

HIV 101: MEDICATIONS, ADHERENCE, AND RISK REDUCTION

Joe¹

Joe is a 32 year old who started medications 3 weeks ago. The Peer Educator gives Joe a call to see how he has adjusted to his medications. Joe tells the Peer Educator that he was prescribed Sustiva and Truvada. He reports that he is taking his medications faithfully. The peer educator asks Joe if he has been experiencing any side effects since starting the medications. Joe reports that he had mild dizziness and vivid dreams.

Discussion Questions:

- What is your typical bed time routine?
- What have you discussed with your doctor?
- How do you relax before going to bed?

Sample Answers:

- Journal bed times and dates of vivid dreams to determine pattern to share with doctor.
- Encourage relaxation before bed.
- Make list of concerns for client to share with doctor, provide information about side effects of medicine)

Carmen¹

Carmen is a 36 year old who has been prescribed Viramune, Zerit and Epivir. Carmen states that she had only missed 1 dose of medications since starting them 6 weeks ago. Carmen reports that she had been experiencing some tingling in her feet and her boyfriend thinks that her face is thinning. She is not sure what she should do.

Discussion Questions:

- How often do you experience the tingling in your feet?
- When did your boyfriend first notice the lipoatrophy or facial thinning?
- Have you shared this concern with your doctor?

Sample Answers:

- Journal frequency and degree of tingling in feet.
- Educate patient about potential side effects of medicine.

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Michael¹

Michael is a 25 year old male who has been prescribed Kaletra and Combivir. Michael is having mild diarrhea. During the conversation Michael tells the peer educator that he has been smoking marijuana about once a week and that he has the habit under control-“it’s to help me chill out after I get home from work.”

Discussion Questions:

- When did the diarrhea begin and how frequent?
- How long have you had the diarrhea?
- Have you tracked side effects in a diary?
- What is your daily food intake, checking for foods that might cause diarrhea?

Sample Answers:

- Document frequency of diarrhea..
- Educate client about common side effects to medications and average time they end.
- Suggest increased fiber diet.

Fred¹

Fred is a charismatic, high energy, newly diagnosed HIV positive man who has enrolled in the peer program at his local clinic. Every time Fred meets with his peer educator he seems to be so hyper that it causes alarm with his peer educator. The source of Fred’s excited mood is methamphetamines. During the session, the peer educator learns that Fred forgets to take his medications. The peer would like to discuss the effects of mixing street drugs with his ARV’s and how forgetting to take his medications could lead to drug resistance.

Discussion Questions:

- What tool does Fred use as a reminder to take his medications?
- Does Fred understand the impact of taking HIV medications and street drugs?
- What is Fred’s understanding of the relationship between adherence and developing resistance to medications?

Sample Answers:

- Offer different tools to help with adherence-calendar, cadex watch, pill boxes
- Educate client about. drug resistance (cause and ways to prevent it).
- Share personal experience if applicable.. Encourage seeking help for substance abuse. Referral to case manager to make SA referral.

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Pedro and Maria¹

Pedro and Maria have been together for a year and have decided to take their relationship to the next level to include sex. Maria was diagnosed with HIV before her relationship started with Pedro who is HIV negative. Their relationship has been very open and built on trust. Maria and Pedro decide to meet with a peer educator to discuss prevention methods. When Maria and Pedro arrive to the meeting it becomes very clear to the peer educator that language is a barrier because Maria and Pedro do not speak English well. The peer educator also notices that when he asks Maria questions about her sexual history, Pedro responds. The peer educator is not sure how to help them as he doesn't speak Spanish.

Discussion Questions:

- Ask client whether they prefer to have an interpreter available or understand English well enough for the session?
- What is HIV and what prevention methods are available to reduce transmission to partner?

Sample Answers:

- The peer teaches the client and partner about HIV (transmission, prevention tools and provides tools-male/female condoms, lube and dental dams)
- The peer answers questions that come up in the session to address needs.

Jodi¹

Jodi is HIV positive and very adherent to her health routines. She takes her ARV's as prescribed by her doctor the right way every time except for one medicine. To her surprise her doctor recommends that she begin a new drug regimen. It seems that she has developed resistance to her current treatment. Jodi visits her peer educator to understand more about resistance.

Discussion Questions:

- Ask client what adherence means to her?
- What is the connection between adherence and medication resistance?

Sample Answers:

- The peer teaches the client the importance of adherence
- The peer educates about causes and prevention of resistance
- The peer offers to attend the next medical appointment with the client.

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Murphy¹

Murphy is an HIV positive health and fitness coach who has been medication free for 7 years because his viral load was low and his CD4 count has remained above 350, until recently. Due to changes in his lab results, Murphy's doctor suggests starting ARV's to manage his HIV disease progression. Murphy believes in herbal treatment methods and does not want to use traditional HIV medications. He schedules a meeting with his peer educator to discuss his concerns.

Discussion Questions:

- What have been your CD4 and VL lab results the last 2 years?
- What are your fears about starting medications?
- What research or questions do you have about medications?

Sample Answers:

- The peer will share their personal fears with taking medications
- Review POZ magazines and other research about starting medications
- Make a list of questions or concerns to address with doctor about medications
- Offer to go to medical appointment with client

¹ This module is part of the online toolkit *Building Blocks to Peer Success*. For more information, visit http://www.hdwg.org/peer_center/training_toolkit. These case studies and scenarios come from the Missouri People to People Training Manual, 2008.

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Edie²

Edie's CD4+ cells have been dropping and her viral load has been increasing. Her doctor let her know that she would have to start HIV medications. Edie was feeling apprehensive and nervous about the side effects, but she was willing to get started. Her doctor prescribed Atripla that she would take once a day at bedtime. After a week of being on medication, Edie had side effects like strange dreams, feeling dizzy, depressed, and emotional.

She shared her medication experience at support group. She was upset and was crying, saying she would not keep taking these meds with these side effects. Participants talked with her, telling her that the side effects would last possibly one to two weeks more, but to hang in there. Her CD4+ cells are now in the 450's and her viral load is less than 95. She was elated to share her results with the support group after her visit with her doctor.

Discussion Questions:

- What medications are in ATRIPLA?
- What were her CD4 and viral loads before her medications?
- Are there food restrictions?

Sample Answers:

- Keep taking the medications at the same time everyday
- If any side effects come up to talk with her Doctor
- Keep her doctor appointments

Ivy²

Ivy, a 39 year-old Caucasian woman who recently returned from Africa is 3 ½ months pregnant. She also has an 8-year-old son. She was diagnosed with HIV in February 2006. Ivy has no income, is living with friends, and has debt from when she left the United States. Ivy says she practiced safe sex and tested regularly; however, she had one incident where the condom broke. Ivy's CD4+ is 1130 and she has an undetectable viral load. She feels there is no need for her to take medicine because her doctor cannot tell her if there will be any long lasting side effects to her unborn child. Ultimately, Ivy decides not to take meds during her pregnancy or AZT at the time of delivery. Ivy's baby tested negative at birth. However, Ivy hasn't contacted you (her peer advocate) for seven months, so you don't know how or where Ivy is.

Discussion Questions:

- What steps can you (the peer advocate) take to find Ivy?
- What can you tell Ivy about HIV medications and pregnancy?
- What kinds of concerns may come up for you as the peer advocate? How can you deal with them?

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Sample Answers:

- Send letter to last known address
- Contact social worker, doctor, therapist
- Taking meds can reduce the transmission rate to less than 1%.
- Tell her that she understands that she is scared, but it's really important that she take care of herself and her baby.
- Peer advocate might be scared that the baby will be born positive and how hard the guilt will be on the mom. This may bring up her own issues—especially if she found out her own diagnosis when she was pregnant. She should talk with her supervisor and get support from other peers.

Linda²

Linda has a triple diagnosis: HIV+, paranoid schizophrenia, and alcoholism. Linda was referred to you by her social worker. Linda has given you permission to accompany her to doctor visits and visits to her payee at a mental health clinic. Linda is not taking any medications for either HIV or her mental diagnosis. She refused to take them. Her social worker, doctor, and you have all notice her psychosis as she speaks and rambles. She lives in a group home, and has a male friend who lives there also. She drinks a couple of half-pints of hard liquor every day. If he does not have sex with her she will accuse him of raping her. You go to visit Linda at her home one day. When you get there, she shows you her lab results. Her CD4+ count is 130 and her viral load is 500,000.

Discussion Questions:

- What are three things you can say to Linda when she shows you her lab results?
- How can you support Linda?
- What kind of support or resources can you get for yourself?

Sample Answers:

- Ask Linda, How concerned is she with her labs?
- Ask Linda, what is making it difficult to take her medications.
- Ask her, what has her doctor told her?
- Don't criticize or judge her
- Listen to her
- Share your story
- Talk with your supervisor, other peers and a therapist if you have one.
- Self-care

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Maria²

Maria is a 49-year-old Puerto Rican woman who was diagnosed HIV+ in 1999. She was later diagnosed with Hodgkin's Lymphoma, and is currently in remission. Over the past six to eight months she has been suffering from vomiting, intense and sometimes debilitating headaches, and diarrhea that keeps her home-bound from time to time. Maria's doctor has looked at everything that could be causing these symptoms, from environmental and physical to psychosocial. She is currently taking Sustiva and Combivir daily. Her T-cells continue to be between 700 and 800 and her viral load is undetectable.

Maria is concerned that her doctor cannot figure out why she is getting the headaches and diarrhea. She has recently become a part of the Consumer Group, but her headaches sometimes stop her from attending the meetings and being involved in her community as much as she wants to. Maria is very frustrated and has expressed interest in switching doctors. She is afraid that she might be dying. Maria has lost 1 brother and 2 sisters from HIV.

Discussion Questions:

- What are the 3 suggestions that you can give Maria to deal with her symptoms?
- What are 3 things you can do to support Maria with her concern about her doctor? (List three options)

Sample Answers:

- Speak with her doctor about the symptoms and what might be causing them.
- Change the time she takes the meds
- Eat small meals more frequently
- Find out what her exact concerns are
- Ask her open-ended questions
- Go with her to the next doctor's appointment
- Let her know that she can think about switching doctors if she is not happy with this one
- Tell her that you understand the way that she feels, but that is she is not her brother or sister who passed away from HIV and that everyone's virus is different.

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Lisette²

Lisette started HIV medications 2 months ago. She has been having very bad nausea and diarrhea. She wants to stop taking her meds and calls you crying one day.

Discussion Questions:

- What are two affirming statements that you could give Lisette to encourage her to continue taking the medications?
- What information or resource can you give to your client in this situation?

Sample Answers:

- Crying is okay, it cleanses the soul
- I know taking the medications is hard, but you are doing a great job
- Side effects are temporary
- Try eating some crackers or dry toast; ask her if her meds have meal restrictions, follow the directions on the prescription.

² This module is part of the online toolkit Building Blocks to Peer Success. For more information, visit http://www.hdwg.org/peer_center/training_toolkit. These case studies and scenarios come from the Lotus Women's Peer Education Training Manual, Center for Health Training and Women Organized to Respond to Life Threatening Diseases (WORLD), 2008.

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Tammy³

You are the peer worker assigned to help this client with adherence issues. Tammy is a 42-year-old woman living in a large urban city. Eight months ago Tammy discovered that her husband Dante tested positive for HIV; soon after, Tammy also tested positive. Diagnosed HIV positive and on a HAART regimen has been challenging when caring for herself, Dante and her children. Her four children are from a previous marriage. Dante has to visit the emergency room frequently due to opportunistic infections. Tammy has experienced many side effects associated with her HAART regimen. The side effects she finds most difficult to tolerate are the itching and nausea. Because of all the added stress, Tammy had to quit her job. Although Tammy doesn't live far from the clinic where she receives care, her compliance with clinic appointments has been suffering because of Dante's jealous fits. Dante accuses Tammy of cheating on him; often making it difficult for her to leave the house to attend her clinic appointments. Because of all the chaos at home, Tammy sometimes forgets to take her HIV medications. Her most frequent missed dose of medication is usually in the morning when preparing the kids for school and caring for her husband. The pressure of keeping her HIV status a secret from her mother, sister, and children is becoming a heavy burden. There are times when she feels alone in this world; she has no one to turn to for support. She no longer attends support groups because of Dante's jealousy; however, she prays often and attends church services as a form of support in dealing with her illness.

Discussion Questions:

- How would you address Tammy's concerns and work with her on adherence issues?

Sample Answers:

- Assess Tammy's beliefs about HIV, treatment, and the impact that missing doses may have on her health.
- Congratulate Tammy for her many strengths and for how well she is handling her situation, including taking care of Dante, her four children, and herself.
- Acknowledge and validate the ways in which she gets support – through the National AIDS Hotline and prayer, for example.
- Talk with Tammy about referrals that might be helpful to her, such as a support group for women living with HIV or an HIV ministry.
- Help her assess the relative benefits of disclosure against the costs of disclosure. If the benefits appear to outweigh the costs, explore to whom she might first disclose and how that disclosure might ease her many burdens, as well as help her with adherence.
- Help Tammy to think about ways she can incorporate taking her medicines into her daily routine. For example, getting up 15 minutes earlier to take some time for herself and to take her medication; putting the medication and water and/or food on her bedside table every night after the kids are in bed so that it is the first thing she sees in the morning.
- If appropriate, share information about difficulties you may have had with adherence, and how you overcame or are overcoming them.

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Jesse³

Jesse is a 22 year-old man who tested positive for HIV two years ago. His suspicions are that he's been HIV positive since his adolescence. You are the peer worker assigned to help Jesse with adherence issues. You have been seeing him for the past nine months. During the sessions, he has shared his concerns about his increase with alcohol/drug use and depression. Over the past month, Jesse has frequently mentioned his fear of failing his HAART regimen. The thought of having to switch medications because of failing his current regimen has caused Jesse to feel depressed; he has been on the current regimen for one year. The combination of fear of failing his HIV treatment in addition to disappointing his doctor has caused Jesse's depression to worsen.

Over the past nine months, Jesse has also been concerned with his body image. Although he works out in the gym regularly with weights, he's never satisfied with his physique. He has noticed changes in body fat buildup throughout his body, loss of fat in the face area, and his limbs have thinned. Jesse has also expressed concern about the effects of long-term treatment. Jesse recently read an article in a HIV/AIDS magazine that heart disease is another side effect of long-term treatment.

Besides his cousin, Jesse does not have anyone else he can talk to about his HIV status. But he rarely shares with cousin his sex life involving men he meets at parks or in clubs. He admits to his peer worker that he often finds extra pills in his bottles at the end of the month. Jesse feels healthy, but his doctor has told him that his CD4 count (T-cells) are dropping and his viral load is increasing.

Discussion Questions:

- How would you address Jesse's concerns and work with him on adherence issues?

Sample Answers:

- Affirm that his life is busy and changing and consequently, that forgetting a dose is easy to understand and, in fact, very common.
- Affirm that being concerned with side effects that impact one's looks is not trivial but, rather, an important concern. It is an issue that affects Jesse's quality of life and adherence to treatment.
- Assess how Jesse is currently coping with his treatment plan and ask what his biggest concerns are (drug use, treatment plan, depression) and goals. Review treatment plan and discuss goals. Discuss barriers to treatment.
 - If drug use is a concern of his, offer referrals for substance abuse treatment programs
 - Offer Jesse referrals for mental health services for his depression
- Assess how Jesse might develop more support for himself (he has a supportive cousin he lives with, but others do not know about his HIV status).
- Help Jesse identify the barriers to a frank discussion with his doctor (e.g., wanting to be the "perfect patient") and help him develop the skills and strategies to be more open with his doctor.
- Help Jesse strategize about ways to account for missed doses, like using a pill box, which will help identify

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when missed doses are occurring, or find out if the pharmacy is providing “extra” pills in the prescription. Demonstrate how to use adherence tools.

- Think about what exactly your role as a peer is: giving information, rather than offering advice, helps Jesse make choice he can “own” and is more likely to follow through on.

Jim³

Peer: You are a peer educator in a hospital. You are in the middle of an educational session with Jim, a 40 year old man who was recently diagnosed with HIV but who does not have an AIDS diagnosis. Jim has just expressed to you that he believes the test he took shows he has AIDS. You educate him about the difference between HIV and AIDS.

Client: You are a 40 year old man who has just been diagnosed with HIV. You are seeing an HIV peer educator in the hospital and you think that your positive HIV test result means you have AIDS.

Mary³

Peer: You are a street outreach worker in HIV prevention. You are providing education to Mary, a 21 year old woman, about how HIV is spread.

Client: You are a 21 year old woman who thinks exposure to HIV can be avoided by not having sex with someone who looks sick. You have met a street outreach worker who is providing you with information about HIV transmission.

³ This module is part of the online toolkit Building Blocks to Peer Success. For more information, visit http://www.hdwg.org/peer_center/training_toolkit. These case studies and scenarios come from the Comprehensive Peer Worker Training, Peer Advanced Competency Training (PACT) Project Harlem Hospital Center, Division of Infectious Diseases, 2008.