USING THE STAGES OF DEATH AND DYING TO ADDRESS MENTAL ILLNESS AMONG HIV+ CLIENTS

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ABOUT THE PRESENTER

- Worked in HIV Prevention for 10 years
- Licensed Professional Counselor
- Health Educator
- Integrated Health Care
- AIDS Service Organizations
  - Mental Health Clinician
  - Prevention Specialist
  - HIV Testing Counselor
  - Clinical Director
  - Program Design/Implementation
  - Evaluation
  - Health Educator
  - Program Consultant
TRAINING OUTCOMES

• Framing the problem: Identify specific challenges of youth 13-24 living with HIV
• Explore a human development model to guide treatment
• Application: stages of death and dying in practice
New HIV Diagnoses Among Youth Aged 13-24 in the United States, by Race/Ethnicity and Sex, 2015

Race/Ethnicity and Sex

*Subpopulations representing 2% or less of the overall US epidemic are not represented in this chart.

HIV AMONG YOUTH

- Youth ages 13 to 24 accounted for more than 1 in 5 new HIV diagnoses in 2015
- Gay and bisexual males accounted for most new HIV diagnoses among youth in 2015
- Overall, new HIV infections are declining among young gay and bisexual men
TRANSITION OF HIV-INFECTED ADOLESCENTS TO ADULT CARE

- Perinatally and behaviorally-infected adolescents are transitioning to adult care

- Considerations for transitional planning
  - Cognitive development
  - Mental health
  - Medication adherence
  - Sexuality
  - Reproductive issues
  - Gender identity
  - Socioeconomic challenges
  - Health insurance status
  - Stigma and disclosure
  - Disrupted relationships with pediatric care providers

Cervia, J., MD, MBA, FACP, FAAP, FIDSA, AAHIVS, 2013
# Erikson's Psychosocial Stages of Development

<table>
<thead>
<tr>
<th>Approximate Age</th>
<th>Virtues</th>
<th>Psychosocial Crisis</th>
<th>Significant Relationship</th>
<th>Existential Question</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infancy 0–23 months</td>
<td>Hope</td>
<td>Basic trust vs. mistrust</td>
<td>Mother</td>
<td>Can I trust the world?</td>
<td>Feeding, abandonment</td>
</tr>
<tr>
<td>Early childhood 2–4 years</td>
<td>Will</td>
<td>Autonomy vs. shame and doubt</td>
<td>Parents</td>
<td>Is it okay to be me?</td>
<td>Toilet training, clothing themselves</td>
</tr>
<tr>
<td>Preschool age 4–5 years</td>
<td>Purpose</td>
<td>Initiative vs. guilt</td>
<td>Family</td>
<td>Is it okay for me to do, move, and act?</td>
<td>Exploring, using tools or making art</td>
</tr>
<tr>
<td>School age 5–12 years</td>
<td>Competence</td>
<td>Industry vs. inferiority</td>
<td>Neighbors, school</td>
<td>Can I make it in the world of people and things?</td>
<td>School, sports</td>
</tr>
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<td>Adolescence 13–19 years</td>
<td>Fidelity</td>
<td>Identity vs. role confusion</td>
<td>Peers, role model</td>
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<td>Social relationships</td>
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<tr>
<td>Early adulthood 20–39 years</td>
<td>Love</td>
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<td>Friends, partners</td>
<td>Can I love?</td>
<td>Romantic relationships</td>
</tr>
<tr>
<td>Adulthood 40–64 years</td>
<td>Care</td>
<td>Generativity vs. stagnation</td>
<td>Household, workmates</td>
<td>Can I make my life count?</td>
<td>Work, parenthood</td>
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<tr>
<td>Maturity 65–death</td>
<td>Wisdom</td>
<td>Ego integrity vs. despair</td>
<td>Mankind, my kind</td>
<td>Is it okay to have been me?</td>
<td>Reflection on life</td>
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BEST SELF VS. WHAT AM I REALLY FEELING?
SELF-LOSS & SELF GROWTH

• Assumption: growth and other benefits arise from losses, suggesting that growth and loss lie on opposite sides of a psychological spectrum

• Clients (HIV+) may experience both “loss” & “growth” processes simultaneously

• Clients may report growth while experiencing what it means to live with HIV

Goluba, S., Gamarelb, K & Rendinab, H., 2014
SELF-LOSS & SELF GROWTH

• **Self-loss** “Having HIV has made me lose part of who I am”

• **Self-growth** “Living with HIV has taught me that I can handle anything”

Goluba, S., Gamarelb, K & Rendinab, H., 2014
SELF-LOSS & SELF GROWTH

• **Self-loss** accounted for a significant proportion of *variance* in both *bothersome symptom reports* and *depression*

• **Self-growth** appeared to *buffer the negative impact of self-loss* on bothersome symptoms, but *not on depression*

• These data suggest that self-loss is a critical construct in understanding adaptation to chronic illness

• Identity processes may influence symptom perception and mental health outcomes

I’m alive and moving forward, but when I reflect I tend to get a little down….
THE PROBING CLINICIAN

• Could patients benefit from therapy interventions that assist with restructuring thoughts and perceptions?
  • Exploring competing thoughts: who I want to be versus who I am today?
  • Explore goals vs. my behaviors (cognitive dissonance)
  • Explore how chronic illness & stigma forces clients to project strong, healthy & dis-ease free
<table>
<thead>
<tr>
<th>Age Period</th>
<th>Stage</th>
<th>Stage Theme</th>
<th>Social Relationships</th>
<th>Psychological Conflict</th>
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Adolescence (Role confusion): stigma, assuming a posture of marginalization, learned helplessness, isolation

Early Adulthood (Isolation): Intimacy overshadowed by status disclosure, illness management, preoccupation with death and dying, suppression of feelings
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<th>Stage</th>
<th>Age Range</th>
<th>Domain</th>
<th>Conflict</th>
<th>Social Relationships</th>
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**Acceleration Towards Latter Stages**

**Adulthood (Stagnation):** Diagnosis of a chronic illness may cause early onset of stages with a morbid outlook towards life.

**Maturity (Despair):** Self-reflection paired with resentment and guilt.
ELISABETH KÜBLER-ROSS
ON DEATH AND DYING

Newman, 2004
STAGES OF DEATH AND DYING

- Denial: refuses to believe
- Anger: no longer able to deny
- Bargaining: accepts death, but wants more time
- Depression: realizes death will come soon
- Acceptance: understands and accepts the fact they are going to die

Newman, 2004
A CLOSER LOOK

• Elisabeth Kübler-Ross overturned how physicians treat dying patients

• 1969: death was a taboo subject and discussing it was considered morbid

• Patients died alone in hospitals, physicians ignored them, and adequate pain medication was underused

• New field of practice—‘narrative medicine’

• Skilled listener and a role model for patient interviewing and active listening

• One of the most effective communicators of the 20th century

• Practice to the forefront—and pressed for more humane treatment of the dying

• Kübler-Ross's work stemmed from the realization that in her native Switzerland, death, like birth, was considered a normal part of the life cycle

Newman, 2004
YES, THE PAST MAY HURT, BUT THE WAY I SEE IT, YOU COULD EITHER LEARN FROM IT OR RUN FROM IT.

TILL WE FIND OUR PLACE ON THE PATH UNWINDING IN THE CIRCLE, THE CIRCLE OF LIFE.

And so we are all connected in the great circle of life.

IT'S THE CIRCLE OF LIFE, AND IT MOVES US ALL THROUGH DESPAIR AND HOPE, THROUGH FAITH AND LOVE, RAFIKI.

- The Lion King

When we die, our bodies become the grass, and the antelope eat the grass.
Facebook: Guy Anthony
Twitter: @IAMGUYANTHONY
Instagram: @IAMGUYANTHONY
"Jon Diggs is a Licensed Associate Professional Counselor (LAPC) with the state of Georgia and a National Certified Counselor. He obtained a Bachelor of Arts degree in Psychology from Morehouse College and a Master of Arts degree in Community Counseling from Argosy University. In his most recent years, he has dedicated his life to reducing new HIV infections and assisting clients in adopting healthy lifestyles to manage HIV/AIDS. He has also been afforded the opportunity to work with clients through sexual identity issues, partner notification (HIV/AIDS) and end of life preparation."

In the early 1960's, Elizabeth Kübler-Ross visited a hospital to speak with dying patients. She identified parallels in their experiences then organized them into five sequential steps to death and dying; Denial, Anger, Bargaining, Depression and Acceptance.

People living with HIV/AIDS often report that they were infected before they were infected. Meaning, internalized negative thoughts about being gay/queer and associations with HIV/AIDS created a seed for destruction. Contracting the virus created a super-infection; creating wounds that bleed over into our spiritual, mental, physical and psychological self.

This chapter is meant to assist those who are yearning for a sense of peace after an HIV or AIDS diagnosis. It is not meant to assume the role of a therapist or counselor; rather, to start you on a path towards living as a critical, conscious, and loving human being. This chapter may ask you to look at life differently.

**Denial**

There is no right or wrong way to react to the words, “Your HIV confirmatory results are back from the lab. We performed a Western Blot test and it detected the presence of HIV infection.”

One truth is, people respond to an HIV diagnosis in different ways. A common reaction is denial. **Denial** manifests itself in different forms. To the outright “Your lying and I want a second opinion” to the more avoidant approach “I'm fine, I'm just
## EXPLORING THE STAGES IN PRACTICE

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<th>Death &amp; Dying</th>
<th>In Practice</th>
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<td>Denial: refuses to believe</td>
<td>Denial: internal religious conflicts, behavioral &amp; lifestyle risk, test technology/competence of provider questioned</td>
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<td>Anger: When no longer able to deny</td>
<td>Anger: towards self, partner, family, community</td>
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<td>Bargaining: accepts death, but wants more time</td>
<td>Bargaining: ongoing with chronic illness, medical routines, loss of loved ones, stigma, ambivalence towards actions steps</td>
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<td>Depression: realizes death will come soon</td>
<td>Depression: surviving versus thriving-push pull/abusive relationship towards living</td>
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<tr>
<td>Acceptance: understands and accepts the fact they are going to die</td>
<td>Acceptance: Parts of me will die and will be reborn (cognitive reframing), self-growth, fluidity in balance</td>
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EXPLORING THE STAGES IN PRACTICE

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<td>Who can I be? Who am I?</td>
<td>“I’m learning to be ok with me”</td>
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**Secure/Healthy Supportive Relationships**

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<th>HIV Diagnosis</th>
<th>“I’m HIV positive”</th>
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<tr>
<td>Homophobia</td>
<td>Navigating sexual identity</td>
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# Exploring the Stages in Practice

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## HIV Diagnosis

| “I’m HIV positive” | What will people think of me? | “I’m living with HIV” |

## Stages of Death and Dying

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<th>Denial Internal conflicts</th>
<th>Anger Self, others, shame, guilt</th>
<th>Bargaining Past vs Future wishes for self</th>
<th>Depression Future may be too overwhelming</th>
<th>Acceptance Resilience Self-efficacy</th>
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A MESSAGE FROM MOTIVATIONAL INTERVIEWING (MI)

• Intrinsic motivation for change arises in an accepting, empowering atmosphere that makes it safe for the person to explore the possibly painful present in relation to what is wanted and valued

• **Ambivalence**
  • Uncertain about what the future holds
  • The past or current situation feels more familiar
  • Doubts about if the familiar will fit into their future goals

• **Develop Discrepancy**
  • Goals vs Behaviors
  • Develop awareness of this gap
  • The gap is were **motivation** is created

Miller & Rollnick, 2002
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| HIV Diagnosis | “I’m HIV positive” | What will people think of me? | “I’m living with HIV” |

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<th>Perceived Self-Growth</th>
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<tr>
<td><strong>Trans-theoretical Model</strong></td>
<td>Precontemplation Not accepted diagnosis Not ready to start treatment</td>
<td>Contemplation Not accepted diagnosis Thinking about treatment</td>
<td>Preparation Framing diagnosis Set first appointment</td>
</tr>
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FINAL THOUGHTS: PROBING CLINICIAN

• HIV has made my life more meaningful
  • Say more about that?

• I date more realistic people
  • What do they look like? How might this be different?

• I’m at a place in my life where…..
  • What could you do to support this new found place?
  • Exploring coping skills: fluidity and threshold

• I live life in the moment…..
  • Meditation, cognitive restructuring, pattern interruption, developing social supports
CORNEL WEST

Paideia concerns the cultivation of self, the ways you engage your own history, your own memories, your own mortality, your own sense of what it means to be alive as a critical, loving, aware human being

Brother West: Living and Loving Out Loud, A Memoir, 2009
INTERESTED IN MORE TRAINING ON MI?

- WWW.SEAETC.COM
- Online Module: Using Motivational Interviewing to Support Providers & Consumers
- Mar 10, 2017 | Online Module
QUESTIONS?
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REFERENCES


• Joseph S. Cervia, MD, MBA, FACP, FAAP, FIDSA, AAHIVS, (2013). Easing the Transition of HIV-Infected Adolescents to Adult Care AIDS PATIENT CARE and STDs Volume 27, Number 12, 2013 Mary Ann Liebert, Inc. DOI: 10.1089/apc.2013.0253


• Simply Psychology http://www.simplypsychology.org/Erik-Erikson.html