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Introduction to Shikamana

Antiretroviral therapy (ART) has greatly decreased morbidity and mortality due to HIV-1 infection and the acquired immunodeficiency syndrome (AIDS) worldwide. However, successful virologic suppression during ART requires good adherence and the avoidance of treatment interruptions, which can lead to drug-resistance mutations. Marginalized patients may have problems with treatment support from providers, family, and friends, and often need additional assistance. Men who have sex with men (MSM) are marginalized and even criminalized in African settings, and many have problems with social isolation, depression, substance abuse, and stigma. The Shikamana project is a new intervention to enhance antiretroviral adherence among MSM in African settings. Shikamana has been developed and is being tested as part of a 3-year developmental research study funded by the U.S. National Institutes of Mental Health (R34MH099946, PI Graham) and carried out by Kenya Medical Research Institute (KEMRI) researchers and colleagues in coastal Kenya.

The Shikamana intervention tests the relative efficacy of patient-centred care and a modified version of Next Step Counselling discussions initiated by providers combined with support from peer navigators (“Washikaji” in Kiswahili) against the standard of care in Kenya. The intervention is practical, relatively inexpensive, does not require extensive training or additional paid staff, and has the potential for easy and widespread dissemination. The Shikamana intervention is conceptually based in the social support literature and social cognitive theory, and is supported by findings from qualitative interviews with MSM in coastal Kenya and focus groups with their providers. This qualitative research led to the development of an access-information-motivation-behavioural skills model situated on several social levels (intrapersonal, interpersonal, institutional/community, and sociocultural/policy) that influence men’s adherence and engagement in care.

Peer navigators (Washikaji) are HIV-positive MSM who have experience taking ART and are judged to be good role models for others. After selection, these men undergo a brief 2-day training and receive regular supervision thereafter. The navigators provide social support to 2-6 assigned patients each, in accordance with a protocol explained and rehearsed in their training. Peer navigators provide information, empathy, and encouragement to target key groups of mediators known to affect adherence:

- Knowledge of the medication regimen
- Negative affective states
- Substance abuse
- Self-efficacy
- Motivation
- Remembering doses
- Keeping appointments

In addition, peer navigators serve as role models for general life coping skills (or resiliencies) that are especially important for men living in a highly stigmatizing environment.
Introduction to Peer Navigator Training Manual

This manual was designed as part of a research project on enhancing antiretroviral adherence among Kenyan MSM. The premise of the study is that combined support from providers and from peer navigators (Washikaji) can help men engage in care, manage problems as they arise, and adhere to treatment. Because MSM often experience stigma, discrimination, and other difficulties, providers need to spend time getting to know men’s situation and their individual facilitators and barriers to engagement in care. For this reason, we have incorporated patient-centred care and aspects of motivational interviewing (both well-established methods to improve care and support adherence) into provider training for the Shikamana intervention. The aim is that providers learn to involve patients in their care and work through any problems together, in order to enhance a patient’s knowledge, motivation, and skills to adhere to their medication regimen.

In addition, support from an HIV-positive MSM peer who has successfully taken ART can be invaluable to men who are just starting treatment. Washikaji can be role models and provide “experiential expertise” regarding the daily realities for MSM living with HIV and taking ART. They often can develop relationships with patients that are more candid and comfortable than those with the treatment team professionals. The aim is that the insight and care the patients provide will enhance a patient’s ability to understand, cope with, and adhere to their medication regimen. It’s important to remember that, after the training, Washikaji require continuing supervision and support from the provider team.
Washikaji Training Objectives

In order to accomplish their goal of supporting patient adherence, Washikaji training will address the following objectives . . .

- Meet the provider team and other Washikaji
- Become familiar with Shikamana Project goals
- Review barriers and facilitators to ART adherence among MSM and transgender individuals
- Learn about the Mshikaji role, rules, and limits
- Consider the basic approach to getting to know an assigned patient
- Learn to provide information to patients
- Understand how to provide emotional support to patients
- Think about ways to provide encouragement to patients
- Learn how to document patient contacts
- Reinforce the importance of “positive living”
- Teach patients about maintaining ART continuity
- Gain an understanding of safe disclosure
- Understand how safety in the field can be guarded
- Become familiar with Shikamana Project procedures
- Discuss teamwork and monitoring of the project

It is hoped that through this training, Washikaji will gain motivation and commitment to being a good peer navigator. They will also have tools to help patients accept their support and understand the criteria by which they will be evaluated, which depends more on their behaviour and commitment than on each patient’s individual outcome.
BACKGROUND

Shikamana Project Overview

The antiretroviral therapy (ART) scale-up has greatly reduced morbidity and mortality due to HIV/AIDS, and has the potential to prevent HIV transmission by reducing plasma viral load. However, adherence is critical for ART success, and poor adherence can lead to continued virus replication, increased transmission risk, drug resistance, treatment failure, and progression to AIDS or even death.

Men who have sex with men (MSM) are at high risk for HIV in Africa, and face significant stigma and discrimination leading to health care disparities. In a small pilot project on the Kenya coast, we found that MSM patients were more likely to have less than 95% adherence than were female sex workers attending the same clinic (40% vs. 11.5% with less than 95% adherence). In addition, these men had poor weight gain on treatment and their CD4 counts increased to a lesser extent than for the women.

We believe that MSM patients may need additional support for their care, due to the many challenges they face. This project aims to identify barriers and facilitators to ART adherence among Kenyan MSM, and design a targeted intervention using support from providers and peers to promote MSM’s engagement in care and adherence. By involving MSM, Kenyan Lesbian, Gay, Bisexual, and Transgender (LGBT) organizations, HIV care providers, and Ministry of Health representatives, we will ensure that the resulting intervention is feasible, acceptable, tolerable, safe, and ready to be tested for efficacy.

Kenyan MSM who are taking ART face a number of challenges that are particular to their HIV status and identity as MSM coping with a hostile environment. Men who are share similar experiences (i.e., HIV-positive MSM taking ART) are their peers and may be their best source of help and support. Evidence suggests that adults are more likely to listen to advice and information when provided by someone who is like them. Similarly, support and guidance from a peer can be very powerful, since they come from someone with similar experiences, particularly if the peer has managed similar situations successfully in the past. MSM who have coped with their HIV diagnosis and managed to take ART to protect their health can serve as role models to other similar patients. Peers can help other patients “navigate” the health care system and develop good provider relationships that could help protect their health.

Our long-term goal in the Shikamana project is to prevent

- Morbidity (sickness due to HIV),
- Mortality (death due to HIV), and
- HIV transmission (i.e., treatment as prevention)

by increasing engagement in care and adherence to treatment for Kenyan MSM. The Shikamana intervention combines improved care from providers (clinicians and counsellors) with peer support as described above. Standard care in Kenya involves teaching patients about ART and the importance of taking medications. To this standard care, we are adding a patient-centred approach and motivational interviewing by providers, support from Washikaji, an option for patients to request reminders for medication-taking and/or appointments, and an option to use a discrete pill carrier when away from home. We believe that this combination of intervention components may increase men’s adherence and engagement in care.
Why have we called this project “Shikamana?” Shikamana is a Kiswahili word meaning “to form a bond or stick together.” We are interested in strengthening the bond between providers and patients. We would also like to form a bond between peer navigators and their assigned patients. We also need a bond of commitment between providers and Washikaji, to ensure teamwork and adequate support. Peers in the Shikamana project are called “Washikaji” (singular “Mshikaji”) because they will help form a bond with the patient that enables that patient to “stick to” HIV care and treatment.

Washikaji will be recruited and trained to help fellow MSM HIV patients with issues of access, information, motivation, and skills for taking ART. We will train the Washikaji over 2 days to provide different types of support to patients, so that patients will be better able to take their medications. Each Mshikaji will be assigned with from 2-3 patients for the pilot test of Shikamana. We will need more Washikaji for a small randomized trial of the intervention that is planned in 2015. For our pilot test of the intervention, we will work only with patients who are starting ART for the first time. This is because the first few weeks of ART are a “risk period” for patients, as they learn how to fit ART into their lives, manage side effects, and develop habits for medication-taking.
MSM and Adherence to Antiretroviral Therapy

Maintaining near-perfect adherence over the long term is very difficult for most people:

- Most studies show that almost no one is 100% adherent.
- Most people are moderately adherent, taking 70-99% of their prescribed doses.
- About 30% of patients are poorly adherent, taking less than 60% of prescribed doses.
- Overall, in chronic illnesses, less than 50% of patients fully comply with treatment.

Medications are harder to take when there are many pills, when they have to be taken frequently, when there are a lot of severe side effects, when the regimen is complicated (for example, medications have to be taken with or without certain kinds of food), and when they have to be taken for a long time.

In summary, adherence is critical for patients with HIV, to prevent sickness, death, and HIV transmission to others. **ART patients need support and encouragement to reach this difficult goal!**

**Necessary skills:** To adhere, patients must be able to:

- Believe they can do it (self-efficacy)
- Feel psychologically well (depression interferes with adherence)
- Not have substance use interfere
- Get the support they need
- Integrate the regimen into their lifestyles
- Problem-solve to accommodate changes in routine and schedules
- Understand the regimen and the importance of not skipping doses

Understanding adherence

Adherence is similar to any behaviour change, such as a healthy diet or smoking cessation. For any given patient, specific facilitators and barriers will help or hinder his or her adherence. One simple model of how adherence may work in MSM is pictured below. Factors on the personal, community, and “Serikali” levels all can affect adherence and ART outcomes. In this model, Serikali represents not only the government, but also policy-makers, non-governmental organizations, and funders.
ART barriers and facilitators for African MSM

Our research in coastal Kenya helped identify specific barriers and facilitators faced by HIV-positive Kenyan MSM. We conducted 30 interviews with HIV-positive MSM and 4 focus group discussions with their health care providers. Barriers we identified included:

- Limited access to care
- Poor availability of MSM-friendly health information and services
- Poverty: lack of food, homelessness, and dependence on sex work
- Inadequate or misleading HIV or ART information
- Lack of psychosocial support
- Non-disclosure of HIV and/or MSM status
- Medication side effects
- Mental health challenges (referred to as “stress”)
- Substance abuse
- Pill fatigue

Facilitators we identified included:

- Tailored information on HIV and ART
- Access to friendly services
• Psychosocial support
• Disclosure of HIV status to select individuals
• Fear of deterioration, looking unwell, or death
• Improvement in physical appearance
• Self-acceptance
• Pill-taking reminders
• Appointment reminders
• Having life goals to motivate one-self
• Financial empowerment
• Belonging to a support group or having some role in the community
• A desire to protect loved ones or help others avoid HIV infection

Most men suggested that the best way to support adherence would be through a trained, ART-experienced patient who would provide individualized support and follow-up, in close collaboration with trusted care providers. This is how we came up with the idea to have Washikaji. The Shikamana intervention combines a new approach by providers (based on patient-centred care and motivational interviewing), with support from trained Washikaji. Together, providers and Washikaji can promote both adherence and engagement in care for HIV-positive MSM taking ART.
SHIKAMANA INTERVENTION

Washikaji Roles, Rules, and Limits
The overall purpose of the Mshikaji role is to support HIV-positive MSM who are taking ART, encouraging them to engage in care and adhere to therapy. The Shikamana pilot study will take place at the KEMRI Mtwapa Clinic, with patients coming from the surrounding area. This pilot study will take place for 4 months, from November 2014 to February 2015, after which we will review the program and the performance of the Washikaji.

Key responsibilities of the Washikaji:
- Meet and introduce yourself to 2-5 assigned patients who are starting ART in the Shikamana adherence support program at KEMRI Mtwapa.
- For each assigned patient, have an in-person meeting (at location of patient’s choice) or telephone discussion every week during the first month of participation and then every other week thereafter to provide support, encourage good adherence, and assist with any problems.
- Inform providers (clinicians and counsellors) of any urgent or important adherence-related problems (such as side effects, substance use, etc.) by telephone in a timely manner.
- Meet with the Shikamana team (providers and peers) every month to discuss patient progress, get feedback on how to help patients, and receive support for your work.
- Be a model for good ART adherence and engagement in care by attending your own clinic visits, taking your medications on time, and living positively.

Characteristics of the Washikaji:
Washikaji are HIV-positive men successfully taking ART who ideally should have the following characteristics:
- Desire to support other MSM taking antiretroviral therapy
- Non-judgmental about men’s personal background and physical appearance
- Proactive, flexible, and willing to problem-solve
- Excellent interpersonal and communication skills
- Commitment to maintaining participant confidentiality and privacy
- Responsible team worker able to recognize personal limits
- Role model for patients (i.e., good adherence, positive living)

Qualifications for the Washikaji:
- Experience taking antiretroviral therapy for 2 or more years
- MSM with one or more male sexual partners within the past 2 years
- At least a form 4 Certificate (minimum requirement C plain)
- Fluency in both English and Kiswahili

The overall supervisor for Shikamana Washikaji is Dr. Murugi Micheni, Clinical Supervisor at the KEMRI Mtwapa Clinic. Washikaji also report directly to the clinical officers and counsellors seeing Shikamana patients. Reporting will be done on a monthly basis at Shikamana team meetings, at which discussions will be held to review progress with patients and Washikaji will receive their transportation stipends and phone credit needed to support their work. Currently, these stipends will be 1500 KSh per Mshikaji for transport and expenses, plus 500 KSh phone credit per month. Transportation reimbursement will also
be provided for each monthly KEMRI meeting (Ksh 200 per meeting) and for Mshikaji to come meet each assigned patient as he or she starts ART.

Of note, Washikaji will likely hear very personal information from their assigned patients. Information shared with Washikaji is strictly confidential and cannot be shared with anyone other than the provider team involved in patient care. Remember, to maintain confidentiality is to keep “secret” information “secret.” Appendix B contains a confidentiality agreement that all Washikaji need to sign. Washikaji should be aware of their limits and refer patients when there is a clinical problem that needs attention. The following actions are recommended when these problems arise:

- If a patient is having side effects,
  - Check that the patient is taking the correct dose
  - Check what other medications or substances (including alcohol, etc.) the patient is taking
  - Notify the provider team for advice and assistance
- If a patient is having depression or substance abuse problems
  - Notify the provider team for advice and assistance

In addition, Washikaji should let patients know that they can’t help with everything that is difficult in the patient’s life. The Washikaji role is focused on improving adherence and engagement in care. When a patient has other types of problems (personal, social, financial, or otherwise), consider sharing your experience if you think you can help. But remember that Washikaji are not responsible these other types of problems, and should refer patients to their own friends and family for assistance with these issues.
Getting to Know Your Assigned Patient

You were selected as a Mshikaji because you have been able to adhere and can serve as a role model to other patients. This is good, but may make it difficult for you to understand patients who don't adhere well. Pay attention to your feelings about non-adherence so they don’t interfere with your ability to provide help — remember that not everyone has the inner resources and facilitators you may have to draw upon. As you start getting to know your assigned patient, think about the following questions:

- What is important when you meet someone as an official helper or “Mshikaji”?
- How can you gain their trust?
- How can you get them to understand your role and what you are trained to help with?

Reflect on the people who have helped you with your ART in the past.

- What have you liked about the help you got?
- Who has tried to help, but not been helpful in the past?
- What did you not like about the help they tried to give?
- How do you think an Mshikaji can be effective at providing help to patients?
- What do you think a “good” Mshikaji should be like? What should an Mshikaji avoid?

To understand your patient’s point of view, you need to learn more about him or her. As you get to know the patient, discuss what HIV means to him or her and how it has impacted his or her life. Ask what the patient thinks about taking medications to treat HIV. Examples of areas to explore and questions to ask include the following:

- **Beliefs about HIV**
  - What does it mean to have HIV?
  - How serious is it compared to other problems?
- **Beliefs about ART**
  - What will happen if you take ART? If you don’t take ART?
  - Will ART help you? If so, how? If not, why?
- **Relationships with providers (whether clinicians or counsellors)**
  - Is there one or more provider with whom you feel comfortable?
  - Do you believe your provider understands your needs?
- **Practical barriers to adherence**
  - Do you understand how to take the pills?
  - Do you need reminders?
  - Do you have a private place to take your pills?

Assessing adherence and engagement in care

When you first meet your assigned patient, it is important to ask the patient questions such as:

- What does he or she know about the medications?
- What are his or her expectations?
- What is his or her potential support for adherence? (What will make it easier?)
- What are his or her potential obstacles for adherence? (What will make it harder?)

Be careful how you ask questions. The way questions are asked can influence the answers:

- “You took all your medication, didn’t you?”
- “You didn’t forget any dose, right?”
• “You took the medicine like I told you, didn’t you?”

These kind of questions expect a certain response, and should be avoided. Instead, try to ask the patient what makes it harder or easier to take his or her ART.

Problems to look for that could lead to difficulties for your patient:
• Prior adherence to other medications unsuccessful
• Inadequate knowledge about regimen, including names of drugs, dosing, special dietary instructions
• Belief that medications don’t work, that the danger of not taking them is minor, that it’s not necessary to take them consistently
• Low confidence in ability to take medications
• No knowledge of what to expect nor how to get help for side effects, not aware that side effects usually decrease over time
• Poor relationship with clinic staff
• Poor access to pharmacy for refills
• No routine daily schedule, no plans for unexpected travel, changes, etc.
• Desires but does not have memory aids such as an alarm or watch
• Discomfort with HIV status disclosure
• Unstable living conditions or inadequate housing, food, other immediate life needs
• Untreated psychological distress or impairment
• Untreated alcohol or other substance use problems
• Inadequate social support network

Obstacles to adherence are many, and these can be a problem even in patients without the above risk factors. For examples of problems related to inadequate knowledge or information, problems may arise if a patient does not understand his or her medication regimen, including what time to take medication, what dose to take, any instructions about food, any interactions with alcohol or other substances, and any interactions with herbal treatments, traditional medicines, or other medications.

A guide for assessing adherence can be found in Appendix C.
Providing Different Types of Social Support

**Information:** Suggestions or information about what has worked for you or others. Remember: NEVER GIVE MEDICAL ADVICE.

- “I use a pill carrier when I’m not sure I’ll make it home the next day. Do you think that might help you?”
- “Even if you stop taking your medications for a short time, they might not work anymore.”
- “Sounds like your medications are making you very sick. Do you think you should call the clinic to ask someone about this?”

**Emotional:** Empathy, support, and understanding. Listening and caring.

- “Sounds like you are feeling down today.”
- “I’m glad you called so we can talk. I care about you and how you feel.”
- “I know. It is really hard being on these medications. I understand you feel like quitting.”

**Encouragement:** Words of encouragement that increase the patient’s belief in themselves and their abilities.

- “You took all your medications since we last talked? That’s great! I knew you could do it.”
- “You seem to be a strong person, like someone who can do what she wants to when she really sets her mind to it.”

Part of being an effective peer navigator is learning when to give each type of support. To do this, sometimes you just have to ask the person what they need.

---

**EXERCISE 1**

Read each of these scenarios and think about which type of support the Mshikaji provided.

**Scenario A**

Mshikaji: “Hello. I’m just calling to check in. How’s it going?”
Patient: “Pretty good. I did miss one dose this week but I made all the others.”
Mshikaji: “That’s wonderful! I knew you could do it. I have always believed you could do this if you really set your mind to it.”

**Scenario B**

Mshikaji: “How have you been doing?”
Patient: “Not so great. I have had a really bad headache all weekend. I don’t know what to do.”
Mshikaji: “What have you tried?”
Patient: “I just took an aspirin.”
Mshikaji: “Do you think you should call the clinic?”

**Scenario C**

Mshikaji: “Hi. I’m returning your call. What’s up?”
Patient: “I just wanted to talk a minute. I’ve just been feeling really down lately.”
Mshikaji: “Oh, you do sound really sad. I’m sorry to hear that. Do you want to tell me about it?”
Providing Information
As part of their role, Washikaji will be called upon to educate patients about how to take medications correctly, providing individualized advice when possible. Washikaji are asked to educate patients about HIV transmission and prevention, HIV care, and why adherence is important. To assist with this, we have summarized information on HIV, AIDS, and antiretroviral therapy in this section.

Basic HIV and AIDS information
HIV is the virus that causes AIDS. The acquired immune deficiency syndrome, or AIDS, is the collection of symptoms people get when HIV has weakened their immune systems. A healthy immune system fights off infections by viruses, bacteria, and parasites like malaria. An unhealthy immune system cannot effectively fight these infections. This causes the HIV-infected person to become weaker and weaker. Eventually or suddenly, one can die from these opportunistic infections.

HIV transmission risk is particularly high among MSM, due to several factors. Male-male sex is more risky than heterosexual sex because:
- Receptive anal intercourse is very high risk for HIV transmission
- Men who are infected are more likely to transmit to an uninfected person when they are the insertive partner
- MSM networks can increase transmission of HIV and STIs

Condoms help prevent HIV transmission, and should be used with lubricants for anal sex. HIV-infected persons should use condoms with all their sexual partners. Condoms should still be used when both partners are HIV-positive, to prevent transmission of different HIV strains and drug-resistance. In addition, HIV-infected persons should avoid sharing needles or other sharp or bloody objects with others, as these can transmit disease.

Antiretroviral therapy
The most common regimen used in Kenya now consists of three medications: tenofovir or zidovudine, lamivudine, and efavirenz. Where possible, these are supplied as a single combined tablet that is taken once a day. Although it is best to take this medication on an empty stomach, it is OK to take it with food that is not very fatty. Very fatty foods (like fried foods) may decrease absorption of the medications. Patients should know how to store these pills: they should be kept in an appropriate medication container in a dry place at room temperature. Medications should always be kept out of reach of children, and should never be shared with others.

HIV drugs work by slowing the virus’ ability to make billions of copies of itself or “replicate.” About 2 weeks after starting ART, your virus levels will decrease dramatically. Within 2 to 6 months, the virus in your blood will be below the level that can be detected in a laboratory. As this happens, the CD4 count increases, and the immune system can recover and do its job. Some people feel ill during this time, as the body starts to fight infections that were there but barely noticed by the immune system. If a patient feels sick after starting ART, he or she should see the clinic staff.

Over time, as ART increases immunity, your chance of suffering from infections and other AIDS-related problems will decrease. If you are able to take all your ART on time and adhere well, your chances of
Keeping undetectable virus levels are EXCELLENT. However, it is important to remember that ART does not cure HIV, which can hide in the body and reproduce if a patient stops taking ART for any reason.

**Drug resistance**

If a patient misses doses or is late for a refill, the level of medication in the drug will drop, allowing the virus to replicate. The virus can then become “resistant” to the drug – it can learn to reproduce when the drug levels are dropping and then that drug will no longer work well.

Drug resistance has several important outcomes:

- The virus levels will increase and no longer be undetectable
- The patient may feel feverish or ill, as when he or she first got HIV infection
- The CD4 count will start to decrease, making infections and other problems more likely
- If drug resistance becomes strong enough, the medications will no longer work at all and the regimen needs to be changed
- If someone has resistant virus and higher virus levels, he or she can transmit that virus to his or her sexual partners

**Rules about Medications**

Remember, there are certain rules about taking HAART medications. Think about whether it is OK for a patient to...

- Skip doses?
- Stretch medications by taking fewer than recommended?
- Take some medications while not taking the others?
- Stop and start medications to get rid of side effects?
- Share medications with someone else?
- Stop taking ART when they are drinking or getting high?
- Stop taking the medications in order to take another medication such as antibiotics?

The answer to each is, “No. NEVER!” Remember that even short breaks (called drug “holidays”) have been shown to lead to higher viral loads of HIV in the blood and the inability of the drug to fight HIV. Rarely, a doctor may recommend a break from someone’s regimen, but this is entirely different than a patient choosing to go on a drug-holiday without consulting their provider.

Rules for Washikaji to tell their patients:

- Take every dose every day.
- Don’t skip doses or take time off from taking your medications unless specifically directed by your provider - if you do this, your medications will become weaker against the virus.
- If you stop taking any one medication, it’s best to stop taking ALL your medications.
- If you miss one dose . . .
  - If it’s less than ½ way to the next dose, then go ahead and take it anyway.
  - If it’s more than ½ way to the next dose, then it’s better to wait until your next dose and take the usual amount then - don’t double your dose of medicine.
More information on missed doses and the “half-time” rule can be found on page 38.

**Side effects**

Side effects of ART can be severe, but often are milder and usually decrease over time. Side effects can be a major reason for patients to report difficulties taking their medications. Effective strategies for dealing with side effects include:

- Discussing possible side effects BEFORE they appear.
- Concentrating efforts to plan for and manage side effects at times when a new drug or regime is being started and side effects are most likely to occur.
- Consulting with clinic staff promptly to evaluate and resolve problems.
- Initiating discussion about side effects, especially when the patient may perceive them as embarrassing or socially unacceptable.

Common side effects are summarized below. Always contact the clinic if you are concerned about a patient.

1. **Headache.** If a patient has a mild or moderate headache, he or she should try to rest in a quiet place, avoid taking too much coffee or tea, and take paracetamol. Patients should contact the clinic immediately if their vision is blurry, they have very painful or frequent headaches, or they have a fever or are vomiting.

2. **Dry mouth.** If a patient is bothered by dry mouth, he or she should try rinsing the mouth with clean, warm, salty water; drinking lots of clean water; and avoiding candy and too much tea or coffee. Patients should contact the clinic immediately if their mouth is very dry and stays this way, or they have trouble swallowing food.

3. **Tingling or pain in the hands and feet.** Some patients get nerve pain from HIV or from their medications. If this bothers a patient somewhat, he or she should try wearing loose-fitting socks and shoes; keeping the feet covered in bed; walking a little, but not too much; and soaking the feet in warm water and massage with cloth. Patients should contact the clinic if tingling or pain does not go away or gets worse; they have too much pain to walk; or they cannot use their hands properly.

4. **Tiredness or dizziness.** If a patient is tired or feeling dizzy, there are a few things he or she could try, like getting up and going to sleep at the same time every day; getting some exercise; balancing their diet with fruit and vegetables; and avoiding alcohol, tobacco, and drugs. The provider should be contacted if the patient has been tired for several weeks, is feeling more and more tired; feels unsteady and dizzy; cannot swallow or eat enough; or has cough, night sweats, or weight loss for over 2 weeks’ duration.

5. **Skin rash.** Some patients may develop a rash after starting medications. If the rash is mild, a patient can try washing often with mild, unscented soap and water; keeping the skin clean and dry; using lotion to relieve itching; avoiding the sun; and drinking plenty of clean water. The clinic should be contacted immediately if a patient with a rash has fever; pain in the mouth, throat, or eyes; blisters; or a rash that persists for weeks.

6. **Jaundice (yellow skin and eyes, dark urine).** If a patient develops jaundice, he or she should try drinking plenty of clean water; getting plenty of rest; and avoiding fatty food. The clinic should
be contacted if a patient with jaundice has fever; weakness; lack of appetite; belly discomfort; swelling of the hands, legs, or belly; or persistent or increasing jaundice over several days.

7. **Diarrhoea.** If a patient has diarrhoea, he or she should eat small meals to avoid bloating, taking bland food like rice, bananas, and biscuits; avoid spicy and fried foods; drink plenty of clean water; and take oral rehydration solution when needed. The provider should be contacted if the patient has bloody stool; more than four loose stools in a day; fever; or is unable to eat or drink properly.

8. **Nausea and vomiting.** If a patient has nausea or vomiting, he or she should try taking medications with food (check with doctor if this is OK); eating small meals to avoid bloating; drinking clean water, weak tea, or oral rehydration solution until vomiting stops; and avoiding spicy or fried foods. Contact the clinic if the patient has sharp stomach pains; fever; blood in the vomit; persistent vomiting; or is unable to eat or drink properly.

9. **Nightmares.** If a patient is having nightmares, he or she should try doing something that calms him or her before going to sleep; avoiding alcohol and drugs; avoiding fatty foods and big meals before sleeping. It may also help to talk to others about the feelings these nightmares cause. The clinic should be contacted if a patient hasn’t been able to sleep for several nights or if a patient is dreaming about terrible things, such as killing himself or herself.

**Knowing what you don’t know: Learning to refer for medical information**

You have been selected to be a Mshikaji because you are having some success with your own medication regimen. This does not mean that you are an “expert” with these medications or that you know what’s right for everyone. That’s OK. Even the doctors do not agree on some of these issues! What was true for you last year may not be true for your patient this week. One important thing to remember is that you do not have medical training and, therefore, you cannot give medical advice to your peers. We hope this is a relief for you in some ways! So when your patient asks you about a medical problem, encourage them to call the clinic staff. Sit there while they call if you have to, or walk to the clinic with them after you meet. Even when you think you know the answer to a medical question, you should refer patients to their providers. You might be wrong, or what worked for you might not work for somebody else.
Reflection

Some people, all of us at one time or another, find it hard to say “I don’t know” or “Why don’t you ask someone else?” Think about why is it hard for us to say these things. Maybe it is because we want to be the experts, not feel stupid, or assume we should know that answer. Maybe we think we are not being helpful if we can’t give someone the answer they are looking for.

When a patient says something like this . . .
- I missed all my doses yesterday. Should I take double today?
- I think this ART medicine is giving me a rash. Is that supposed to happen?
- I can’t take the pill on an empty stomach. I’ve missed the last two doses, because I’m not finding food before I’m due to take the pill.
- I’m having bad diarrhoea. I think it’s the ART medication. What should I take to get rid of it?
- I’m feeling so much worse since I started this ART. What can I do about all these side effects?
- A friend of mine said it’s best to stop taking your medications every once in a while. I’m thinking about taking a break this weekend.
- My provider said to take the ART twice daily, but I never take my morning dose because it gives me a headache during the day.

Then a Washikaji should say something like this . . .
- That sounds like something you should talk to your provider about. Let’s call the clinic.
- Why don’t you ask the nurse at the clinic?
- I had a similar experience, but things may be different for you. Why don’t you ask your doctor?
- Who do you think can give you the answer to that question?
- I don’t have any training in those kinds of medical issues, but your doctor would be able to tell you the answer.
- When I had that problem, I called the clinic and they helped me work it out.

W.I.S.E. suggestions

So now that you’ve personally experienced the effects of different types of responses, let’s listen to some sample interactions between a Mshikaji and a patient. After each one, we’re going to discuss was supportive and what was not supportive about the Mshikaji’s response.

Scenario A
Mshikaji: “So how did it go taking your medications over the weekend?”
Patient: “Awful. I missed all my doses.”
Mshikaji: (in a mean and critical manner) “Wow, that’s so stupid! Don’t you know you can’t miss any doses? You’re probably going to get really sick now.”

Scenario B
Mshikaji: “So how did it go taking your medications over the weekend?”
Patient: “Awful. I missed all my doses.”
Mshikaji: (very fast and pressurized) “Oh, I know why. You must be depressed! When I missed my doses, it was always because I was feeling depressed. What works for me is going to see my counsellor. You need to go to a counsellor!”
Scenario C
Mshikaji: “So how did it go taking your medications over the weekend?”
Patient: “Awful. I missed all my doses.”
Mshikaji: “Yeah, that happens sometimes.”
Patient: “What can I do so I don’t forget?”
Mshikaji: (emphatically) “You definitely need to get a pillbox with a timer on it. I never tried one, but they are supposed to work. Go buy one!”

Reflection
When sharing strategies that have worked for you, it is important that you give what we call “W.I.S.E.” suggestions. Think about the four strategies for W.I.S.E. suggestions, and why they are important to consider.

W = WANT
Does the person want to hear suggestions?
- Have you asked the patient if he or she would like to hear about some strategies that have worked for you or for other people?
- Make sure the patient first has a chance to talk and vent and that you have listened patiently first.

I = INFORMED
Are you informed about what the person has already tried?
- Have you asked about and actively listened to what the patient has tried to do?

S = SUCCESSFUL
Have the suggestions you want to give been successful for you or people you know?
- Is the strategy something that works for you or something that you have heard about being helpful for other people?

E = EMPATHIC
Are you trying to be empathic and caring as well as helpful?
- Are you just trying to show off or demonstrate that you are successful, or are you really trying to help the patient develop confidence in himself or herself?

Here are some tips about making suggestions:

- Remember that some people do not want suggestions; they just need someone to listen.
- Suggestions are not the same as advice. Although suggestions come out of the Mshikaji’s own experience, they should be very specific to the patient’s needs rather than the needs of the Mshikaji.
- Suggestions are almost always stated as questions and not commands.
  - “Could you try this?”
  - “Have you thought about that?”
  - “Would it work for you if you did this?”
- Suggestions are best if they are very detailed. You may need to break a suggestion down into several parts. If the patient thinks he or she would be interested in using a cell phone alarm then
there he or she needs to have a cell phone, keep it charged, and know how to set and turn off the alarm.

Read and reflect on the following conversation, which demonstrates the W.I.S.E. components. Go through again statement-by-statement and identify the W.I.S.E. components.

Mshikaji: “So how did it go taking your medications over the weekend?”
Patient: “Awful. I missed all my doses.”
Mshikaji: “Yeah, that happens sometimes.”
Patient: “What can I do so that won’t happen again?”
Mshikaji: “Well, what do you think? What have you tried so far?”
Patient: “I have been using an alarm and that was working for a while. But the truth is that I’ve started to hang out with some of my old friends and I started using again. When I’m getting high, I just don’t take my medications very well.”
Mshikaji: “I understand. That used to happen to me. Do you want to know what I did about it?”
Patient: “Yes, please! I need some help.”
Mshikaji: “What I did that worked to help me was to make plans to hang out with my friends who were clean and sober. Then, I wouldn’t use drugs and I could do a better job of taking my medications. Do you think that something like that would help you?”

Above all, don’t tell patients what to do! It is far better to work together with the patient and help him or her figure out what to do.
Providing Emotional Support

Now we are going to talk about ways that you as a Mshikaji can give emotional support to your assigned patient. First of all, your attitude toward your assigned patients can be a form of giving support. An attitude or way of relating to the patient that focuses on the patient and not YOU can be very supportive.

Patient-centred values

Washikaji can provide emotional support to a patient in several ways:

- **Understanding**
  Try to be understanding, put yourself in the patient’s shoes, and identify with the patient’s feelings even if you have not had the same experiences.

- **Validating**
  Listen to and support your patient’s feelings, affirming the soundness of his or her emotions given his or her current experiences or circumstances. Validation is often an important first response before problem-solving or giving suggestions.

- **Non-judgmental**
  Don’t judge the patient’s actions or behaviours, show respect for the patient’s decisions, and demonstrate that your primary concern is with how the patient feels about his or her own actions.

- **Respectful and caring**
  Believe in the patient’s value as a human being no matter what he or she does or has done. Show that you have confidence in the patient’s ability to solve his or her own problems when he or she has the resources and support needed.

- **Genuine**
  Behave in a “real” way with the patient, using words and body language that are sincere and not fake.

Support strategies

Although we may feel these patient-centred values, we need to communicate them to our patients. Aim for patient-centred strategies. These strategies focus on the patient and information the patient provides you:

- **Silence** (not asking any questions or talking about yourself, instead allowing the patient to share their story)
- **Body language** (lots of eye contact, attentive posture)
- **Nonverbal prompts** (nodding your head)
- **Subtle verbal prompts** (“yes,” “I see,” “uh huh,” “and?”)
- **Open-ended questions** (How, when, what?) that pull for longer responses from your patient (rather than “yes/no” questions)
- **Summary statements** scattered throughout the conversation (show you have been listening carefully)
Avoid Mshikaji-centred strategies. These focus on YOU and what you think or believe. They are not focused on what the patient says.

- Advice giving (instead of making “W.I.S.E.” suggestions)
- Moralizing (making judgments about the patient’s behaviour – what he or she “should” or “shouldn’t” do)
- Arguing (you may disagree but try to encourage rather than argue)
- Preaching (telling the patient what to do in a self-righteous way)
- Storytelling (relating long-winded narratives about YOU that are not really relevant or helpful to the patient)

The strategies may feel artificial at first, but each person will develop his or her own style. These are IDEALS; these strategies require practice and experience.

### Building a vocabulary for feelings.

It’s important and useful for Mshikaji to have many words for feelings in their vocabulary. This will help identify feelings in your patients.

**SAD:** blue, cheerless, dejected, depressed, despondent, disconsolate, discouraged, disheartened, dismal, gloomy, grief-stricken, heartbroken, lonely, pathetic, pitiful, solemn, sorry

**HAPPY:** beaming, blessed, blissful, bright, cheerful, chipper, content, delighted, ecstatic, elated, excited, exhilarated, fortunate, fun, jolly, joyful, lively, lucky, optimistic, perky, playful, pleased

**ANXIOUS:** afraid, agitated, apprehensive, concerned, distressed, disturbed, eager, edgy, excited, fearful, fidgety, frantic, high-strung, hopeful, impatient, nervous, panicky, paranoid, scared, suspicious, tense, troubled, uneasy, upset, uptight, worried

**ANGRY:** agitated, annoyed, antagonistic, cross, enraged, exasperated, furious, hateful, hot, incensed, irritable, mad, offended, passionate, provoked, raging, seething, sharp, spiteful, stinging, testy, touchy, violent

Strategies for providing emotional support need to stay patient-focused. This will let the patient know you are listening and are interested in what the patient wants to talk about. Washikaji should give patients the chance to hear themselves and to correct or add to what has been said. This is important to establishing trust in the beginning of a relationship and to maintaining the relationship later on.
Reflection
As a Mshikaji, you are probably already good at giving emotional support – maybe that’s one reason you wanted to be a Mshikaji in the first place. So let’s see some of the different ways you all do this.

Read the statements below and consider possible reactions. What might be a helpful or feel good reaction? What might be a problematic response? Why?

1. “I try and I try but I just can’t seem to stick to this regimen.”
2. “Sometimes I wish I had someone to talk to about my medications.”
3. “Whenever I talk to my partner about my side effects, he just tells me to stop whining. That makes me so mad!”
4. “Why is God punishing me with all these side effects?”
5. “No one ever helps me take my pills.”
6. “My partner found my medications last night; I think he knows I have AIDS now!”
7. “I missed a lot of doses when I was drinking, but I know I can do this now that I’m sober.”
8. “You seem to be able to stick to your regimen so well. Not me. Do you think I’ll ever be able to do it?”

Techniques for Offering Emotional Support
Some possible ways to offer emotional support include the following. You may have other methods of your own.

- **Mirroring**: State what you think the patient is saying either in words (“I’m so down today”) or behaviour (patient cries). This is like holding up a mirror in front of the patient. You might make statements starting with “It sounds like you feel...” or “I can see you are feeling...” or “Today you seem to be...”

- **Making sense of feelings**: Help the patient understand why they are feeling the way they are. Ask questions to tie in emotions with their more objective report.

- **Silence**: Sometimes not saying anything but actively listening is all that the patient wants.

- **Showing your interest by asking questions about how the patient is feeling**: Help the patient understand why they are feeling the way they are. Ask questions to tie in emotions with their more objective report.

- **Overcoming barriers to asking for or receiving help**: Sometimes it can be very difficult for people to ask for help. As part of your work as a Mshikaji, you will need to learn how to help your assigned patients get the help that they need. To do this, there are a few steps you’ll need to take when a patient seems unable to ask for or receive help. First, find out what makes it hard for your assigned patients to seek help. Then validate and normalize their concerns, sharing with them your own previous experiences, how you have reached out for help. It takes strength to do that. Reassure them that you also are on the medications and, therefore, might be able to understand what they are going through. Remind them you have been especially trained to provide help and that you will keep everything private and confidential. Help them learn to trust you. Emphasize that the relationship works both ways – at times, your assigned patients may teach and assist you, too.
Providing Encouragement

We know two important things about people’s behaviour.

1. First, we know that people behave in certain ways then they get rewards for the behaviours. For example, if I take my medications and my viral load drops, that motivates me to continue to take my medications. Can you think of any other examples? [When I exercise, I feel healthy. When I eat well, I keep my weight where it should be. When I take care of a friend in need, we become closer.]

2. We also know that when people believe they can achieve their goals (such as taking their medications), they actually do achieve their goals much better.

These two facts are the reason why Washikaji should try to give a lot of encouragement to their assigned patients. Washikaji should try to:

- Make sure the patient feels you are confident that he or she can adhere
- Increase each patient’s belief in himself or herself and his or her abilities
- Be sure not to stigmatize or look down on patients
- Recognize stigma experienced by the patient and tell the patient he or she should reject stigmatizing views

Combatting stigma

Stigma is very important to recognize. Stigma involves attitudes, language, or behaviour that label people, set them apart, and lead to loss of status and discrimination. Stigma can take many forms, including physical and social isolation; gossip, name calling, and condemnation; or a loss of rights and decision-making power. Self-stigma occurs when people blame or isolate themselves because they believe they are “bad” or inferior to others. Stigma by association can occur when an entire family or group is stigmatized because of attitudes towards one member of that group.

Stigma is common in relation to HIV infection. This can be due to many factors, including:

- Lack of knowledge, misbeliefs, and fears about HIV
- Moral judgments about people assumed to have been sexually promiscuous
- Fear about death and disease
- Lack of recognition of stigma and its effects

Poverty increases stigma, as poor people cannot hide easily and are more likely to be exposed to stigma and discrimination. MSM are particularly targeted by stigma due to societal attitudes, judgments, and criminalization of male-male sex. Transgender patients may be particularly prone to stigma because they don’t conform to expectations about gender roles. You can help combat stigma by doing the following:

- Watch your own language and avoid stigmatizing words
- Provide a caring ear and support to the patients you work with
- Encourage patients to use available services without fear
- Share what you have learned about stigma and its consequences
- Speak out when you see stigma in action
Not everyone is good at providing encouragement and combatting the effects of stigma. In fact, we sometimes get used to complaining when we don’t like what people are doing, instead of encouraging them when we do like what they are doing! It’s good to practice this.

**Reflection and Exercise**

Read the conversation below and reflect on what the Mshikaji says.

<table>
<thead>
<tr>
<th>Patient:</th>
<th>Mshikaji:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yesterday I took all my pills.</td>
<td>“Great! I knew you could do it.”</td>
</tr>
<tr>
<td>I took my pills this week, but I didn’t always eat when I was supposed.</td>
<td>“That’s really good that you took all your pills.”</td>
</tr>
<tr>
<td>I tried to take all my pills this week, but it was hard.</td>
<td>“You are a strong person to put all that effort into it.”</td>
</tr>
<tr>
<td>I’ve been doing better with the medications lately, but I’m still not sure I can really do it.</td>
<td>“That’s wonderful you’re doing better. I believe in you.”</td>
</tr>
</tbody>
</table>

Now, think about what you would say, in your own words...

<table>
<thead>
<tr>
<th>Patient:</th>
<th>Mshikaji:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I didn’t miss a single dose last week!</td>
<td>_____________________________________</td>
</tr>
<tr>
<td>I asked my provider if I could get SMS reminders last week.</td>
<td>_____________________________________</td>
</tr>
<tr>
<td>I’ve been taking the medicine for my headaches, so I haven’t missed as many doses this week.</td>
<td>_____________________________________</td>
</tr>
<tr>
<td>I asked my boyfriend for help in taking my pills; he said yes.</td>
<td>_____________________________________</td>
</tr>
</tbody>
</table>
Assessing and enhancing social support

We believe people can help each other in many ways. One thing they can do is to help others take their medications regularly. In fact, research studies have shown that people who have a lot of support from others are more likely to take their medications. One of your most important duties as a Mshikaji is to be a source of support for your patients. We have already discussed some ways that you can share your knowledge about taking anti-HIV medications, but there are other ways as well. Today we are going to discuss how you can give different types of support to your patients.

Social networks. First, let’s consider your own sources of support. We call this your own social network or social support system. Think for a minute about your regular partner, your friends and family, maybe even neighbours, anyone you come in contact with. These people are your social network. Some of you will be able to think of many people, others just a few, and some of you may have no one regular person in your social network.

Helpful and unhelpful support. Now think about the types of support or help you get from people in your social network in taking your medication. Some people may be very supportive and help you, for example, in reminding you to take your medications. Others might not even know about your diagnosis, but they may listen to you and be supportive in other ways. Other people in your social network might not be very supportive. You may like hanging out with them even if you realize they don’t always help you to stay healthy. Think about all the specific ways that they help you or don’t help you. Helpful activities might include giving you specific information, listening and trying to understand, making you feel less down and lonely, giving you confidence or encouraging you. Unhelpful activities might include being abusive toward you, demanding a lot of time and attention without reciprocating, or constantly nagging you.

Enhancing support. One way to stay healthy is to try to increase the time we spend with people in our social network who are supportive and decrease the time we spend with people who are not good for our health. This is, of course, a very personal decision for people. It’s often difficult because the people who are not helpful at times might be the same people who are helpful at other times. Another strategy is to expand your network with more helpful others. There are a lot of ways to meet new people, including joining a group or organization that is or is not HIV-related, going to a religious organization, or reaching out to people you’ve lost touch with.
Documenting Your Work

Washikaji should document the work that they do, so that information provided is not lost and to ensure that communication with patients and the provider team is clear and accurate. Each Mshikaji will be asked to a logbook, with a section for each patient to which he is assigned. We ask that you use initials rather than names in this logbook, to ensure confidentiality. Write an entry in the logbook each time you have contact with your assigned patients.

Shikamana Log Book Sample

A sample log book entry is below:

<table>
<thead>
<tr>
<th>Date: 18/9/2014</th>
<th>Time: 13:24</th>
<th>Duration: 35 minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of contact:</strong> In person meeting at AG’s house</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Topics discussed:</strong> greetings, role of Mshikaji, review of adherence since started ART</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Successes:</strong> tolerating medications well, has only missed 1 dose when left for a family funeral in Malindi</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Problems:</strong> did not make plan to take meds for funeral, drinking a lot before and after cousin’s funeral, not eating well</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Suggestions:</strong> Reviewed possible ways to plan for unexpected travel, including carrying a dose in the pill carrier. Spent some time discussing positive living and eating well. Recommended that AG think about drinking less.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Next meeting:</strong> Will telephone early next week (Monday or Tuesday) to arrange next meeting.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix D includes a blank logbook form that could be used by Washikaji to document their patient interactions.
Positive Living
While ART may be the key to preventing both disease progression and HIV transmission to sex partners, there are many other aspects of “positive living” that are important for MSM living with HIV/AIDS. In the words of one of men we interviewed: “After you know your status, you need to use a condom with any other person that you do not know their status, when you start on the meds you need to eat well and adhere on the pills time. Moreover, you are required to reduce on alcohol consumption, and also reduce on sex work... “

Accepting the diagnosis
Men who accept their HIV diagnosis experience less stress and are able to obtain needed services and social support. Counsellors and providers need to work with recently diagnosed men to provide emotional support, information, and other care as needed in order to help men accept their HIV diagnosis. Again, in the words of one of the men we interviewed: “This is my life and I have accepted that I am positive and I cannot accept to just lose my life unless the meds just refuse to work because I understand they can refuse to work. But I cannot accept to die because I failed to use my meds ... to me it will never happen that way.”

Seprin (co-trimoxazole) prophylaxis
When taken every day, seprin can reduce the risk of bacterial infections and malaria in HIV patients. MSM should have access to this important preventive intervention, which is usually started before ART initiation and continued indefinitely. Some men do not understand the importance of seprin prophylaxis and think that ART is enough. While taking ART is extremely important, seprin is needed for protection against infections, especially for men with lower CD4 counts (200 or less).

Nutrition and self-care
Many patients need education on a healthy diet, which can help prevent weight loss and improve quality of life for patients living with HIV infection. MSM who are homeless or have unstable housing, in particular, may benefit from education and counselling on nutrition and self-care, with referrals to additional support as needed. Family support can be particularly valuable if it is available. In the words of another man we interviewed, when asked what motivated him to take his ART faithfully: “I was eating well because I was staying with my grandmother who was taking care of me. In the morning she would make sure I had fruits such as pawpaw, after that I would take tea and at around 10 o’clock she would bring me milk. At lunch time I would eat well and in the evening I would take porridge before taking supper.”

Psychosocial support
Support from friends and family is important for patients who need help with transportation, finances, or personal care (for example, if bedbound or hospitalized). Disclosure to select individuals is recommended for this reason, and is discussed later in this training manual. In addition, men may benefit from support groups for people living with HIV, whether specifically for MSM or for the general population. Some men may need access to more intensive counselling support, including mental health treatment. Although resources for addressing mental health problems in African settings are limited, training and programming are both increasing and should eventually allow greater access for MSM
patients in need. In the words of another interviewee: “...Initially it was difficult to speak to anyone. But it was my close friends at that point, and then afterwards there was a time that I became ill and it reached a point that I had to involve family. Then I was encouraged to speak to my parents but initially it was my close friends.”

Depression
Depression is a problem that is more common than many people think. Everyone feels down, sad, depressed, or stressed sometimes, and HIV can make this worse. Research has shown that about 1 out of every 4 people become severely depressed at some point in their lives. MSM may have higher rates of depression, due to stigma and social isolation.

For some people, depression becomes a problem that interferes with their ability to live a normal life. How can you tell if someone is feeling this way? Someone who is depressed may have the following symptoms:

- Sad mood
- Loss of interest in activities
- Weight change
- Sleep changes
- Slow movements or thinking
- Feeling worthless or guilty
- Difficulty concentrating
- Suicidal thoughts or statements

As a Mshikaji, your first job is to assess if your patient is feeling overly depressed. Your next task is to let the clinic know of your concerns. Finally, you need to help the patient figure out how the depression may interfere with taking ART, and come up with ways to address that. Research shows that depression makes it harder for people to take their medications properly.

One sign of depression is very important to note. If a patient mentions feeling suicidal or says anything about hurting himself or herself, tell the clinic IMMEDIATELY and they will handle the situation. If the person seems in imminent danger, find out where he or she is so someone can go to the patient and accompany him or her to the clinic. Your job, then, is to REFER. This is similar to what you learned to do regarding medical information: referring means informing someone else who knows more about the topic then you do and who is there to help you.

Substance abuse
Substance abuse is another challenge you may encounter. Drug and alcohol use, especially heavy use, can decrease adherence and increase the patient’s chances of treatment failure and other medical problems. When someone has a problem with alcohol and drugs, it begins to interfere with their ability to function normally. He or she may not be able to stop drinking or using, or to limit the amount he or she is drinking or using. This can result in physical harm, either directly from the alcohol or drug, or from situations the patient may encounter when his or her judgment is impaired.
As a Mshikaji, if you notice a patient may be having adherence problems or other issues due to alcohol or drug abuse, tell us IMMEDIATELY. Again, your job is not to conduct counselling but to assess your patient and get help for him or her. We will do our best to connect the patient to counselling and other resources, such as Alcoholics Anonymous.

**Sexual risk reduction**

All HIV-infected individuals need information about routes of HIV transmission and information about reducing the risk of transmitting HIV to others. Many HIV-positive MSM may have good intentions of using condoms, but fail to use them with at least some of their partners. For example, see the conversation below:

**Interviewer:** “Do you use condoms?”

**Interviewee:** “I use.”

**Interviewer:** “With him (your main partner)?”

**Interviewee:** “No not him, he doesn’t like, he doesn’t like anything to do with that.”

Washikaji can help support men’s use of condoms and lubricant with partners. Discuss with each patient how HIV is transmitted, ensure that he or she knows about the risk of anal sex, and encourage consistent condom use with all partners, regardless of HIV status. Because drug-resistant strains of HIV can be transmitted from person to person, it is not OK for an HIV-infected person to have sex with an HIV-positive partner.
Safe Disclosure for HIV-Positive MSM
(This material was adapted from (3))

HIV disclosure is a lifelong process. Many people have their own personal strategies and reasons for disclosing. Disclosure should be carefully planned to bring about positive outcomes. Common facilitators and reasons for disclosing include:

- trust in the person to whom you disclose
- positive experiences with previous disclosure
- existence of strong social support
- to gain social support
- to obtain relief from the stress of withholding a secret
- obligation and duty to inform (for example, a regular partner)
- self-acceptance of HIV-positive identity
- to share knowledge
- to control disclosure (i.e. to disclose before someone else exposes you)

Common barriers to disclosing include:

- negative experiences with previous disclosures
- fear of discrimination, stigma, and rejection
- lack of a strong social network
- feelings of shame and guilt regarding your status
- struggle with being HIV positive
- cultural factors (i.e., homophobia) within the community
- lack of HIV education
- inability to cope with the outcome of the disclosure
- concern of harming or burdening others

The outcomes of HIV-disclosure vary. Negative outcomes can include rejection, abuse, violence, stigma and discrimination. However, positive outcomes include increased social support, stronger relationships, reductions in anxiety and depression, and improvements in physical health. Most studies of disclosure have found more positive outcomes than negative ones, particularly over the long term. Furthermore, the majority of people who have disclosed have reported little to no regret after disclosing.

It takes time to adjust to being HIV positive. With that in mind, it’s a good idea to not rush patients into disclosing their HIV status without first giving it some thought. Wanting to share this knowledge with someone else may be a perfectly natural reaction, especially when the diagnosis is new and the patient is feeling overwhelmed, vulnerable, and uncertain about his or her life and future. The reality is that people with HIV need to be selective about disclosing. They need to be selective about whom they tell and when they tell them. This process of selection often involves uncertainty and can sometimes be an anguishing experience.

That old fashioned maxim, "easy does it" is a good approach to consider when thinking about disclosure. Even if a patient has been living with HIV for a while, he or she will likely find situations continuously
arising in which he or she may be forced to think about having to disclose. Wanting patients to tell family members and friends is very natural. However, the truth of the matter is that it can also create problems. Over the many years of the HIV epidemic, there have been some significant improvements in the general public’s awareness about and understanding of HIV issues in many African settings. Unfortunately, there is still a stigma attached to HIV. In addition, unsympathetic and prejudicial reactions are still common, especially for HIV-positive MSM.

For patients in the Shikamana Project, disclosure to providers is required, and disclosure to Washikaji is encouraged. Although Washikaji are an essential part of Shikamana, a patient could choose to participate but refuse all contacts with a Mshikaji. This would be unfortunate, and we expect that most if not all patients will choose to learn from the Washikaji. Other disclosures (to family, friends, and partners) are NOT REQUIRED for Shikamana. However, discussion of disclosure is inevitable, since non-disclosure can cause problems for adherence. We encourage Washikaji to consider sharing with assigned patients how they have disclosed their HIV status and to whom. Consider sharing how disclosure and support from those who know your status has helped you. If you are comfortable with this, consider also sharing situations where disclosure was a problem and how you dealt with this.

Above all, respect decisions by patients to disclose to others or not to disclose. Confidentiality is critical for the protection of all Shikamana staff, Washikaji, and patient participants.
General disclosure tips for patients

◊ You don’t have to tell everyone. The choice is yours about whom to tell. Be selective.

◊ Be sure to consider the five "W's" when thinking about disclosure: who, what, when, where and why. Who do you need to tell? What do you want to tell them about your HIV infection, and what are you expecting from the person you are disclosing your HIV status to? When should you tell them? Where is the best place to have this conversation? Why are you telling them?

◊ Easy does it. In most situations, you can take your time to consider who to tell and how to tell them.

◊ Consider whether there is a real purpose for you to tell this person or if you are simply feeling anxious and want to "dump" your feelings.

◊ Telling people indiscriminately may affect your life in ways you haven't considered.

◊ Having feelings of uncertainty about disclosing is a very common reaction in this situation.

◊ You have a virus. That doesn’t mean you've done anything wrong. You don't have anything to apologize for simply because you are HIV positive.

◊ Keep it simple. You don’t have to tell the story of your life.

◊ Avoid isolating yourself about your status. If you are still not able to tell close friends, family members or other loved ones about your HIV status, allow yourself to draw upon the support and experience available to you, through organized support groups.

◊ There’s no perfect roadmap for how to disclose. Trust your instinct, not your fears.

◊ Whatever the response you receive in a specific situation, and even if it doesn’t go the way you’d hoped, you're going to survive it and your life will go on.

◊ Millions of others have dealt with this experience and have found their way through it. You will get through it too.

◊ Choosing whom to tell or not tell is your personal decision. It's your choice and your right.
Maintaining ART Access

Maintaining uninterrupted access to ART medications is critical for several reasons:

- Missed doses can lead to drug resistance and treatment failure
- Treatment interruptions, especially those over 48 hours, are more likely to cause drug resistance and treatment failure
- Treatment failure can lead to increased morbidity and mortality, as well as increased HIV transmission
- HIV strains with resistance to medication can be transmitted

Consider the following situations a patient might find himself or herself in:

- Nzioka is 3 hours late returning home from a short trip, and his medication bottle is at home.
- Mugo has two drinks at the bar, and then realizes it is time to take his ART.
- Kigoro travelled upcountry to visit his family, and now realizes he won’t be back home in time to get his medication refill.
- Mwambi gets thrown in jail for prostitution and loitering, and does not have her medication with her.

Missed doses and the “half-time rule”

Missed doses are unfortunate, but they happen to all patients from time to time. Sometimes, patients can think that if they miss their scheduled dose, they have “ruined” their adherence for the entire day. It is important to dispel this myth, and to encourage patients to follow the half-time rule. This rule can be explained as follows:

1. If less than half the interval until the next dose has passed, take the medication.
2. If more than half the interval until the next dose has passed, wait until the next scheduled dose.

Another way to say this is that if you remember when the time is closer to the missed dose than the next scheduled dose, take the medicine.

For example, if a patient takes one combination ART tablet every day at 6 am (i.e., every 24 hours) and misses this dose for some reason, he should still take this dose if he is able to do so before 6 pm (i.e., within 12 hours, or half the scheduled interval). If he is unable to take his missed dose until after 6 pm (i.e., over 12 hours have passed), he should wait for the next dose.

Similarly, if a patient takes one pill twice daily (every 12 hours) and misses a dose, she should still take the missed dose if less than 6 hours have passed since the scheduled time. If over 6 hours have passed, she should wait until the next scheduled dose time.

Ideally, patients would miss no doses at all, but it is unrealistic to expect this over the patient’s lifetime. It is better to take a dose a few hours late than to miss it altogether. Similarly, although reducing alcohol or drug use is an important goal, patients need to take their medication regularly even if they have a drink or use drugs on the same day. There are some precautions to take with patients that drink heavily or use a lot of drugs:

- Warn patients that excessive alcohol or drugs may damage the liver
- Warn patients that substance abuse can make patients forget doses
Remember, a missed dose is a learning opportunity. Patients should ask themselves what happened to make them miss the pill and what might be needed to ensure that it doesn’t happen again. Patients who miss doses due to drug or alcohol use should discuss this with their provider. Similarly, patients who use herbal or over-the-counter medications should discuss this with the provider to make sure there are no drug interactions of concern.

**Planned travel and emergency refills**

At each refill visit, providers will ask whether patients have any travel plans. The usual refill interval in Kenya is one month, although longer refill intervals (up to 2 or 3 months) are possible at patient request. Patients just need to communicate with their providers – Washikaji can remind their assigned patients to let providers know about planned travel.

All patients should also be counselled about what to do if they run out of drugs while away from the clinic. It is critical to maintain a supply of ART at all times, as treatment interruptions are a very strong risk factor for drug resistance. We suggest the following recommendations for patients who have travelled or are otherwise unable to come to their “home” clinic for a refill as scheduled:

1. Before the drugs are completely finished, visit the nearest health facility where ART is provided.
2. Explain to the provider in charge the reason you need an emergency supply of drugs, and for how many days you need this (e.g., for the return trip home, plus 2-3 days extra to ensure you can get to the clinic).
3. Show the doctor the remaining drugs you have, plus your clinic appointment card so that he or she can tell which drugs to give you.
4. Most health facilities will issue a maximum emergency supply of 2 weeks.
5. Patients should be advised to call the clinic immediately if they need a longer supply or if the outside clinic provider asks for more information. Each patient should have a clinic card with a contact number to call for emergencies.
6. Come for a refill immediately after you return home.

For all patients who come late for their scheduled refill, ask whether an emergency refill was obtained and record the details in the patient chart.

**ART access in prison or jail**

Some MSM patients participate in sex work or other activities that could potentially lead to an arrest. Because ART is very important and it is hard to predict who will have this problem, all patients should be counselled on what to do if they are arrested or sentenced to jail:

1. Always carry your appointment card with you
2. If you get arrested for more than a night, request the welfare officer to allow you to call your doctor.
3. Call the clinic number and explain your situation. The clinic staff will advise you what to do, which will usually be one of three options:
   a. Ask a relative or friend to bring you the medicine
   b. The clinic will bring you emergency doses
c. The prison can give you emergency doses

If the prison stay will be longer than a month, transfer of care to the prison facility is recommended.

Transfer of care
Adult patients, particularly men, move frequently in Kenya, and MSM are no exception. If a patient needs to be away from his or her “home” clinic for more than 3 months, consider a transfer of care. To do this, the following steps are needed:

1. Ask the volunteer if they have a preferred ART site near their new residence.
2. Complete an ART transfer form and ask the volunteer to present it to the new ART site as soon as they arrive.
3. Provide the patient with a copy of his or her blue clinic card (MOH257) to complete the transfer at the new clinic site and ensure that important medical history is not lost.
Community Engagement and Safety

KEMRI conducts community engagement activities in order to promote good relations with the communities it works with, and to provide information on its research activities and the health care issues it is targeting. For its HIV prevention activities, KEMRI targets a number of stakeholders including key populations and their representatives, members of civil society, religious leaders, public officials, and human rights organizations. Interactions and discussion between these groups are fostered by the provision of education and information on ongoing activities and needs addressed.

Until LGBT rights are protected in a Kenyan constitution, there is always some degree of risk involved with working to provide services and research to MSM. This risk exists for MSM, as well as for KEMRI staff.

Washikaji are encouraged to be discrete and cautious, in order to avoid risk. When working in the community, we encourage Washikaji to be mindful of patient confidentiality and safety at all times. In addition, Washikaji should be mindful of their own confidentiality and safety at all times.

When preparing for work in the field, we recommend that Washikaji do the following:

- Be aware of your surroundings and remove yourself and your patient from potentially risk situations
- When trying to locate a patient, be careful not to say or do anything that might break confidentiality or disclose information, even accidentally
- Maintain privacy during discussions about sensitive issues, and never discuss private patient information in the presence of others
- Choose meeting locations that are safe and relatively anonymous, with private locations
The Shikamana Project and Team

The Shikamana Project will result in a new intervention designed to promote engagement in care and ART adherence for Kenyan MSM. This work is being conducted in three stages:

1. Interviews and focus groups which were conducted in 2013-2014 in order to understand the challenges and facilitators men have with respect to ART adherence,
2. A pilot study in 2014-2015 which the intervention is tried with 10 patients who will volunteer to “try out” the intervention with us, and
3. A randomized trial of the intervention planned for 2015, in which 60 men will be randomized to either the Shikamana intervention or standard care and undergo monitoring for 6 months to see if the intervention is safe, feasible, tolerable, and acceptable.

The Shikamana intervention adds components to standard care in Kenya, which consists primarily of education and counselling about HIV and its treatment. To this basic package, the Shikamana project adds provider training in patient-centred care and motivational interviewing, to increase counselling skills and improve men’s interactions with providers. In addition, we add peer support from a trained Mshikaji. Shikamana patients will undergo the following procedures:

- ART teaching before and at ART initiation
- Study visits at baseline and month 3 with questions on risk factors for adherence problems
- Monthly refills with counselling and questions on adherence
- Use of a special “MEMS” bottle that will monitor when they take each pill

After training, each Mshikaji will work with his assigned patients, in close collaboration with the providers. Washikaji will meet each assigned patient as he or she initiates ART. Washikaji will work with from 2-3 patients each, arranging meetings in person or by telephone and encouraging patients to take their medication every day as prescribed.

Roles on the provider team

In general, HIV care in sub-Saharan Africa is provided by teams of individuals including clinicians (usually clinical officers or nurses), counsellors, and pharmacists (who are often the same as clinicians). In the Shikamana project, the following roles were assigned to each of these three groups in order to support the Washikaji and patients:

1. **Clinicians** are assigned the role of evaluating the patient clinically, staging the patient’s disease, ensuring eligibility for ART, reinforcing teaching on ART and the importance of adherence, and managing medications. This includes the management of side effects. Clinicians are responsible for seeing patients at baseline, at month 1 (to monitor for side effects and clinical response), at month 3, and then quarterly thereafter. In addition, clinicians see and evaluate patients who have symptoms or other complaints.
2. **Counsellors** are assigned the role of engaging patients in education about ART and its risks and benefits, drawing blood when needed for clinical monitoring, and counselling patients at baseline and monthly refills visits to promote ART adherence and engagement in care.
3. Pharmacists are assigned the role of collecting patient monitoring devices (MEMS caps will be used in the Shikamana pilot), capturing adherence data (through MEMS and through a brief audio computer-assisted self-interview or ACASI), and refilling medications. Education concerning use of MEMS as well as medication storage or other relevant issues should be provided as needed. We ask pharmacists to be neutral in their interactions with patients as much as possible, in order not to bias the adherence data collected in the pharmacy.

Providers at our clinic meet weekly to review the clinic work-load, discuss complicated cases, and plan for the next week’s activities. A clinical Section Head oversees these meetings and is responsible for the oversight and supervision of clinic activities. The section head plays an important role in ensuring the smooth running of the intervention, providing ongoing training reinforcement and refreshers, and helping to integrate the Washikaji into the health team.

Mshikaji role and teamwork
From our interviews and focus groups, we learned that Kenyan MSM can be socially isolated or lack support. To fill this gap, the Shikamana project is recruiting HIV-positive MSM who have experience taking ART to be Washikaji. Washikaji are role models to others and provide support to fellow MSM patients. Washikaji have been identified from among MSM working in our outreach network, with assistance from local LGBT groups. Each Mshikaji is selected on the basis of his maturity, professionalism, and motivation. Washikaji are trained on the basics of HIV and ART, on how to assess barriers and facilitators to adherence among MSM, and on how to provide different kinds of support to their assigned patients.

Wahikaji will provide support in person or by telephone weekly during the first month of ART, and then monthly thereafter. At each contact, Washikaji will provide social support and encouragement, as well as basic information on HIV transmission, safe sex, and other information as needed. Washikaji are specifically instructed not to give medical advice and instead defer to clinic staff. The main focus of the Washikaji’s work will be psychosocial support and problem-solving with patients to help them incorporate medication-taking into their daily routines. Washikaji will receive ongoing support through monthly meetings with the clinical staff, at which patient progress and overall successes and challenges will be discussed. Honesty and trust are critical for communication on teams, and are expected from staff and Washikaji alike.

Wahikaji will be asked to maintain a log of all patient contacts. They will be invited to monthly clinic meetings to discuss patient progress, using a case management model. Providers and Washikaji will work together to problem-solve patients’ specific adherence barriers. For example, the Mshikaji or a provider could send a patient SMS reminders to take his or her ART or to attend clinic visits, if remembering is the major barrier. If a patient is having problems carrying pills when away from home, a discrete pill carrier could be provided. Working as a team, the Washikaji,
providers, and their patients can form a bond (Shikamana) to promote good health and prevent HIV transmission.

In our qualitative research, MSM participants chose an experienced peer as the intervention component most likely to be of help to them. We believe this intervention has a very good chance of helping MSM patients adhere. However, in order for the Washikaji to be helpful to patients, they need to be:

- Well trained in HIV and ART information
- Motivated to take their own medicine and use their experiences to help others
- Extremely careful to maintain patient confidentiality at all costs
- Professional and responsible in the role that they have
- Aware of their limits – they are not clinicians nor are they therapists
- Supervised and supported by clinical staff

**Openness to diversity**

Throughout this manual, we have used “he” and “she” to be inclusive of transgender individuals who may participate in Shikamana as patients. Transgender women may be more open to discrimination and stigma then many MSM, who often are able to “act straight” if needed to protect themselves. We hope that Shikamana will serve a range of gays, other MSM, and transgender individuals. We will also include patients from a number of ethnic, religious, and social backgrounds. Many patients will be sex workers, and some will prefer to remain hidden and not be “out” as MSM. We therefore want to endorse a commitment to diversity and support of all patients.

Generalizations and stereotypes about individuals and groups of people do occasionally show up in group and they can be very painful to hear. We all make generalizations and have stereotypes – they’re there whether we like it or not. But it’s NOT useful to bring them up with your assigned patient. Generalizations and stereotypes can have several negative effects:

- Breaks the trust and alliance
- Makes people feel unwelcome
- Distracts from what’s important – the challenges we ALL face regarding adherence
- Contributes to a power structure or hierarchy where some beliefs or ways of being are considered better than others

For these reasons, we value celebrating diversity and mutual respect. We hope that these values can:

- Bring more ideas and perspectives to the table
- Create an open environment where everyone feels welcome
- Give everyone a voice

Allow us to discuss the usefulness of ideas and beliefs without moralizing about them.

**Boundaries and professionalism**

You are being asked to fulfil a volunteer role, with some help to enable you to meet your responsibilities. While we do want you to get to know your assigned patients and support them as you can, it is important to respect boundaries between both of you so that your relationship can remain
productive in a professional sense. If you find you can no longer keep an objective role with a patient, please discuss this with a supervisor as soon as possible. It may be best to change your assignment to another patient. We will reassign patients to different Washikaji if the patient requests this, the Mshikaji requests this, or the relationship is simply not work, in the view of the study team.

**Boundaries with Patients**
What would you do in each of the following situations? Discuss each situation in small groups, and then report your responses to the group as a whole.

1. Your assigned patient asks you if you want to use drugs with him or her.
2. Your assigned patient persists in asking you detailed questions about your personal life.
3. When you call your assigned patient, you feel that you could talk for hours.
4. Your assigned patient asks you on a date for that night . . . or when the study is over.

Washikaji should keep in mind that success as a Mshikaji depends more on your own efforts and behaviour than on the patient’s outcomes.

**How do you define success as a Mshikaji?**

| My assigned patient likes me | OR I listen to, respect, and care for my patient |
| My patient knows everything | OR I am a good resource for my patient about taking medications |
| My patient no longer uses drugs | OR I accept my patient where he or she is at, encouraging and supporting his or her efforts |
| My patient thinks I’m perfect | OR I do the best job I can and admit it when I make a mistake |
| My patient does just what I do | OR I help my patient find out what’s best for him or her |
| My patient takes his or her medications perfectly | OR I have provided all the different types of support I was trained to |

**Goals of the first meeting**
The first meeting with an assigned patient is important, and it’s good to think about your goals.

**Engagement:**
- Remember that patients may have mixed feelings about accepting your help. They may want it but not trust you at first. You might mention to the patient that it may be awkward to meet at first and that it is OK to be a little nervous. You can say that you are nervous if you feel that way (remember to use feeling words and be genuine!).
- Build rapport, develop mutual trust, listen actively, remain flexible, be yourself. You were picked because people thought you could be a good Mshikaji.

**Contracting:**
- You will need to cover with the patient the boundaries of the relationship. The clinic staff will have already talked with them about this to a certain extent, but you will need to repeat it.
• Define relationship, establish parameters, determine goals of the interaction, and identify mutual expectations. Your goal as a Mshikaji is to provide support: information, emotional support, and encouragement, and to show the patient that ART adherence is possible.

• Discuss how the patient should contact you and exchange phone numbers. Find out what times are best to call and when is too early or too late. Discuss where you might meet in person and how to arrange those meetings.

Termination:
• How one ends the relationship is very important and sometimes difficult. You will need to explain at the first meeting how contacts with patients will last 3 months. After that time, the patient can still call you and you can answer the calls or meet, but you will not continue to initiate contacts with the patient. Not because you don’t want to, but because that is the agreement for now.
Protocol for a visit or telephone call

Your job as a Mshikaji includes contacting each patient assigned to you every week for the first month and then at least once a month thereafter. When you first meet with your assigned patients, you should discuss when it will be a good time to meet (mornings or evenings, weekdays or weekends, and so on). Sometimes you will see the patient in person, but if this is not possible, try to check in by phone.

During the visit or phone call, try to cover some or all of the following points.

- Praise and thank the patient for keeping the appointment.
- Ask how they are doing with their ART (for example: “How did everything go with your medications yesterday?” or “Did you remember to take your morning dose this morning?”).
- Remind them to take their medications (for example: “so your evening dose is due in about an hour, right?” or “I just saw the time and thought I’d remind you that your dose you’ve been forgetting about is due in a few minutes.”)
- Ask “What’s going well?”
- Ask “What’s not going so well?”
- Review goals you’ve been working on.

End by telling the patient that you enjoyed talking with him or her and look forward to talking again at the next scheduled time. Remind patients that they can call you if they like.

Throughout the visit or phone call, provide social support as follows:

1. Give information. Emphasize the importance of not skipping doses. Share strategies that work for you. Use examples of what you have tried and been successful with to help motivate and guide the patient. Encourage the patient to call clinic staff for any questions of a medical nature.
2. Give emotional support. Be warm, friendly, and understanding. Listen and understand. Empathize. When worry or concern is expressed, let the patient know that worry is a normal, human reaction. Reassure the patient that things are going to be OK. If the patient says that he or she is really depressed or suicidal, encourage them to call the clinic and talk to a counsellor. Tell the clinic staff immediately.
3. Give encouragement. Praise all steps in the right direction, no matter how small. Praise partial adherence even if total adherence is not yet attained. Encourage the patient to adhere by expressing confidence in the patient’s ability to do what needs to be done.
EXERCISE: Working with patients

Now that you have learned and discussed the roles and responsibilities of a Mshikaji, think about what would make an ideal Mshikaji to help MSM patients taking ART, in terms of:

- Personal characteristics
- Qualifications and skills
- Support from providers

Write your thoughts below.

Personal characteristics:

Qualifications and skills:

Support from providers:
References


Appendices

Appendix A – Performance Objectives

Performance objectives were developed for Washikaji based on the intervention mapping approach of Bartholomew et al (4). This process involves first conducting a needs assessment, which we did through our interviews with HIV-positive MSM, focus groups with their providers, and input from community LGBT groups. Second, we identified expected outcomes that were desired, and analysed what would be needed to achieve each specific outcome. This process resulted in specific performance objectives for Washikaji working with HIV-positive MSM patients taking ART. The mapping process was then used to map performance objectives to the information, motivation, and skills or self-efficacy that Washikaji will need to achieve these objectives, as well as perceived social norms and outcome expectations integral to the Shikamana intervention.

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<thead>
<tr>
<th>Performance Objectives for Peer Navigators</th>
<th>Information</th>
<th>Motivation</th>
<th>Skills/self-Efficacy</th>
<th>Perceived Social Norms</th>
<th>Outcome Expectations</th>
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<tbody>
<tr>
<td>Teach others about HIV, what the virus does to the body, and how this impacts health</td>
<td>Understand what it means to be HIV infected</td>
<td>Endorse the importance of alleviating fear surrounding HIV and AIDS</td>
<td>Instil confidence in talking about HIV</td>
<td>Recognize that ignorance leads to alienation and social isolation</td>
<td>• Expect that an understanding the outcomes of HIV infection will motivate adherence</td>
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<tr>
<td>Understand disease progression and prognosis</td>
<td>Endorse acceptance of HIV status</td>
<td>Instil confidence in avoiding transmission to others</td>
<td>Recognize that knowledge is needed for understanding and acceptance</td>
<td>Endorse the need for MSM to have tailored information in order to understand risk</td>
<td>• Expect that a good understanding of HIV transmission, including risk from male-male sex, will motivate risk reduction</td>
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<tr>
<td>Understand how HIV is transmitted from an infected person, including through male-male sex</td>
<td>Promote a positive outlook (&quot;living positively&quot;)</td>
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<td>Teach others about ART, how it works, and its benefits</td>
<td>Understand how ART adherence works (maintaining drug levels)</td>
<td>Endorse the importance of ART and its benefits</td>
<td>Express confidence in teaching patients about ART</td>
<td>Recognize that patients who take ART can have healthy, productive lives and decrease their risk of transmitting HIV to their sex partners</td>
<td>• Expect that having peers teach patients about ART’s effects will help promote adherence</td>
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<td>Describe the benefits of ART to infected individuals and to their sex partners</td>
<td>Endorse the need to maintain an adequate drug level</td>
<td>Express confidence in teaching patients about maintaining adequate drug levels</td>
<td>Recognize that MSM may have specific additional challenges for accessing care and adhering to ART</td>
<td></td>
<td>• Expect that having peers teach patients about drug levels will help promote adherence</td>
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<td>Know about Septrin prophylaxis and how its benefits differ from those of ART</td>
<td>Promote treatment as prevention</td>
<td>Express confidence in assessing patients’ adherence needs</td>
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<td>• Expect that peers will endorse the personal and public health benefits of ART for MSM</td>
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<td>Understand the importance of ART barriers and facilitators for MSM patients</td>
<td>Promote Septrin prophylaxis as an adjunct to ART</td>
<td>Instil confidence in promoting ART as a critical intervention</td>
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<td>Performance Objectives for Peer Navigators</td>
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<td>Demonstrate ways to ensure regular pill-taking and keeping appointments</td>
<td>Explain the importance of pill timing</td>
<td>Reinforce the importance of making ART a priority</td>
<td>Express confidence in demonstrating regular pill taking and use of an alarm device</td>
<td>Recognize that due to the busy health system, men need to be patient and persistent when accessing care</td>
<td>• Expect that modelling regular pill taking behaviour will promote adherence</td>
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<tr>
<td></td>
<td>Explain what to do if a dose is missed</td>
<td></td>
<td>Express confidence in helping patients understand what to do if a dose is missed or a refill is needed</td>
<td>Recognize that substance abuse can interfere with pill taking and is therefore undesirable</td>
<td>• Expect that peer guidance for coping with missed pills and refill needs will promote adherence</td>
</tr>
<tr>
<td></td>
<td>Explain why on-time refills are critical for good adherence</td>
<td></td>
<td>Express confidence in helping patients manage appointments and refills</td>
<td>Recognize that pill taking should be a priority even when using substances</td>
<td>• Expect that stressing on-time appointments and refills will promote adherence</td>
</tr>
<tr>
<td></td>
<td>Explain how missed doses can lead to drug resistance</td>
<td></td>
<td>Express confidence in discussing planning ahead and carrying pills when traveling</td>
<td></td>
<td>• Expect that teaching patients to cope with unexpected events will support adherence</td>
</tr>
<tr>
<td></td>
<td>Explain that side effects need to be reported promptly</td>
<td></td>
<td>Express confidence in helping patients report persistent or bothersome side effects</td>
<td></td>
<td>• Expect that providing help for side effects will lead to greater adherence</td>
</tr>
<tr>
<td></td>
<td>List three strategies to cope with minor side effects like nausea or drowsiness</td>
<td></td>
<td>Express confidence in discussing the importance of taking pills despite substance use and in reducing substance use when possible</td>
<td></td>
<td>• Expect that stressing the need to take ART despite ongoing alcohol or substance use will support adherence</td>
</tr>
<tr>
<td></td>
<td>Explain why adherence is still important even when using alcohol and other substances</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promote disclosure to family and friends who can provide support</td>
<td>Understand that support is necessary when learning to take ART and maintaining adherence over time</td>
<td>Describe having social support as positive</td>
<td>Express confidence in ability to protect patient confidentiality and promote safety</td>
<td>Recognize that you are a role model to patients and an important supporter</td>
<td>• Expect that the trained peer and another personal supporter (if available) will help promote adherence</td>
</tr>
<tr>
<td></td>
<td>Explain the availability of ART in Kenya and how patients can access care when traveling or moving, or in prison/jail</td>
<td></td>
<td>Express confidence in ability to counsel patients about disclosing HIV status to other supporters if possible</td>
<td>Recognize that friends and family who understand the importance of ART can also be supportive</td>
<td>• Expect that accessing care regardless of circumstances is critical to adherence</td>
</tr>
<tr>
<td>Teach others about Kenyan HIV care points and clinic policies pertinent to travel, moves, or prison/jail time</td>
<td>Describe maintenance of adequate drug levels in all situations</td>
<td>Express confidence in increasing patient knowledge about obtaining care when traveling/moving or in prison/jail</td>
<td>Recognise that refills are available in government facilities because uninterrupted pill-taking is a priority</td>
<td>• Expect that enabling peers to be spokesmen for HIV prevention and care for MSM will improve community knowledge and support ongoing engagement efforts</td>
<td>• Expect that enabling peers to be spokesmen for HIV prevention and care for MSM will improve community knowledge and support ongoing engagement efforts</td>
</tr>
<tr>
<td>Discuss the HIV prevention and care needs of MSM with community leaders</td>
<td>Know basic information about HIV risk among MSM in Kenya</td>
<td>Endorse the importance of community engagement for work with MSM</td>
<td>Express confidence in discussing why access to good HIV prevention and care services is vital for Kenyan MSM</td>
<td>Recognise the value of community acceptance, and the detrimental effects of social isolation</td>
<td>• Expect that enabling peers to be spokesmen for HIV prevention and care for MSM will improve community knowledge and support ongoing engagement efforts</td>
</tr>
</tbody>
</table>

*Shikamana Peer Navigator Manual* 51 version 2015-1-11
<table>
<thead>
<tr>
<th>Performance Objectives for Peer Navigators</th>
<th>Information</th>
<th>Motivation</th>
<th>Skills/self-Efficacy</th>
<th>Perceived Social Norms</th>
<th>Outcome Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Act as key liaison between assigned MSM patients and providers</td>
<td>Understand the importance of a strong healthy link between the peers and patients in ensuring program success</td>
<td>Endorse honesty and trust as key to working with MSM patients</td>
<td>Express confidence in ability to listen and communicate with patients about their needs; Express confidence in being able to help link patients to services outside the scope of Shikamana</td>
<td>Recognize that individual MSM may have different priorities and needs; Recognise that the program cannot cater for all needs, but will do its best to link men to needed support when available</td>
<td>• Expect that effective communication between peers and patients will promote adherence; • Expect that addressing of problems such as mental illness, substance abuse, and financial need will promote adherence</td>
</tr>
<tr>
<td>Interact effectively with providers as part of the care team</td>
<td>Understand the importance of a strong healthy link between the peers and providers in maintaining satisfactory service provision</td>
<td>Endorse trust in (MSM-friendly) providers</td>
<td>Express confidence in communicating with providers about patient needs and problems identified</td>
<td>Recognize that health providers generally want to help patients</td>
<td>• Expect that effective communication between peers and providers will promote adherence</td>
</tr>
</tbody>
</table>
Appendix B – Confidentiality Agreement

HIV STUDIES CONFIDENTIALITY AGREEMENT

I, ____________________________ do understand that I may have access to, or have disclosed to me, confidential information relating to the participants in HIV studies. This may include, but not limited to, information about spouses or partners of participants, HIV status, persons accessing comprehensive care and prospective volunteers considering participation in HIV research.

I agree to hold this information in strict confidentiality as described in SOP D5: Handling Confidential Volunteer Information, which by signing below I confirm to have read and understood.

I understand that communication of confidential information to unauthorized person/s or organization/s outside the study team is strictly prohibited.

Further, I understand that it is my responsibility to inform my supervisor or PI of any breach in confidentiality.

I confirm the above agreement by signing below.

Name of Staff: ____________________________ Signature: ____________________________ Date: ____________________________

Name of PI: Dr. Susan Graham Signature: ____________________________ Date: 19-11-2014
Appendix C – Adherence Needs Assessment

Directions: Washikaji need to assess the following with each patient, exploring adherence and checking on how the patient is doing with each contact. It is best to use your own words but try to cover each of these areas. Remember that problems change over time, and patients may reveal more to you as they get to know you better.

For each problem rated 1 or 2, help the patient determine how exactly this interferes with adherence. Different pathways will require different solutions. For example, is drinking a problem because the patient is at the bar late and misses evening doses or because the patient purposely doesn’t not take medications before a drinking binge because he or she believes it’s harmful to do so? Feel free to share your own experiences and to model the appropriate behaviour.

Rate each of the following as:

0 = not a concern 1 = probably a concern  2 = definitely a concern

_____ Prior experience with adherence to other medications was not successful
Try to anticipate similar problems this time and to build upon strengths from the past

_____ Inadequate knowledge about own regimen, including names of drugs, dosing, special dietary instructions
Make sure that the patient gets a clinic card to carry and programs the KEMRI clinic number into his or her cell phone

_____ Belief system: that medications don’t work, that the danger of not taking them is minor, that it’s not necessary to take them consistently, or no knowledge of resistance
Explain the benefits of medication, the dangers of missing even a few doses, how resistance can develop and lead to drugs not working, how adherence is important

_____ Low confidence or self-efficacy in own ability to take medications
Offer encouragement, model your own struggles and successes, encourage even small steps toward adherence

_____ Side effects: does not know what to expect nor how to get help, feeling sick from side effects without adequate medical care to address them, them not aware that side effects usually decrease or disappear after the first few weeks
Encourage patient to contact clinic staff, provide hope that the side effects can be managed

_____ Does not have good relationship with clinic staff or a specific provider
Encourage patient to talk to providers about what they want and need in the relationship, mention that it is possible sometimes to switch providers

_____ Has difficulty remembering or getting time to come for refills
Discuss with the patient what reminders would be helpful and how to organize refill scheduling with the clinic to ensure he or she never runs out of medication
_____ Does not have a routine daily schedule with good times and reminders for doses. Doesn’t have a plan if he or she needs to travel or stay away from home unexpectedly
   Help patient come up with a reasonable daily schedule or learn to make plans for disruptions such as having extra doses on person at all times, give a pill carrier for use and remind the patient that he or she should remember how many doses were taken from the MEMS early and report this at the next study visit.

_____ Desires but does not have memory aids such as calendar, timers, watches, or alarm
   See if the patient’s cell phone has an alarm that can be set. Discuss whether an SMS text reminder will be helpful and when it should be set. Arrange with the clinic staff for timely reminders for pill-taking and/or appointments.

_____ Discomfort with disclosure of HIV status (especially to roommates or housemates) and whether this interferes with adherence
   Help patient assess whether it would be better to disclose or, if not, what strategies are available to work around stigma and secrecy

_____ Unstable living conditions or inadequate housing, food, financial resources, or transportation which are more pressing than HIV adherence
   Encourage the patient to try not to let these problems interfere with taking ART. Ask the clinic staff for any suggestions about help or referrals.

_____ Is experiencing untreated psychological distress or impairment
   Refer to and discuss with clinic staff, encourage them to seek treatment, explain how this interferes with adherence

_____ Has untreated alcohol or other substance use problems leading to chaotic lifestyle or other impediments to adherence
   Refer to and discuss with clinic staff, encourage them to seek treatment, explain how this interferes with adherence

_____ Is isolated, has an inadequate social support network
   Assess whether people in the patient’s social network are helpful and encourage patient to seek helpful people out for support, educate patients about other available sources of support such as support groups and LGBT organizations

At meetings with providers, share the problems your patient has that are making him or her miss medication doses. Also share other concerns or fears about what might interview with adherence in the future (mental health problems, substance abuse, other problems...).
Appendix D – Sample Logbook

Date:    Time:    Duration:

Type of contact (phone or in person):

Topics discussed:

Successes:

Problems:

Suggestions:

Next meeting: