



Values and Meaning in PLWH:

**A key component to engagement
and retention in care**

Leonardo Aguilar, MACP

Program Coordinator

Medical Case Manager

Registered Mental Health Counselor Intern

Southeast Aids Education And Training Center

Comprehensive AIDS Program



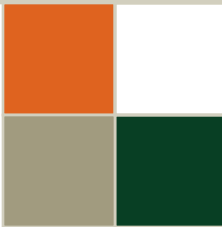
Presenter & Acknowledgements

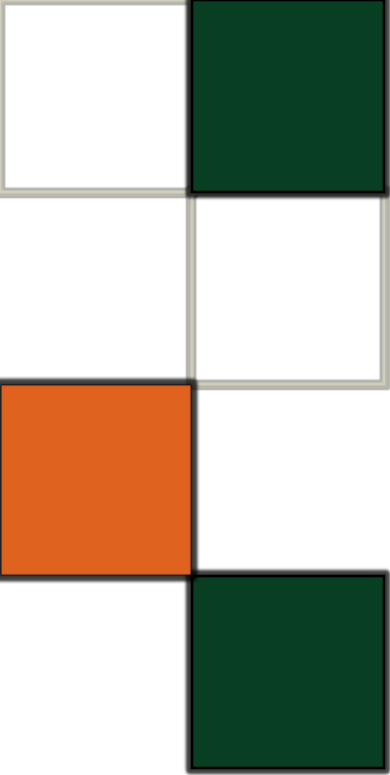
Leonardo Aguilar, MACP

This speaker does not have any financial relationships with commercial entities to disclose

LEARNING OBJECTIVES

- 1 & 2) Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care
- 3) Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care





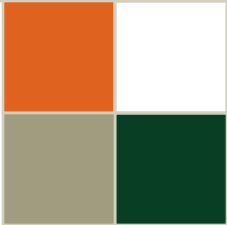
OBJECTIVE 1 & 2

- 1) Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care

OBJECTIVE 1 & 2: Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care

BARRIERS TO ENGAGEMENT RETENTION IN CARE

In your experience, what is the most prevalent barrier to engagement / retention in care and treatment adherence that your clients articulate?



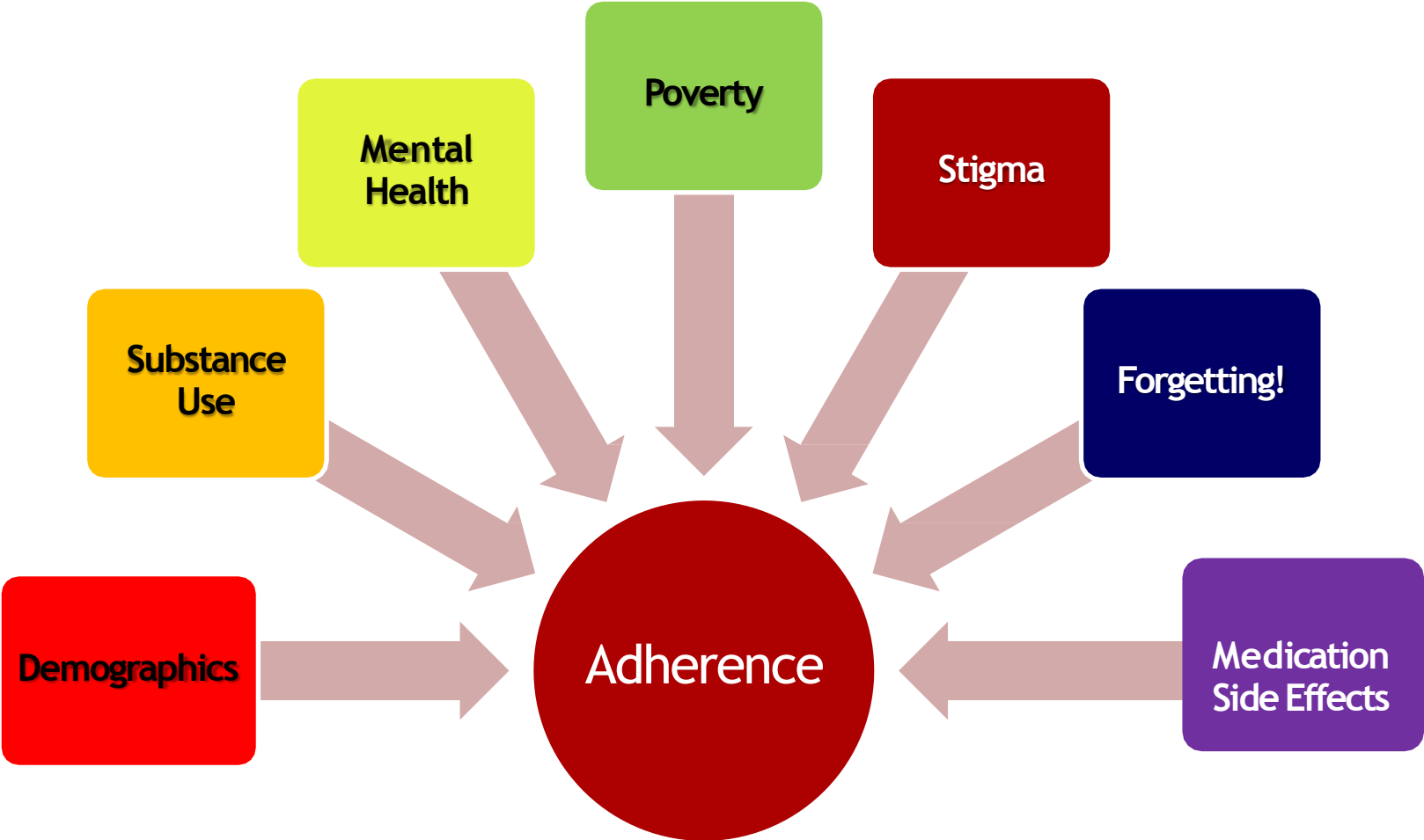
Barriers	Selected patient quotes	Total patients	Retained	Not retained
1. Competing Life Activities	"Of course, mother of four. Work 40-hour full-time job, come home to a full-time job, single mom. So yeah, I mean, there are times, like I said, from exhaustion. Sometimes – most times, it's just sheer exhaustion. I'm tired, you know. Before I know it, I'm asleep somewhere and I'm sleeping so long, it's the next day. But when I get up, I will take it. It's far and few between, but it happens. It happens." -NR Female	High	High	High
2. Feeling Sick	"Maybe because it was cold or it was raining and I was sick and I didn't feel like coming, even though I was sick, because I know like in the past I will be feeling sick as hell, but I couldn't even have the strength to get up to come to see the doctor." -R Female	High	High	High
3. Stigma	"You don't want to see nobody you know and all that kind of stuff. I hate the waiting room, I wish I could put on my hood and walk right through there when I leave." -R Male	High	Medium	High
4. Depression & Mental Illness	"It impacts a lot. It can impact a lot especially depending on I guess my emotional state. Depending on how bad I feel I'm not gonna move at all, I'm just not gonna come out the house, no matter what the reason that may have brought it on, whether it was me, an argument or fight with my husband, the kids driving me crazy today, no matter what brought it on, depending on how bad I feel, I'm just not gonna come because of my depression." -NR Female	High	High	High
5. Expensive & Unreliable Transportation	"Well, what makes it hard sometimes if you don't have money to get here. If you don't have a car, that's one thing. And what makes it easy is when you have transportation to come here. And it's accessible if you're on a bus route. It's right on the [Specific bus route]. It's easy to get here. And that's about it. Sometime you can't come because you don't have the money. That's a factor." -NR Male	High	Medium	High
6. Insufficient Health Insurance	"I'd say about the last two years, it's gotten to a point whereas though things they used to cover they don't cover no more. And being – having this disease, we need a lot of things done. They don't send out no letter, no nothing, just saying you can't have this done no more or it's going to be an extra charge. They don't say nothing. I get to the place like the dentist. I have bone loss. And I had an appointment. I went to the appointment, and they're telling me it's not covered." -R Male	Medium	Low	High
7. Forgetfulness	"If I'm rushing out of the house and I forget to just grab them and put them in my purse or something. That's most of the time when I forget." -R Female	Medium	Medium	Medium
8. Substance Abuse	"I forgot a lot of appointments. I was on drugs and I didn't – I wouldn't come in for like months, six months, to a year. I'm just getting back on track." -R Female	Medium	Medium	Medium
9. Negative Experiences with Clinic Spaces & Processes	"I still went...He just run in and out of the office, leave me sitting – first of all, you sat an hour just to get triaged. Then they stuck in a room, you sat another half an hour, 45 min. Then he'd come and he's be on the phone, he'd be in and out, just write you a script and send you on your way. Every once in a while he gave you blood work. Back then it was like an easy gig. But I left him and I found – the Gods called up, no for real man, it was a blessing." -R Male	Medium	Medium	Medium
10. Challenges with Appointment Scheduling	"Then if I come to appointment, I have to schedule back and forth. She say 11:30, but on the paper I got last time, it was 12:30. So I get her 12:00, she say it's too late, I have to go back and reschedule. And I rescheduled again for the 26th, it took another month." -NR Female	Low	Low	Medium
11. Difficult Relationships with Clinic Staff Including Providers	"The social worker, [Participant's Social Worker], and I am not a fan of her. I am not a fan of her. She thinks she's here doing you a favor. She is manipulative, ring the rule, send you up the steps and down and around and about and then all around. I cannot take that social worker behavior. Just get to the point and lead me in the right direction and tell me what the steps to take. I'm not here to ask you for a handout or what you can offer me personally from a clinical standpoint, a professional standpoint, please assist me with this matter. She make it seem as if she is doing you a favor." -R Female	Low	Low	Medium
12. Inconsistent, Unstable, or Inadequate Housing	"I'm going through a situation right now with my living conditions. I haven't took my medications in about three weeks now. I discussed - because I am going through – I'm living right now in a warehouse with my cousin who was also evicted because of some of the legal bullcrap we had to go through with my niece and other stuff which annoys me. But right now I'm staying with him so I'm going through a lot of stress with that. I guess I could have continued taking it but I just never been down to get the pills or whatnot." -R Male	Low	Low	Low

Abbreviations: R retained, NR not retained

<https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-015-0990-0/tables/2>



OBJECTIVE 1 & 2: Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care



OBJECTIVE 1 & 2: Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care

Adherence



Benefits of Adherence



OBJECTIVE 1 & 2: Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care

FORMS OF MEDICATION NONADHERENCE

Failing to initially fill or refill prescriptions

Omitting medications or taking more than the prescribed doses

Prematurely discontinuing medications

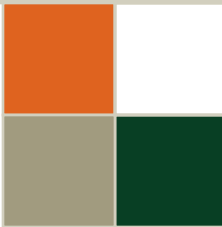
Taking doses at the wrong time

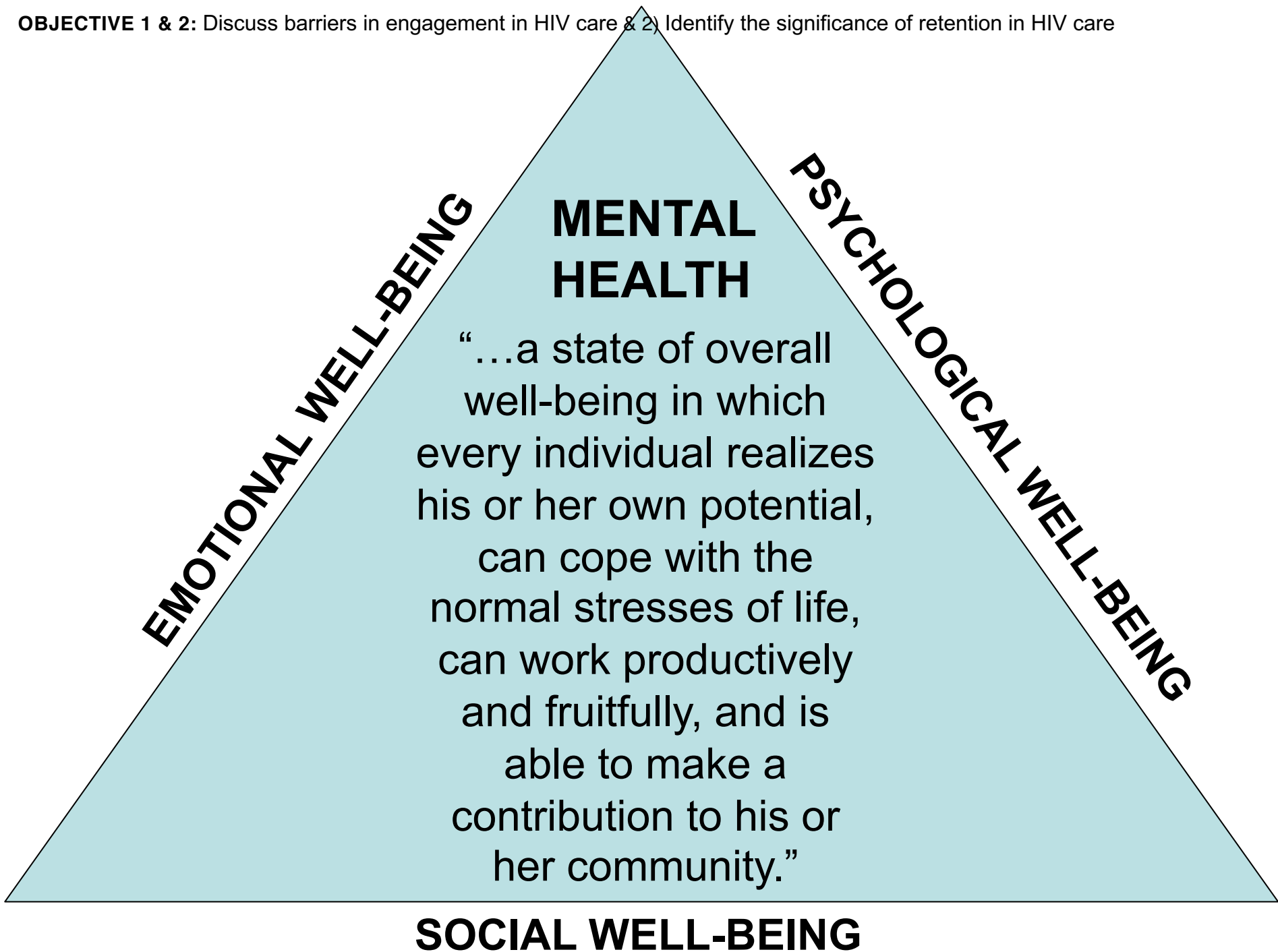
Taking medications with prohibited foods, liquids, or other medications

Taking outdated or damaged medications

Improperly storing medications

Improperly using medication administration devices (eg, inhalers)





OBJECTIVE 1 & 2: Discuss barriers in engagement in HIV care & 2) Identify the significance of retention in HIV care



MENTAL HEALTH DISORDER	WITHOUT HIV	WITH HIV
<u>Any Serious Mental Illness¹</u>	<u>5%</u>	<u>1-24%</u>
<u>Major Depressive Episode²</u>	<u>6.9%</u>	<u>22-61%</u>
<u>PTSD (in women)³</u>	<u>6%</u>	<u>30%</u>
<u>Panic Disorder⁴</u>	<u>2.5%</u>	<u>10.5%</u>
<u>Generalized Anxiety Disorder⁵</u>	<u>2.1%</u>	<u>15.8%</u>

¹Moore, D. J., Posada, C. (2013). HIV and psychiatric comorbidities: What do we know and what can we do? High-quality care for HIV-infected individuals also requires vigilance regarding the mental health needs of patients. *Psychology and AIDS Exchange Newsletter*,

²Depression. Primary Care of Veterans with HIV. Neurology, Psychiatry, and Pain retrieved from <https://www.hiv.va.gov/provider/manual-primary-care/depression.asp> on June 3, 2018

³ Neigh, G. N., Rhodes, S. T., Valdez, A., & Jovanovic, T. (2016). PTSD co-morbid with HIV: Separate but equal, or two parts of a whole? *Neurobiology of Disease*, 92(Pt B), 116–123. <http://doi.org/10.1016/j.nbd.2015.11.012>

⁴Robertson, K., Bayon, C., Molina, J. M., McNamara, P., Resch, C., Munoz-Moreno, J. A., Kulasegaram, R., Schewe, K., Burgos-Ramirez, A., De Alvaro, C., Cabrero, E., Guion, M., Norton, M., Van Wyk, J. (2014). Screening for neurocognitive impairment, depression, and anxiety in HIV-infected patients in Western Europe and Canada. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* Vol 26 Issue 12, 1555-1561 <https://doi.org/10.1080/09540121.2014.936813>

⁵ Andriote, J. M. HIV Mental Health Treatment Issues: HIV and Anxiety. American Psychiatric Association Office of HIV Psychiatry www.psychiatry.org

RISK FACTORS impacting Mental Health

Having a blood relative, such as a parent or sibling, with a mental illness

STRESSFUL LIFE SITUATIONS

Brain damage as a result of a serious injury (traumatic brain injury)

TRAUMATIC EXPERIENCES

Having few friends or few healthy relationships

AN ONGOING (CHRONIC) MEDICAL CONDITION

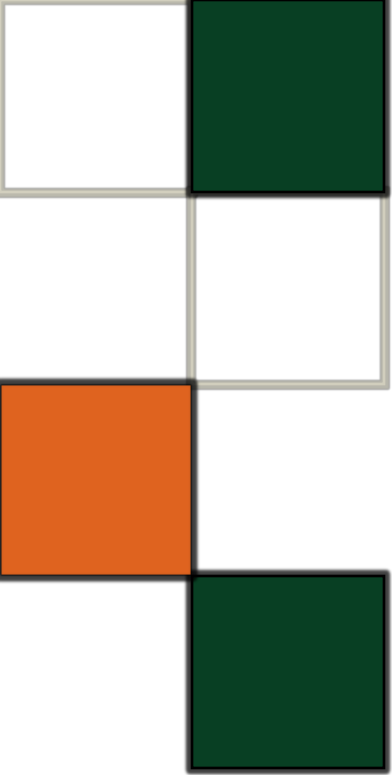
Being abused or neglected as a child

USE OF ALCOHOL OR RECREATIONAL DRUGS

A previous mental illness

WHO secretariat (2012). RISKS TO MENTAL HEALTH: AN OVERVIEW OF VULNERABILITIES AND RISK FACTORS.
http://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf





OBJECTIVE 3

Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

VALUES

“Values are words that describe how we want to behave in this moment and on an ongoing basis. In other words, values are your heart’s deepest desires for how you want to behave—how you want to treat yourself, others, and the world around you.”

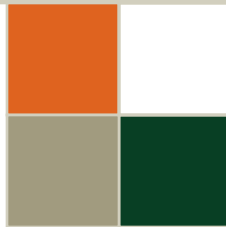
Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



VALUES

Some clients do not like the word “values,” so make sure you have some alternative terms up your sleeve:

- *being yourself*
- *being true to yourself*
- *living life your way*
- *behaving like the sort of person you want to be*
- *your heart’s deepest desires for how you want to behave*
- *personal qualities and strengths you want to act on/live by/bring into play,*
- *qualities you want to model for/show to/demonstrate to/inspire in/encourage in others.*



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

VALUES

Aim:

To clarify our values so we can use them as an ongoing guide, for both overt and covert behavior. We can use them for inspiration, motivation, and guidance to help us do the things that **give our lives a sense of meaning or purpose.**

Synonyms:

Chosen life directions; what you want to stand for; desired personal qualities.

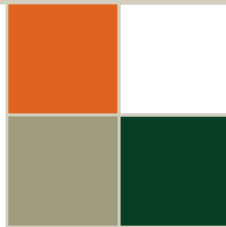
Method:

Distinguish values from goals; help clients connect with and clarify their values so they can use them to inspire, motivate, and guide ongoing behavior.

When to Use:

When looking for guidance from within; when motivation for action is lacking; as a guide for goal setting and action plans; to facilitate acceptance; to add richness, fulfillment, and meaning to life.

Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



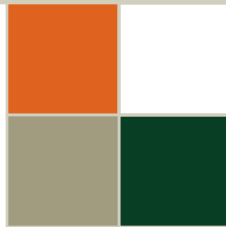
VALUES

When we describe values to our clients, we could verbalize a statement such as:

“**Values** are our deepest desires for how we want to behave; how we want to treat ourselves, other people, and the world around us. They describe what we want to stand for in life, how we want to act, what sort of person we want to be, what sort of strengths and qualities we want to develop”

We often describe values as an “inner compass”

They give us guidance, help us find a direction, help us stay on track, and help us find our way again when we go off track.



3 COMPONENTS OF VALUES

1) ONGOING ACTION

Values refer to “ongoing action”:
how you want to behave—**overtly or covertly**—on an ongoing basis.

For clients living with HIV for example a good question to ask is:

How do you want to behave in your relation to your health care?

If client’s answer is: I want to **A) maintain or improve or look after my physical and mental health. B) to be caring toward myself.**

Then we’d say to the client:

“these aspired qualities are your **values**. And seemingly, you’d want to behave with these qualities on a regular basis; you wouldn’t want all of the sudden stop acting this way tomorrow, or next week, or next month.



3 COMPONENTS OF VALUES

2) GLOBAL QUALITIES

Values refer to *“global qualities”* of ongoing action.

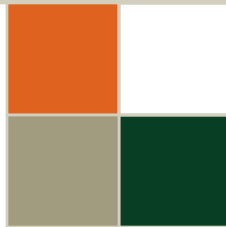
To illustrate, let’s suppose clients says: I want to take my HIV medication.

we can say:

*“Now clearly, to Adhere to your HIV medication is something you can do on an ongoing basis—it is an ongoing action, but it’s not a **quality of action**.”*

*To clarify this, here are **three** possible qualities of that particular ongoing action:*

- 1) Adhere to your HIV medication enthusiastically,*
- 2) Adhere to your HIV medication passionately,*
- 3) Adhere to your HIV medication half-heartedly.”*



3 COMPONENTS OF VALUES

2) GLOBAL QUALITIES

So what do we mean by a global quality? We mean a quality that “unites” many different patterns of action.

For example, if client’s value is **“to be caring toward myself”**, then there are many different actions the client can take with the quality of **“caring.”**

A possible way to get to client’s **values around Adhering to HIV medication**

We could ask questions such as:

“How do you Adhere to your HIV medication?”

“What personal qualities or strengths do you want to model or demonstrate as you adhere to your HIV medication?”

.”



3 COMPONENTS OF VALUES

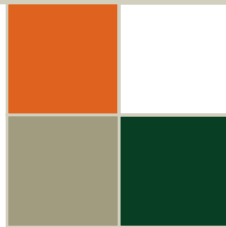
3) DESIRED

Values are “desired.”

They’re statements about how one wants to behave, how one desires to act.

They’re not about what one **should do** or **have to do**, or what’s the “**right thing**” to do..”

(Chosen is a synonym to Desired because one not only desires these qualities in one’s actions but we also consciously choose to employ them.)



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

VALUES VS GOALS

We need to explain that goals are things you are aiming for in the future: **things you want to get, have, or achieve.**

In contrast, **values are how you want to behave right now and on an ongoing basis for the rest of your life,**

It is important to note that in values you are deciding how you want to behave every step of the way toward achieving your goals

whether you achieve them or not.

Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



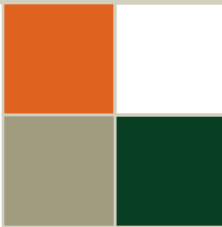
VALUES VS GOALS

To help clients get this distinction, it's useful to give them a couple of examples.

A very good one is is “getting married” versus “being loving” (Hayes et al., 1999).

If you want to be **loving and caring, that's a value**—it's ongoing, never completed; you want to behave that way for the rest of your life. And in any moment you have a choice: *you can either act on that value or neglect it.* **But if you want to get married, that's a goal.**

It's something that can (potentially) be completed, achieved, “crossed off the list.” And you can achieve the goal of marriage even if you completely neglect your values around being loving and caring.



VALUES VS GOALS

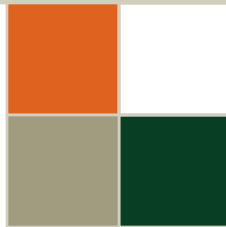
Values are always available to us. In any moment, we can act on them or neglect them the choice is ours.

Not so for goals. We can't guarantee we'll ever achieve the goal we are pursuing. We can obviously do things that increase our chances of success, but we can never guarantee the outcome.

For example, if we want to get married, we can't 100 percent guarantee it will happen, but in any moment, we can act on our **values of being loving and caring.**

We can do this even if we don't have a partner; we can be loving and caring toward ourselves, our friends, our neighbors, our family, our environment, our pet kangaroo, and so on.

\



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

VALUES VS GOALS

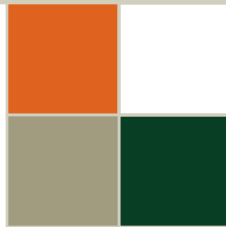
Here's another example

if you want a **good job, that's a goal.**

Once you've got it: "mission accomplished." But if you want to be **helpful and reliable and honest, those are values:** desired qualities of ongoing action.

And in any moment, you can act on those values—even if your job sucks or if you don't currently have one.

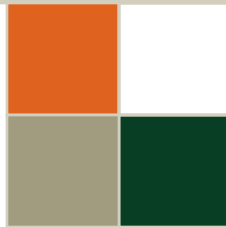
Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



SIX KEY POINTS ABOUT VALUES

There are at five key points about values to be mindful of:

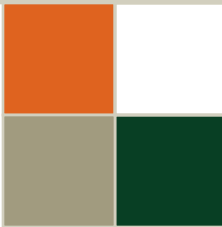
1. Values are here and now; goals are in the future.
2. Values never need to be justified.
3. Values often need to be prioritized.
4. Values are best held lightly.
5. Values are freely chosen.



TECHNIQUES TO IDENTIFY VALUES

REMEMBER, THEY'RE ONLY A MEANS TO AN END:

**TO HELP OUR CLIENTS CONNECT WITH THEIR OWN HUMANITY AND FIND OUT WHAT SORT OF
PERSON THEY REALLY WANT TO BE.
SO THEY CAN LIVE THEIR LIVES WITH A SENSE OF MEANING AND PURPOSE.**



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

TECHNIQUES TO IDENTIFY VALUES

Ten Years from Now

“Looking Back Imagine that you are in the future, ten years from now, and you are looking back on your life as it is today.

Complete these three sentences:

I spent too much time worrying about...

I did not spend enough time doing things such as...

If I could go back in time, what I'd do differently is...”

Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

TECHNIQUES TO IDENTIFY VALUES

MINDFULNESS EXERCISE DROPPING ANCHOR

<https://www.actmindfully.com.au/wp-content/uploads/2018/06/Drop-Anchor-Audio-Exercise-2-minutes-1.mp3>

Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger



UNIVERSITY OF MIAMI
MILLER SCHOOL
of MEDICINE



TECHNIQUES TO IDENTIFY VALUES

One year from Now

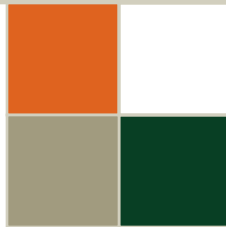
“Imagine that one year from now, you are looking back at the difficulty you are facing today. Imagine that you have handled it in the best possible way, behaving like the person you really want to be, deep in your heart.

From that perspective, answer these questions:

What qualities or strengths (e.g., courage, kindness, compassion, persistence, honesty, caring, supportiveness, honesty, integrity, love, commitment) did you live by or act upon in the face of this?

How did you treat yourself as you dealt with this?

How did you treat others that you care about?”



OBJECTIVE 3: Demonstrate the importance of values and meaning exploration as an approach to engagement and retention in care

VALUES UNDERLYING A GOAL

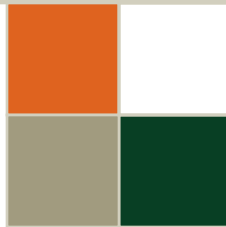
To get to the values underlying a goal, we can ask any or all of the following questions: Let's suppose you achieve this goal. If so...

What personal qualities or strengths would achieving this goal allow you to demonstrate?

If people you love get to know about this, what qualities and strengths would you like it to inspire in them?

What would achieving this goal show that you stand for or support (or stand against or oppose)?

Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger

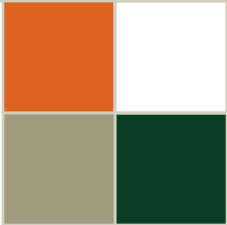


EXERCISE: A Values Checklist

Below are some common values. (They are not ‘the right ones’; merely common ones.) Please read through the list and write a letter next to each value, based on how important it is to you: V = very important, Q = quite important, and N = not so important. Of course, some values will be more important in one area of life (e.g. parenting) than in another area (e.g. work) – so this is just to get a general sense of the values that tend to matter to you most.

1. Acceptance/self-acceptance: to be accepting of myself, others, life, etc.
2. Adventure: to be adventurous; to actively explore novel or stimulating experiences
3. Assertiveness: to respectfully stand up for my rights and request what I want
4. Authenticity: to be authentic, genuine, and real; to be true to myself
5. Caring/self-care: to be caring toward myself, others, the environment, etc.
6. Compassion/self-compassion: to act kindly toward myself and others in pain
7. Connection: to engage fully in whatever I’m doing and be fully present with others
8. Contribution and generosity: to contribute, give, help, assist, or share
9. Cooperation: to be cooperative and collaborative with others
10. Courage: to be courageous or brave; to persist in the face of fear, threat, or difficulty
11. Creativity: to be creative or innovative
12. Curiosity: to be curious, open-minded, and interested; to explore and discover
13. Encouragement: to encourage and reward behavior that I value in myself or others
14. Engagement: to engage fully in what I am doing
15. Fairness and justice: to be fair and just to myself or others
16. Fitness: to maintain or improve or look after my physical and mental health
17. Flexibility: to adjust and adapt readily to changing circumstances
18. Freedom and independence: to choose how I live and help others do likewise
19. Friendliness: to be friendly, companionable, or agreeable toward others
20. Forgiveness/self-forgiveness: to be forgiving toward myself or others
21. Fun and humor: to be fun loving; to seek, create, and engage in fun-filled activities
22. Gratitude: to be grateful for and appreciative of myself, others, and life
23. Honesty: to be honest, truthful, and sincere with myself and others
24. Industry: to be industrious, hardworking, and dedicated
25. Intimacy: to open up, reveal, and share myself, emotionally or physically
26. Kindness: to be kind, considerate, nurturing, or caring toward myself or others
27. Love: to act lovingly or affectionately toward myself or others
28. Mindfulness: to be open to, engaged in and curious about the present moment
29. Order: to be orderly and organized
30. Persistence and commitment: to continue resolutely, despite problems or difficulties.
31. Respect/self-respect: to treat myself and others with care and consideration
32. Responsibility: to be responsible and accountable for my actions
33. Safety and protection: to secure, protect, or ensure my own safety or that of others
34. Sensuality and pleasure: to create or enjoy pleasurable and sensual experiences
35. Sexuality: to explore or express my sexuality
36. Skillfulness: to continually practice and improve my skills and apply myself fully
37. Supportiveness: to be supportive, helpful and available to myself or others
38. Trust: to be trustworthy; to be loyal, faithful, sincere, and reliable
39. Other: _____
40. Other: _____

QUESTIONS



References

1. Andriote, J. M. HIV Mental Health Treatment Issues: HIV and Anxiety. American Psychiatric Association Office of HIV Psychiatry www.psychiatry.org
2. ²Depression. Primary Care of Veterans with HIV. Neurology, Psychiatry, and Pain retrieved from <https://www.hiv.va.gov/provider/manual-primary-care/depression.asp> on June 3, 2018
3. Harris, R. (2019). ACT Made Simple Second Edition: An Easy-To-Read Primer on Acceptance and Commitment Therapy. Oakland, CA: New Harbinger
4. ¹Moore, D. J., Posada, C. (2013). HIV and psychiatric comorbidities: What do we know and what can we do? High-quality care for HIV-infected individuals also requires vigilance regarding the mental health needs of patients. Psychology and AIDS Exchange Newsletter,
5. ³ Neigh, G. N., Rhodes, S. T., Valdez, A., & Jovanovic, T. (2016). PTSD co-morbid with HIV: Separate but equal, or two parts of a whole? *Neurobiology of Disease*, 92(Pt B), 116–123. <http://doi.org/10.1016/j.nbd.2015.11.012>
6. ⁴Robertson, K., Bayon, C., Molina, J. M., McNamara, P., Resch, C., Munoz-Moreno, J. A., Kulasegaram, R., Schewe, K., Burgos-Ramirez, A., De Alvaro, C., Cabrero, E., Guion, M., Norton, M., Van Wyk, J. (2014). Screening for neurocognitive impairment, depression, and anxiety in HIV-infected patients in Western Europe and Canada. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV* Vol 26 Issue 12, 1555-1561 <https://doi.org/10.1080/09540121.2014.936813>
7. WHO secretariat (2012). RISKS TO MENTAL HEALTH: AN OVERVIEW OF VULNERABILITIES AND RISK FACTORS. http://www.who.int/mental_health/mhgap/risks_to_mental_health_EN_27_08_12.pdf
8. <https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-015-0990-0/tables/2>

