

Counselling Guidelines for Clients with High HIV Anxiety and No/Low Risk

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High HIV Anxiety No/Low Risk Working Group

Alliance for South Asian AIDS Prevention
AIDS Committee of Toronto
Asian Community AIDS Services
Black Coalition for AIDS Prevention
CATIE (Canadian AIDS Treatment Information Exchange)
Halton Region Health Department
Hassle Free Clinic
Ontario Ministry of Health – AIDS Bureau
Ontario Ministry of Health – AIDS & Sexual Health Infoline
Toronto Public Health

In May 2008, the Hassle Free Clinic in Toronto organized a meeting among service providers concerned about clients with high anxiety but low or no risk for HIV. From this meeting, a working group was formed to address the need for effective counselling strategies that would address the complex experiences of these high anxiety clients. We recognize that standard HIV testing protocols often do not serve these clients well. Because of this, counsellors, testers, and other service providers often report frustration that their best efforts do not always help resolve client anxiety. This working group aims to enhance both client and counsellor empowerment by providing professional resources and training opportunities throughout Ontario.

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WHY THESE GUIDELINES?

These guidelines and materials are intended for HIV counsellors, testers, and educators who work with clients that experience high HIV anxiety and no/low risk (HHANLR). Working with HHANLR clients can put significant demands on service providers. In response, these guidelines provide tools and resources to support these clients. The focus of the guidelines is to encourage appropriate counselling and referrals, in place of repeated and unnecessary HIV testing.

HOW DO I USE THESE GUIDELINES?

At first glance, some suggestions in the guidelines may seem different from common approaches to HIV testing counselling practice (e.g., reviewing risk factors).

However, keep in mind that anxious, low/no risk clients have unique characteristics and require a specific counselling approach.

To understand and support them, counsellors need to delve into the context of the client's situation. This may

include exploring their history with anxiety, difficult feelings such as sexually-related guilt and shame, as well as experiences of sexual trauma. Throughout this guide we suggest approaches and questions that may open up deeper issues for clients and ourselves. Sometimes, you may be unsure of how to handle strong emotions or sensitive information. It is important to keep in mind that a counsellor's role is not to solve problems for the client.

The most important thing a counsellor can do is to provide **active listening, empathy, and non-judgment**. These guidelines were produced to help you focus on the core issues that fuel the client's anxiety. In some cases, this refocusing will be enough to help clients resolve their anxiety. In other cases, referrals for more intensive counselling/therapy may be needed.

Keep in mind that your training, time constraints, and the mandate of your workplace will influence when and how you use these guidelines. The information contained in the materials can be used in part or in whole within a variety of HIV counselling and testing settings.

WHAT ELSE IS IN THIS PACKAGE?

Along with these practical counselling guidelines, this package includes: a checklist to help counsellors determine whether they may be working with a HHANLR client, and a reference guide for use in time-constrained counselling situations.

DISCLAIMER...

These guidelines are not appropriate to use with clients at high risk for HIV. While they will help us identify HHANLR clients and complement our current work with them, they are not meant to replace any existing HIV counselling and testing protocols (i.e. *Guidelines for HIV Counselling and Testing 2008* produced by the Ministry of Health and Long-Term Care). In a testing site, it is assumed that the counsellor has provided pre- and post- testing counselling, and that basic counselling skills are used.

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ABOUT LANGUAGE...

This guide avoids the term 'worried-well' because of its potential to minimize the client's experience.

REMEMBER....

You may not always feel successful. Keep in mind that small steps can often be significant.

CHECKLIST: Does my client have high HIV anxiety, and no or low risk?

The list below, though not exhaustive, is meant to assist service providers in identifying HHANLR clients. If the client's situation warrants a "Yes" to many of these questions, it may be appropriate to use the counselling guidelines in this package.

1. Has a low- or no-risk activity prompted the client's concern about HIV?
2. Does the client continue to worry even though they understand that the activity is low or no risk? Or, does the client contest the risk assessment?
3. Does the client ask the same question (the possibility of HIV infection from a particular incident) repeatedly, at multiple places (such as clinics, hotlines and community centers)?
4. Has the client spent many hours researching HIV – transmission, testing technologies, symptoms and disease progression?
5. Does the client present for repeat testing, or manifest an intense desire for repeat testing, without having new risk factors since the last test?
6. Does the client believe that they are HIV-positive, even though one or more HIV tests (after the window period) have come back negative?
7. Does the client doubt the accuracy of HIV testing technology?
8. Does the client feel that they are a rare case in which it takes longer than the window period to test positive?
9. Do thoughts about HIV interfere with the client's relationships and/or daily activities? Have their concerns about HIV impacted their personal life?

1. Address symptoms and risks as a starting place for conversation but not as the dominant subject.

- State the facts and check for the client's understanding. If understood, do not repeatedly state facts.
- Do not argue with the client. Listen. Dismissing symptoms or risks may make client more adamant in talking about them.
- Acknowledge the client's feelings – e.g., it's scary to feel/see symptoms, to feel not believed, and to feel vulnerable.
- The client may return to symptoms or perceived risks to “prove” that they are infected. Observe and address the client's feelings/motivations behind this.
- If the client repeatedly returns to talking about symptoms, they might be trying to tell you something that they feel you do not understand.



The client might say:

“I have HIV because I have these symptoms...”

“Look at this cut... is it big enough?”

1. Address symptoms and risks as a starting place for conversation but not as the dominant subject.



May Be Less Helpful

“We don’t use symptoms to assess. If your test is negative, then you are negative.”

- The client may look for more convincing “evidence”, and digress from the underlying issues.
- May make the client argumentative, to “prove something” to you.
- May increase stress for both parties.

“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. The client might conclude that it *is* possible.



May Be More Helpful

“It must be scary to experience all these symptoms.”

- May allow 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.

“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?”

- It is important to observe and explore the client’s reactions. This may assist the client develop insight into their situation.

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

- Even after a negative result, the client may not feel the relief they (and we) were hoping for. They may question the test's accuracy, the handling of the specimens, and so on.
- Do not use the test result to end conversation, shut the client down, or as a remedy for anxiety.
- Our job is not to take away the anxiety, but to have a willingness to explore with empathy.

Why?

- Something other than HIV may be making the client anxious.
- A test result does not address the feelings associated with the "risk" event. The symbolic aspects of the "risk" event may not respond well to scientific/logical information/ evidence (i.e., according to Just World Theory, moral misconduct will bring about punishment).



The client might say:

"Can you test me again?"

"Are there factors that can give me a false negative result?"

"Can I do a PCR test?"

"How accurate is this test?"

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



May Be Less Helpful

"The POC test is 99.6% accurate"

- The 0.4 % inaccuracy may become an object of focus, thus increasing anxiety and leading to digression.

"The PCR Test is..."

"I've been doing this for 20 years. I've never seen a negative test outside the window period turn positive"

"You can't use up public resources like this..."

- May prompt the client to offer payment for further testing – another digression from the "real" issues.



May Be More Helpful

"Sometimes, test results may be anticlimactic. And this is common for people who feel ..."

"For some people, a negative result might lead to temporary relief but the anxiety can come back..."

- Temporary relief might be a sign that the underlying issue has not been resolved. Encourage client to connect with you or other resources if anxiety returns.
- Take this opportunity to contract with client around limiting their internet use, accessing community services, calling clinic and phone lines about HIV/AIDS.

"So, your result is negative but your anxiety has not subsided. What does this mean for you?"

- May help address factors (i.e., symbolic level emotions) that make the test difficult to trust.

3. Initiate conversation about issues that underlie the anxiety.



Listen and pick up on the client's cues. They might say:

"I did something very stupid."

"I've never done anything like that before..."

"I've totally messed my family up..."

"I deserve this..."

- The above cues indicate judgement, guilt, regret, or shame for which the client may be anticipating punishment or consequences.
- While HIV-test counsellors are not 'therapists' we are in a unique position to help clients see their situation in new ways and to explore other avenues (e.g., further counselling).
- The counsellor needs to initiate this conversation. However, the client may not be prepared to do this, or may only be able to start the process. Move the conversation along with care.

3. Initiate conversation about issues that underlie the anxiety.



May Be Less Helpful

“Everyone makes mistakes.”

- While intended as reassurance, it tends to shut down the conversation about anxiety.

“Are you listening? We’ve been through this three times!”

- Scolding the client could derail their progress. Their need to return to symptoms could indicate unexplored underlying issues.

“Yes, what you did was very stupid, but it wasn’t anything risky!”

“You were lucky this time. Be thankful you have nothing to be anxious about!”

- Shows the counsellor’s judgement and can contribute to client guilt.
- Misuses authority to direct how the client should be feeling.



May Be More Helpful

“Can you tell me more about this experience? What exactly about it makes you feel so stupid?”

- These reflect instead of negating the client’s feelings.

“It sounds like you really regret this experience, and that you’re very hard on yourself. What is this like for you?”

- May foster a feeling of being understood. “Hard on yourself” comes from the client’s perspective, as opposed to “You’re overreacting”, which comes from the counsellor’s perspective.

“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?”

- May bring the client to another level of awareness, and illuminate the context around the anxiety.

4. Help client develop a plan to manage anxiety.

- Clients may manifest their feelings of anxiety in various behaviours, including obsessively researching on the internet, calling info lines, and so on.
- 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 focusing on anxiety *behaviours* (these may include calling hotlines, surfing the internet for HIV symptoms, repeated testing, etc.), 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.

4. Help client develop a plan to manage anxiety.



May Be Less Helpful

“You need to get over it.”

“What will it take for you to... [stop the anxiety behaviour]?” (anxiety behaviours may include calling hotlines, surfing the internet for HIV symptoms, repeated testing, etc.)

- May take agency away from the client, and direct them towards goals that may not be relevant, appropriate, or realistic.

“I really don’t know what to tell you...”

- May be a sign that you have taken on too much responsibility for change in the client’s behaviour. Take a step back, and work with the client from where they are at.



May Be More Helpful

“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 can help empower and prepare them.

“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 attainable is this goal that we’ve set?”

If it is low, then also: *“What do you need, or how can we change the goal, to make it more attainable?”*

“When you feel very anxious, or feel a strong urge to repeat the [anxiety behaviour], observe what may be triggering it. Are you alone? What time is it? What’s in your surroundings?”

- Can help the client intervene on their own anxiety behaviours. With more work, they may also help the client identify the source of their anxiety.

5. At the appropriate time, work with the client towards closure.

- Recognize that this counselling session is likely not the final step in resolving anxiety. “Next Steps” may be needed (e.g., community referral).
- Clients often anticipate an HIV-positive test result as their source of closure. In the face of a negative result, work with the client to find alternative forms of closure (i.e., recognise 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 forgiveness.
 - Are often ritualistic or commemorative (e.g., remembering a date, writing a letter)
- Empower the client to take charge of the situation. Outline the steps they have already taken, and work with them on planning future steps
- Client may not want to let go for fear of forgetting what they learned. Remind them that forgiving is not forgetting.
- Encouraging a client to disclose “mistakes” or deception is not necessarily helpful. Instead, explore the *impact* of not disclosing, and the possibilities for full, partial, or non-disclosure.

5. At the appropriate time, work with the client towards closure.



May Be Less Helpful

“I hope you are convinced after 3 negative results that you are HIV negative.”

“If this doesn’t give you peace of mind, then maybe you should see a therapist/psychiatrist. We can’t help you.”

“Life is short. Learn your lesson and move on.”

- These are directive, and do not come from the client’s perspective.



May Be More Helpful

“In the past, what other things have caused you this kind of anxiety, and how have you coped?”

- This helps the client build on their plan by highlighting their strengths. Build on the plan they have suggested.

“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.

6. Consider whether repeating the test is in the client's best interest.

- Repeat testing can fuel the cycle of anxiety; it does not address the underlying anxiety.
- Testing tends to relieve 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).
- Use your judgment. Whether to discourage testing depends on your relationship with the client, and your awareness of the situation.
- In order to respect the Guidelines for HIV Counselling and Testing 2008, only consider discouraging testing when there is no risk, or testing has been done outside the window period.

6. Consider whether repeating the test is in the client's best interest.



May Be Less Helpful

"OK, we'll test you one last time"

- Testing for the sake of pacifying the client is not a sustainable response. Sometimes we do this because of burnout, and yet, this in turn can contribute to counsellor stress.



May Be More Helpful

"In the past you may have found that testing alleviates your anxiety briefly but then it comes back."

- Identifying the client's anxiety cycle helps them gain insight into their experience and encourages alternative actions that can sustain anxiety reduction.

If you decide to discourage testing...

"We are not testing you."

- May create an argumentative situation that increases client anxiety and counsellor frustration.

Summarize the client's (lack of) risk, anxiety patterns, test results, and other circumstances, then:

"My suggestion is that you don't test today. And instead, we make a plan to address your anxiety because that seems to be the most immediate issue."

"How do you feel about not getting tested today?"

- This shows the client that you've heard them and want to help them make an informed choice. It opens up the option of not testing, and an opportunity to address what might be the client's true objective – to find peace of mind. This can also lead to further exploration, and more appropriate referrals.

7. Recognize and address your triggers.

- Sometimes, clients may offend or trigger us, and we may want to challenge them.
- Common triggers include:
 - Disparaging comments about those living with HIV/AIDS, or certain groups commonly associated with HIV, and/or discriminated against.
 - Having your competence or your organization's work questioned by a client
 - Disclosures of abuse, cheating or other kinds of deception, as well as aggressive or agitated behaviour.

Outside of the counselling situation:

- Develop self-awareness – What triggers you? What expectations do you have of clients and of yourself? How does other people's anxiety affect you?
- Develop support systems and coping strategies in advance.

During a counselling session:

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

After the counselling session:

- Debrief with fellow counsellors.
- Have reasonable expectations of yourself (i.e., you are not responsible for solving every problem).
- Accept that you were probably not as effective as you could have been. However, take note of what you have learned and what you need to work on.

7. Recognize and address your triggers.



May Be Less Helpful

“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 behind the statement as opposed to the truthfulness or fairness of the statement.

“You need to stop saying that.”

“You should tell your partner that you’ve cheated. It’s the right thing to do.”

- Be careful about enacting your own agenda.



May Be More Helpful

“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 about having had sex with them?”

- Can enrich the counsellor’s understanding of the client’s worldview.
- Can help inform how the client’s worldview impacts their anxiety.

“During this session, can we use the word _____ instead of (something that triggers you) ? It would help me hear you better.”

- One way of setting boundaries for the counselling session.

“What impact does holding a secret have on you?”

- Understand where the client is coming from rather than imposing your version of morality.

8. Take time for self-care.

- Helping people recognize and examine emotional pain, guilt, self-blame, and relationship difficulties can contribute to vicarious distress whereby counsellors internalize the client's trauma and/or anxiety.
- For counsellors, self-care is a set of practices and attitudes that help them cope with the emotional stressors of supporting clients.
- Using more effective counselling strategies can be a part of self-care – they help counsellors navigate difficult interactions with anxious clients.
- Self-care can involve a range of activities that recognize and prevent 'burn out', as well as enhance mental, physical, and spiritual well-being.
- Self-care practices are not only the responsibility of individual counsellors. A workplace conducive to staff health likely has a collective strategy that builds mutual support, engages in staff education, and actively addresses environmental conditions that lead to occupational stress.

8. Take time for self-care.



May Be Less Helpful

- Ignore your feelings and tell yourself to get over it.
- Keep suggestions for improving counselling services to yourself.
- Disregard aspects of your life that give you pleasure and ignore important relationships because you are too consumed with your work.




May Be More Helpful

- Speak to a trusted peer or manager about your concerns and develop concrete/realistic strategies to address the issues.
- Know the signs of occupational burn-out within yourself and in fellow staff:
 - Being increasingly cynical, critical, angry, or irritable
 - Loss of energy and feeling that you face insurmountable barriers
 - Losing the ability to take pleasure in life and work
 - Changes in sleep and eating patterns
 - Self-medicating to feel better
- Contact your Employee Assistance Program or other workplace supports. Seek help from health practitioners about changes in your health due to occupational stress.
- Managers often depend on front-line staff to keep them informed on what does and does not work in the delivery of service. Offering some of your observations can lead to workplace change.
- Health is a state of equilibrium. Maintaining a balanced life is not only an important self-care practice but can help us become more effective at work.

High HIV Anxiety No/Low Risk Counselling when you only have 5 minutes

Exploring the underlying factors of HIV anxiety for those with little to no risk takes time, patience, and empathy. However, even within strict time constraints, service providers can be supportive resources for anxious clients. Here is a list of practical strategies for providing support when time is limited.

Things to consider in 5 minutes	 Ways to respond in 5 minutes
<p>When a client presents intense anxiety related to a low or no risk activity clarify the level of risk only once. Repeating the same information leaves you with little remaining time to explore the anxiety and establish a follow-up plan.</p>	<p>“It sounds like this situation is really stressful for you. Can you tell me when your anxiety began?”</p>
<p>Listen and be empathic. A dismissive demeanor or tone causes clients to work harder to convince you that they are indeed HIV positive.</p>	<p>“What is it like for you to be carrying this anxiety?”</p>

<p>When clients speak about symptoms reflect on the anxiety underlying the symptoms.</p>	<p>“What is it like for you to experience all these symptoms?”</p> <p>“Other than symptoms what else is contributing to your anxiety?”</p>
<p>Get the bigger picture. Focusing exclusively on risk and symptoms does not help clarify the client’s situation and how their anxiety is related to current relationships and other aspects of their lives.</p>	<p>“How is this anxiety affecting your relationship [with family, partners, friends, work]?”</p>
<p>Listen for guilt and shame. This can be a powerful entry point into understanding the underlying factors associated with the anxiety. People who feel they have done something wrong sexually may punish themselves and/or await punishment.</p>	<p>“Can you tell me more about feeling ... [i.e. guilty, foolish, irresponsible <i>*use client’s words</i>]?”</p>
<p>Explore practical and realistic coping strategies. If possible make a referral or a follow-up appointment.</p>	<p>“How have you dealt with anxiety in the past?”</p> <p>“How might you deal with future anxiety?” i.e. Contract about internet use and repeatedly calling clinics or info lines.</p>