### Religion and LGBTQ Care

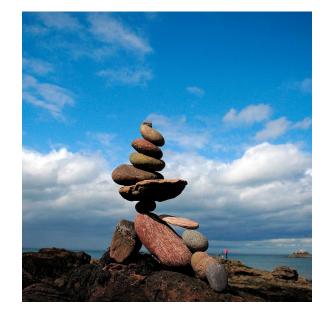
- "It was very worrying, trying to find the right place for my wife to be in. I went in to a couple of places. I went to a Methodist foundation. First of all, I'm not religious at all. I didn't feel able to say, 'I'm looking for a place for my wife." Trisha, 61, wife to Gloria, living with dementia
- "It was one of the hospice chaplains that still brings back some warmth to the memory; she walked into the room and introduced herself and just sat with Diane. She did not ask if we had any religious affiliations or wanted to pray. She held her hand and said, 'I can sing something for you if you like and then sang her favorite piece." –Carol, partner to Diane, who had breast cancer

#### Assumptions About Identity and Family Structure

- ► The assumption is generally that people are heterosexual/cisgender
- Staff may deliberately avoid conversations around sexuality and gender identity
- Partners or loved ones may be discredited
  - Assumption is biological family is the closest
- Best practices
  - ▶ Who is your support system vs. Do you have a husband? Children?
  - Give and ask for pronouns
  - Avoid assumptions
  - Don't forget the pets!



- Assumptions About Identity and Family Structure
- "They don't ask you about your sexuality, they ask about your heterosexuality"
  - Do your children live nearby?
  - Does your wife plan on coming to appointments with you?
  - Calling women Mrs.



# Fears About Death and Dying

- Being outed in death
- Inappropriate curiosity regarding themselves or their body
- Who will be handling their body after death, and concern that they will be treated with a lack of respect
- Having to hide sexual orientation or gender identity



# Fears About Death and Dying

- Their relationships or gender will not be acknowledged
- Being misgendered, dead-named or misremembered
- Who will organize the funeral or memorial service and that these will not be in keeping with the deceased's wishes
- Concerns regarding the safety of mourners who will wish to attend the funeral or memorial service



# Challenges for LGBTQ After a Death

- Disenfranchised grief
- Misgendering
- Exclusion of "chosen families"
- Multiple bereavements



# Disenfranchised Grief/Stigma

What happens when no one understands? And they don't want to.



# Challenges for LGBTQ After a Death: Disenfranchised Grief

- A person loses something or someone in their life that is important to them
  - The loss is not valued or recognized by others AND/OR The way they're grieving is not considered to be socially acceptable
  - Often experienced by disenfranchised people or populations
  - Loss that no one understands (they don't want to)



# Challenges for LGBTQ After a Death: Disenfranchised Grief

#### Loss of:

- A pet
- A loved one who was incarcerated
- A loved one who died by suicide
- A loved one from an overdose
- A Social Media friend
- A client or patient



# Challenges for LGBTQ After a Death: Disenfranchised Grief

Loss of:

- A loved one when one/both of you weren't "out"
- A loved one due to HIV/AIDS complications
- A loved one whose family doesn't accept/support their sexuality (" his friend/roommate")
- A victim of an LGBTQ hate crime/homicide that you did not know personally
- Someone to COVID



# Challenges for LGBTQ After a Death: Misgendering

- For transgender and non-binary people, there are barriers to acquiring legal documentation that reflects their gender identity
- In death, this can lead to medical or funeral home staff misgendering or dead-naming the deceased
- For the loved ones left behind, this can be very distressful at a time of vulnerability



# Challenges for LGBTQ After a Death: Misgendering

- Transgender people are misgendered, even in death
- Is there a legal marriage and/or legal documents in place?
- Biological families don't always respect the gender identity of the deceased and may have death records reflect the assigned sex at birth/deadname
- "If they're not blood related, then they're not family," he says. "Legally, they just have no say."



# Challenges for LGBTQ After a Death: Misgendering

- Christopher Lee
- California Assembly Bill 1517 (2015)
  - Coroners and funeral directors to record a person's gender identity rather than anatomical sex on the death certificate
  - If there's a dispute, a driver's license or passport will be sufficient legal documentation to trump family opinion



# Challenges for LGBTQ After a Death: Chosen Families

- Statistically more likely to be estranged from biological family
- Statistically more likely to not have children
- May rely on a close network of friends, "chosen family"
- Workplace bereavement policies may not include these individuals
- May not be accepted by biological family and be excluded from services



# Challenges for LGBTQ After a Death: Multiple Bereavements

### Loss of multiple partners/loved ones

### Those that lived through the AIDS epidemic

- Survivor guilt
- "Gay life was a whirl. Vibrant and free. Until the 1980s and 1990s. Everybody that I ever knew was dead [...] Now I'm 65 and living like a recluse. Recovering from life's greatest trauma. Still, almost everybody that I have ever known is dead." "George"

#### Higher rates of suicide

Can mean experiencing multiple, and often traumatic deaths



# Challenges for LGBTQ After a Death: Multiple Bereavements

- "Bereavement Overload"
- Multiple ongoing individual and community wide losses
- Systems are heteronormative
- Having to "come out" to multiple people (medical and funeral staff, etc.)



# "Gay Grief is Different"

- Invisibility
  - Social stigma
  - Interpretations of "valid" grief
  - Family disapproval
- Illegitimacy
  - Must face people who think your relationship didn't "count"
- Isolation
  - Your grief isn't always acknowledged
  - Your relationship isn't always recognized



# "Gay Grief is Different": Gay Grief is Marginalized

- Can you tell your employer your same sex partner died and receive support? (Bereavement leave?)
- Will staff (medical, funeral, legal, etc.) be considerate and respectful of your relationship? Will they recognize your relationship?
- Is there a grief support group that understands your loss?
  - "David" lost husband "Kenneth"



# "Gay Grief is Different": Gay Grief is Marginalized

- Are you allowed to fully participate in the planning for services?
- Do you have legal documents prepared if you are not married?
- Does your loved one's family recognize your relationship?
- Are you comfortable sharing your loss with your co-workers, neighbors, acquaintances?



## **Best Practices**

Meeting the needs of our clients and their families.



# Best Practices: Language

- Deliver care and communicate in a way that is inclusive, affirmative and respectful
- If unsure, use neutral language such as "partner" or "spouse"
- When referring to the deceased, use language that they had chosen for themselves
  - How would X have wanted to be referred to?
  - How would X have described their gender?



# Best Practices: Support

- Avoid the assumption that someone is a friend
  - How would you and X describe your relationship?
- Avoid the assumption that biological family had the closest relationships

- Who was important to X?
- Be sensitive
  - A bereaved partner may be expecting to face discrimination



# Best Practices: Legal Considerations

- Gender is not recorded on a medical certificate of Case of Death, but is recorded on the extract of the death certificate that is supplied by a Registrar to the person who registers the death
- There is no legal requirement for the gender recorded on a birth and death certificate to be the same
- After a death, maintain confidentiality regarding a person's LGBTQ status in line with legal regulations



# Finding LGBTQ Centered Care

- Ask friends with similar circumstances who they have worked with and whether they felt respected and comfortable
- Contact your local SAGE (Advocacy and Services for LGBT Elders) or LGBTQ aging provider, LGBTQ community center or PFLAG chapter
- Look to see if there are service providers that advertise in your local LGBTQ newspapers/magazines/online forums
- Reach out to your local HIV/AIDS service providers



# Finding LGBTQ Centered Care

- Ask or look for information about whether an agency's staff have been trained on how to provide culturally competent care to LGBTQ people
- Check the SAGECare website for agencies that have received the SAGECare credential for completing training by SAGE (<u>www.sageusa.org</u>)
- Ask providers directly if they serve LGTBQ individuals, and if so, find out whether that answer is concrete (current or past clients) or hypothetical ("we welcome everyone")
- Most providers have non-discrimination policies. Ask to see them and check if they include sexual orientation and gender identity. Ask how the policies are enforced
- Review the provider's materials. Are they inclusive?



# Questions/Comments?

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### Please complete your evaluation

### Will add tiny URL or QR code for evaluation



## MATEC Resources

- Clinical Consultation Center <u>http://nccc.ucsf.edu/</u>
  - HIV Management
  - Perinatal HIV
  - HIV PrEP
  - HIV PEP line
  - HCV Management
  - Substance Use Management
- AETC National HIV Curriculum <u>https://aidsetc.org/nhc</u>

- AETC National HIV-HCV Curriculum <u>https://aidsetc.org/hivhcv</u>
- Hepatitis C Online <u>https://www.hepatitisc.uw.edu</u>
- AETC National Coordinating Resource Center <u>https://aidsetc.org/</u>
- Additional Trainings <u>https://matec.info</u>



