Counselling Guidelines

Clients with High HIV Anxiety and No/Low Risk

Updated 2021

Hassle Free Clinic

Contents

Some Commonly Asked Questions

How do I use these guidelines?

These guidelines are intended for HIV counsellors, testers, and educators who work with clients experiencing high anxiety about HIV infection, and no or low HIV risk (HANLR).

Depending on their role, time constraints, comfort level, and the mandate of their workplace, providers can use these guidelines in different ways:

- Use the checklist (page 5) to assess a client situation during a counselling session
- Look at the whole document once in a while as a refresher
- Post a hard copy of the 5-minute guide nearby
- Discuss HANLR case studies at team meetings using the guidelines
- Include the document in new staff onboarding
- Use it in combination with other practices of your particular setting

Why do these guidelines exist in addition to the Ontario Guidelines for Providers Offering HIV Testing?

These guidelines start where standard HIV pre-test and post-test counselling leave off. Any client seeking HIV testing should receive all of the standard information and risk assessments as per the Ontario Guidelines. Only at the point where a client has been confirmed HIV negative (through an HIV test outside of the window period), and as HANLR clients, should we begin using these guidelines.

These guidelines exist because standard HIV pre-test and post-test counselling is almost always ineffective with HANLR clients. Standard HIV test counselling focuses on HIV risk and infection as the core issues, whereas, for HANLR clients, the core issues are anxiety and emotional pain.

Standard HIV test counselling focuses on HIV risk and infection as the core issues, whereas, for HANLR clients, the core issues are anxiety and emotional pain.

These guidelines help providers understand, empathize with, and address HANLR clients' core issues while preserving time, energy, and emotional resources. The goal of these guidelines is to provide appropriate counselling and referrals to HANLR clients, in place of repeated and unnecessary HIV testing.

What is so different about counselling HANLR clients?

These guidelines diverge from common approaches to HIV testing counselling protocols because HANLR clients have different core needs than other clients seeking HIV testing.

To understand and support HANLR clients, providers need to delve into the larger context around the specifics of a client's situation. This may include exploring their experience and history with anxiety, difficult feelings such as sexuality-related guilt and shame, as well as traumatic sexual experiences.

Can I do this if I'm not a therapist?!

Yes! Throughout this guide, we suggest approaches and questions that open up deeper issues for clients. While the degree to which you do this will depend on your role, addressing underlying issues in itself is not outside of the scope of HIV test counselling. In fact, addressing anxiety when we notice it allows the client interaction to be authentic. Ignoring a client's anxiety and focusing only on what the provider deems relevant misses the mark of client-centered care.

Remember that most important thing a provider can do is to offer active listening, empathy, and non-judgment. It is equally important to offer appropriate and timely referrals to address challenges outside of your scope as a provider. So even if you are not a therapist, you can be a witness to a client's reality. You can offer a metaphorical mirror so that they can see their lives more clearly. At the least, you can abstain from deepening the misconception that they have an HIV challenge while they actually have challenges with anxiety

These guidelines will help you focus on the core challenges that fuel a client's anxiety. In some cases, this shift in focus will be enough to help guide clients toward addressing their anxiety. In all cases, proactive referrals for more intensive counselling/therapy should be made available to the client.

What if I'm not successful even if I follow these guidelines?

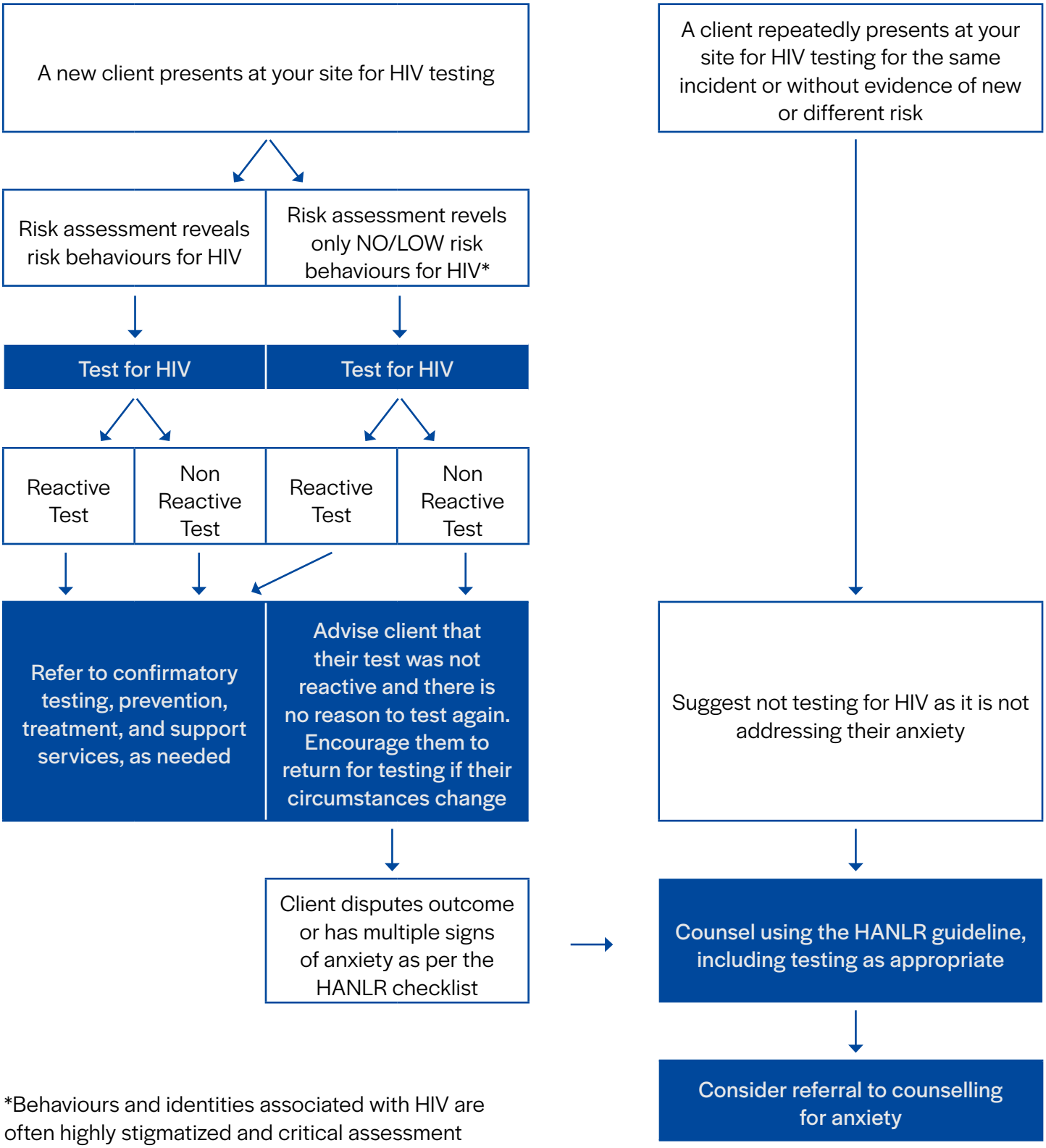
You may not always feel successful! However, your definition of success may need to be redefined.

With a HANLR client, we are working with complex and often historical challenges. At the point-of-care where the client is seeking testing or picking up a self-test kit, their issues likely will not get resolved, entirely. Our role is to contribute to their journey toward wellness. Even being still (like being with their regret or fear) instead of spinning in circles (like repeatedly calling help lines or testing unnecessarily) are great successes.

When is it not appropriate to use these guidelines?

These guidelines are not appropriate to use with clients at actual risk for HIV; they are not meant to replace any existing HIV counselling and testing protocols.

When do the Hassle Free Counselling Guidelines for Clients with High HIV Anxiety and No/Low Risk (HANLR) Apply?



*Behaviours and identities associated with HIV are often highly stigmatized and critical assessment information may not be revealed.

Checklist - Does my client have high HIV anxiety, and no or low HIV risk?

The list below can help in identifying HANLR clients. It is not exhaustive or diagnostic.

"Yes" to many of these = These guidelines are appropriate

"No" to many of these = These guidelines may not be appropriate

- [ ] Did a low-risk or no-risk activity prompt the client's concern about HIV?

  If so...

  - [ ] Does the client continue to worry even though they understand that the activity is low or no risk?
  - [ ] Does the client contest the risk assessment?

- [ ] Does the client ask the same question repeatedly at different places such as clinics, hotlines, and community centres? (The question may be about their HIV risk, about a rare strain of HIV, about false negatives, etc.)
- [ ] Does the client spend many hours researching HIV – transmission, testing technologies, symptoms and disease progression?
- [ ] Does the client present for repeat testing, or have an intense desire for repeat testing, without new risk factors since the last test?
- [ ] Does the client repeatedly request or perform HIV self-tests without new risk factors since the last test?
- [ ] Is the client secretive or deceptive with providers about their HIV testing frequency?
- [ ] Does the client believe that they are in fact HIV-positive, even though one or more HIV tests (outside the window period) have been negative?
- [ ] Does the client report symptoms of HIV infection that coincide with symptoms of anxiety? (e.g., insomnia, depression, stomach/gut pain, diarrhea, thrush, skin changes)
- [ ] Does the client doubt the accuracy of HIV testing technology?
- [ ] Does the client feel that they are a rare or unique HIV case? (This may mean that it takes longer than the window period to test positive, that existing technology cannot identify the strain, or that it is transmissible in ways that HIV is not).
- [ ] Do thoughts about HIV infection interfere with the client's relationships and/or daily activities?
- [ ] Does the client believe HIV infection to be a deadly and incurable disease? Do they think of it as a "life sentence"?

HANLR Counselling when you only have 5 minutes

Exploring the underlying anxiety factors for HANLR clients takes time, patience, and empathy. Here is a list of practical strategies for providing support when time is limited.

Keep In Mind	What To Say
Don't get stuck giving out facts. When a client has intense anxiety related to a low/no risk activity and a confirmed negative test, you should clarify the level of risk only once. Repeating information leaves you little time to explore the anxiety and establish a follow-up plan.	*It sounds like this situation is really stressful for you. Did this anxiety begin at a particular time? When did it start?*
Listen and be empathic. A dismissive demeanor or tone causes clients to work harder to convince you that they are at risk or already HIV positive.	*Tell me more.* *[Reflect back what you hear]*
Ask about anxiety. Focusing on risk and symptoms does not help clarify the client's situation.	*What is it like for you to experience all these symptoms? What is it like for you to be carrying this anxiety?* *Other than symptoms what else is contributing to your anxiety?* *How is the anxiety affecting your relationship [with family, partners, friends, work]?*
Listen for regret, guilt, and shame. These are entry points to underlying anxiety. People who feel they have done something wrong sexually may punish themselves and/or await punishment.	*Can you tell me more about feeling [guilty, foolish, irresponsible]*?* **use client's words*
Make a plan to cope with anxiety. Help the client make a plan about what to do when the anxiety arises. Keep it realistic and practical. Make referrals to address the client's anxiety. Explore with the client their plan to follow through with referrals. Help the client set goals or limits regarding Internet use, repeated tests, clinic visits, or calling helplines.	*How have you dealt with anxiety in the past?* *How might you deal with future anxiety?* *It can help to set a goal or limit for yourself regarding the behaviours that add to your anxiety (like reading about this on the Internet). What goal or limit might make sense for you for the next few weeks?*

Guideline 1: Address symptoms and risks as a starting point for conversation, not as the dominant subject

State the facts about HIV and check for the client's understanding. Once understood, do not repeatedly state the facts.

Do not argue with the client – a debate about HIV risk can seem like an intellectual disagreement but in fact, it is the client saying "I am under threat". Repeatedly having a "debate" about facts is saying "No, you're not". While that may be true, it does not make anxiety go away. Instead, it makes the client feeling unheard, and frustrates the provider.

So, instead, listen. Listen deeply for what's under the surface. Acknowledge the client's symptoms as well as their feelings. You do not need to agree with the facts of threat in order to understand their experience of feeling threatened.

The client might say:

I have HIV because I have these symptoms...

Look at this cut on my finger. It's 6 mm, and isn't that a significant entry point?

I can see dots on my tongue, it's obviously thrush.

Let me show you my lymph nodes.

Less Helpful Responses	More Helpful Responses
We don't use symptoms to assess. If your test is negative, then you are negative. The client will look for more convincing "evidence", to "prove something" to you. This response does not address the very real suffering and terror associated with having symptoms. Increases stress for both parties.	**It must be scary to experience all these symptoms.** Allows the client to feel heard and decrease their need to go over symptoms. Acknowledging the client's state of mind does not mean agreeing with their assessment of risk.
Like I said before, it is only a theoretical risk. Clients with high anxiety often feel like their experience is the exception rather than the norm. A small possibility communicates that infection is possible, not improbable.	**When I tell you that it is a theoretical or low risk, it doesn't seem to alleviate your anxiety. Let's talk about that. What do you think is going on?"** Prompts the client to observe and explore their own reactions, and possibly develop and share some insight into their situation.

Guideline 2: Accept that a negative test result may not alleviate the client's anxiety; explore their reaction

Do not expect that a negative test result will end the conversation or remedy anxiety. The client may not feel the relief they (and you) were hoping for. They may question the test's accuracy, the handling of the specimens, your credibility, and so on.

Many HANLR clients will speak of a "risk" event or series of events. The symbolic aspects of the risk event(s) are not necessarily logical or scientific. A negative test result does not address the feelings and meanings associated with the "risk" event, which is why it does not resolve the anxiety. Your job is not to take away the anxiety, but to have a willingness to explore it with empathy.

The client might say:

Can you test me again?

I would like a PCR test.

What are your stats on false negatives?

I think I have a strain that is not detectable.

How accurate is this test? Was it expired?

Less Helpful Responses	More Helpful Responses
The point-of-care test is 99.6% accurate, so you're fine. **I've been doing this for 20 years. I've never seen a negative test outside the window period turn positive.** **The PCR Test is [insert factoids here]...** Meant to comfort, these responses actually create more discomfort. The 0.4% inaccuracy, the limits of your experience, or some minute fact about the PCR test can become the next objects of focus, thus increasing anxiety. This means that, if the client asks you for the accuracy of a test, facts about a procedure, and/or to outline your experience, consider responding not with "the answer", but with something more helpful and to the point of the anxiety.	**Sometimes, test results may be anticlimactic. And this is common for people who...[insert client's experiences with anxiety here]** **For some people, a negative result might lead to temporary relief but the anxiety comes back.** Temporary relief is a sign that the underlying issue has not been resolved. Encourage the client to connect with you or other resources if/when anxiety returns. Take this opportunity to contract with client around limiting their Internet use, their visits to community services, and their repeated calls to clinics and phone lines about HIV.

You can't use up public resources like this... Prompts the client to justify their needs (e.g., by offering payment for testing), which is further another digression from the core issues.	**So, your result is negative but your anxiety has not subsided. What does this mean for you?** Addresses symbolic level emotions about the risk event(s) that make test results difficult to trust

Guideline 3: Initiate conversation about issues that underlie the anxiety

Listen and pick up on the client's cues. Often, what they say will show judgement, guilt, regret, or shame for which the client may be anticipating punishment or consequences. These feelings are often directly about a "risk" event, and other times, a "risk" event brings up unresolved situations from earlier life.

Initiate a conversation about these situations by reflecting back what you hear and observe from the client. The client may not be prepared to "go there", or they may feel a great relief to finally address a core issue. Move the conversation along with care. Don't aim to have a particular outcome, just point the client in this direction and then go at their pace.

The client might say:

I did something very stupid.

I don't know what came over me, I'd never done anything like that before.

I can't believe I just ruined my life

I deserve this, but my kids don't!

I started feeling anxious right after [risk event]... but that was 15 years ago.

Less Helpful Responses	More Helpful Responses
Everyone makes mistakes. **Don't say it was stupid. You're not stupid.** While intended as reassurance, these shut down the conversation about anxiety.	**Can you tell me more about this experience? What exactly about it makes you feel so stupid?** This reflects back the client's feelings, instead of negating them.

We've been through this three times! **Do you know how many people are in a worse situation than you?** Scolding the client can derail their progress and create animosity between you. The client feels even more alone.	**It sounds like you really regret this experience, and that you're very hard on yourself about it. What has it been like for you for the last few months?** This can foster a feeling of being understood. "Hard on yourself" comes from the client's internal perspective, as opposed to "overreacting", which comes from a judgemental, external perspective.
I hope this scare taught you a lesson. You won't be this lucky every time. This is judgemental and can contribute to client guilt. It also misuses authority to direct how the client should be feeling.	**When did you start feeling so anxious?** **When you were tested last, did you feel as anxious as this time? If not, what is it about this time?** **When is your anxiety at its highest/lowest? What is going on that causes the anxiety to fluctuate?** **Besides symptoms, what else contributes to your anxiety?** **Do you feel anxious about other things in your life?** **How is this anxiety affecting your relationships?** These are good entry points into having a conversation about anxiety. They can bring the client to another level of awareness and illuminate the context around the anxiety.

Guideline 4: Help the client develop a plan to manage anxiety

HANLR clients manifest their feelings of anxiety in various behaviours. In addition to repeat tests, they might compulsively do research on the Internet, call info lines, imagine symptoms in their loved ones, and make plans around their eventual illness.

Developing a plan for anxiety management can extend the work done in the short time of your session. Involving the client as an active agent in their own health is empowering and ensures that planning is realistic, achievable, and relevant.

By not being preoccupied with anxiety behaviours, the client may be able to redirect energy towards the source of the anxiety and/or its resolution.

Note: This step is only possible after you and the client have begun to address their anxiety and associated feelings.

Less Helpful Responses	More Helpful Responses
You need to get over it. **What will it take for you to... [stop the anxiety behaviour]?** May take agency away from the client, and direct them towards goals that may not be relevant, appropriate, or realistic.	**It can be tempting to [repeat the anxiety behaviour]. But, [that behaviour] does not seem to bring your anxiety down in a sustained way. In fact, it has increased the anxiety.** **When the anxiety returns, try not to blame yourself. It isn't a failure on your part. It only shows that there is something important and unresolved.** These explain to the client what to expect after the session, and coach them toward different responses.
I really don't know what else to tell you. **I can't believe we're still talking about this.** Expressions of exasperation are signs that you have taken on too much responsibility for changing the client's behaviour. Take a step back, and work with the client from where they are at, at their pace.	**Can we talk about how you might deal with future anxiety?** **Is it possible to limit or cut down that behaviour? What's realistic for you right now?** **On a scale of 1 to 10, how doable is this goal that we've set?** If it is low, then also: **How might we change the goal – or support you – to make it more doable?** **When you feel very anxious, or feel a strong urge to repeat the [anxiety behaviour], observe what may be activating it. Are you alone? What time is it? What's in your surroundings?** These can help the client intervene on their own anxiety behaviours. With more work, they may also help the client identify the source and triggers of their anxiety.

Guideline 5: Point out that repeated HIV testing is not achieving the intended outcome

Repeat testing does not address the underlying anxiety for HANLR clients. In fact, it can fuel the cycle of anxiety.

For many, testing relieves anxiety only temporarily, if at all. Testing when unnecessary can erroneously reinforce the idea that there is actually a risk or a reason to test. It can become a point of preoccupation – the brain's way of distracting from difficult challenges.

At the same time, on occasion, you may go ahead with testing as a way to de-escalate a client's anxiety, so that they can better engage with you in addressing their repeat testing.

Less Helpful Responses	More Helpful Responses
We will not test you today. While the end goal is to stop the client from repeatedly testing when there is no risk, the process toward that goal makes a big difference. When not testing is the provider's decision, and the client is positioned against it, we actually recreate the dynamic we do not want (where the client pushes and we pull away).	**My recommendation is that we do not do the test today, given how testing (and its results) do not address the source of your anxiety. What do you think about that?** In order to be effective as a strategy, not testing has to be the client's decision, or at least a joint effort. The decision to not test needs to connect the client and provider, rather than oppose them. **In the past you may have found that testing alleviates your anxiety briefly but then it would come back.** **If there is a different way toward a different outcome, would you be interested in exploring?** **What would be a good outcome going forward?** Identifying the client's anxiety cycle helps them gain insight. Observing that their course of action is not creating a desired outcome can shift the reactive nature of their behaviours toward goal-oriented responses. Together, you can explore what desired outcomes are, and how to achieve them.

OK, we'll test you one last time. But just once more. Testing for the sake of pacifying the client is not a sustainable response. Sometimes, providers resort to this as a way of giving up on the frustrating interaction and in an attempt to pacify the client. Unfortunately, it simply delays the interaction, and extends the client's journey.	**We can go ahead with a test; not because you have an actual risk, but because I can see how your anxiety will get in the way of our discussion.** **Why don't we do the test first? Then, when it is a negative result, we can explore the source of your anxiety.** Here, testing is offered as a way to connect with the client. When the client is highly anxious, going ahead with the testing may de-escalate the anxiety enough in order for the client to engage explore its root causes.

Guideline 6: At the appropriate time, work with the client towards closure and next steps

Your counselling session is likely not the final step in the client's journey. Further supports are probably needed to fully resolve anxiety (e.g., community referrals).

Clients often anticipate an HIV-positive test result as their source of closure. So in the face of a negative result, the client needs support to find alternative forms of closure (e.g., recognize the significance of the event or "mistake", and move forward).

Effective closures:

- Have to be felt.
- Are personal, and will vary from client to client.
- Explore and lead to acceptance, integration in the client's life story, and self-forgiveness.
- Are often ritualistic or commemorative (e.g., remembering a date, writing a letter, watching a candle burn down)

Empower the client to take charge of the situation. Outline the steps they have already taken, and work with them on closure as well as future steps. The client may not want to let go for fear of forgetting what they need to learn. Remind them that forgiving is not forgetting.

Encouraging a client to disclose "mistakes" or deception is not necessarily helpful (e.g., telling their spouse about cheating). Instead, explore the impact of not disclosing, and the possibilities for full, partial, or non-disclosure.

Less Helpful Responses	More Helpful Responses
I hope you are convinced now that you are HIV negative. **You should see a therapist/ psychiatrist. We've done all we can here.** These are directive, and do not come from the client's perspective.	**In the past, what other things have caused you this kind of anxiety, and how have you coped?** **What do you think would work in terms of responding to the anxiety when it comes up?** These help the client build their own plans and highlight their strengths. You can build on the plan they have suggested.
Life is short. Learn your lesson and move on.	**You've been through a lot during this struggle with your anxiety. At this point, can you think of any way to commemorate or mark what happened?** Closures are important because they acknowledge the client's experience and mark a point of transformation.

Guideline 7: Recognize and address your triggers

Sometimes, clients may hurt, offend, or trigger us.

Common triggers for service providers include:

- Disparaging comments about people living with HIV/AIDS, or marginalized groups commonly associated with HIV.
- Having your competence or your organization's work questioned by a client.
- Disclosures of abuse, cheating or other kinds of deception.
- Aggressive, agitated behaviour.
- Despair and hopelessness.

Outside of the counselling situation:

- Develop self-awareness – What activates your emotions? What expectations do you have of clients and of yourself? How do other people's anxiety affect you?
- Develop self-compassion for the parts of you that are reactive.
- Develop support systems and coping strategies in advance.

During a counselling session:

- Do not let your triggers hijack the conversation. Assess if you are able to continue counselling in a fair, non-judgmental and client-centered way. If not, draw on your coping strategies (e.g., leave the room for a moment, pause the call and ask for help, take deep breaths, other grounding techniques).

After the counselling session:

- Debrief with fellow providers and supervisors.
- Have reasonable expectations of yourself (i.e., you are not responsible for solving every problem).
- You may not have been as effective as you wanted to be.
- Take note of what you have learned, what you need to work on, and what kinds of support you need.

Less Helpful Responses	More Helpful Responses
AIDS is not a punishment! **What you said is really homophobic!** **Well, I belong to that social group you just put down!** Becoming angry, dismissive, or argumentative shifts the focus to a larger political issue (your issue), rather than recognizing the client's biases as part of their anxiety. Focus on the feelings and meaning behind the client's worldview as opposed to its fairness. It is less important that the client be correct, and more important that they are understood.	**Can you tell me what getting HIV means to you?** **If that's how you feel about [a particular group of people], how do you feel that you had sex with someone from that group?** These enrich the provider's understanding of the client's experience, which in turn informs how their worldview and values impacts their anxiety.
You need to stop saying that.	**When you say [inappropriate term], do you mean [alternate term]? Yes? Can you use [alternate term] instead? It would help me hear you better.** One way of setting boundaries for the counselling session.
You should tell your partner that you've cheated. It's the only right thing to do. Take care not to enact your own agenda.	**What impact does holding a secret have on you and your relationship?** Understand where the client is coming from rather than imposing your version of morality.

Guideline 8: Take time for self-care

Helping clients recognize and examine emotional pain, guilt, self-blame, and relationship difficulties can contribute to vicarious distress, which is when providers internalize the client's trauma and/or anxiety. Self-care is a set of practices and attitudes that help you cope with the emotional toll of the work.

Self-care is different for everyone. It can involve a range of activities that recognize and prevent "burn out", as well as enhance mental, physical, and spiritual well-being. Using more effective counselling strategies can be a part of self-care – they help counsellors navigate difficult interactions with less resistance and more connection.

Self-care practices are not only the responsibility of individual providers. A workplace conducive to staff health likely has a collective strategy that builds mutual support, supports staff through continued education, and actively addresses environmental conditions that lead to occupational stress.

Less Helpful Responses	More Helpful Responses
Ignore your feelings and tell yourself to get over it. Be complicit in problems within service provision or protocols (when they exist). Deprioritize aspects of your life that give you pleasure because you are too consumed with your work.	Know the signs of occupational burn-out within yourself and in fellow staff: ✱ Being increasingly cynical, angry, or irritable ✱ Low energy and feeling like your challenges are insurmountable ✱ Losing the ability to take pleasure in life and work ✱ Significant changes in sleep and eating patterns ✱ Self-medicating to feel better Speak to a trusted peer or supervisor about your concerns and develop concrete/realistic strategies to address them. Contact your Employee Assistance Program or other workplace supports. Seek help from health practitioners about changes in your health due to occupational stress. Take breaks – throughout a day, and also longer periods of time-off, when possible. Supervisors often depend on front-line staff to keep them informed on the efficacy of service provision. Offering your observations and suggestions can lead to workplace change.