

## **Adherence**

### **Vicki Tepper, PhD**

Vicki Tepper: Hi, my name is Vicki Tepper, and I'll be speaking with you about adherence. And we have a few objectives to cover today. First, I'd like to help you understand the unique aspects of adherence within the pediatric population. As we do that, we're going to understand the components of a good adherence assessment, as well as how to identify tools to enhance and monitor adherence.

Now as most of you know, adherence is a very complex topic to talk about, and it's really defined by a whole bunch of different issues that can come up. Today we're only going to focus on a few of these, but I wanted to just bring your attention to the many different aspects of the complex issues that can impact adherence. For example, the characteristics of the disease, the treatment regimen that might be indicated for your patient, the clinical setting in which you're seeing your patient, aspects of your patient as well as the relationship you have between yourself and your patients.

And we're going to talk about that first, because what we've learned over our experiences here have been that the factors that affect adherence most are the factors having to do with the relationship that we establish with our patients. So as a provider, we first have to think about our style when we approach our patients. For example, do we approach our patients in a comfortable style, where they feel at home and comfortable talking with us?

When you're working with pediatric patients, of course you're working with both the caregiver -- who might be the mother or father, or another relative or someone else providing care for the child -- as well as with the patient, the child themselves. So your style in how you approach them is really important to making them feel comfortable and prepared to talk with you about the complex issues that might be involved in helping them to take their medication.

Another factor is our skill as a clinician in terms of assessing adherence, and the way we go about asking questions. We're going to talk a bit more about this in a few minutes, but just our assessment skills in understanding what the issues are, and how the families are adjusting to the medical regimen and the different issues relating to treatment.

Another really important factor for us to consider is cultural sensitivity. Many times, we see patients who come from different backgrounds than ourselves. We have to understand and appreciate those differences, because sometimes it's those differences which might be a barrier to them understanding what our requirements for their treatment are, or for us understanding why some of the things we're asking them to do might be more challenging.

In that regard, we must be non-judgmental. What we're asking families to do oftentimes is very different, and has a lot of different impacts on other members of the family. So being non-judgmental and open to the different issues that a family might bring to you really makes it possible for you to have a good and safe environment for the family to feel comfortable in talking about medication.

We also have found that it's often helpful to have more than one person working with you to help a family when we're talking about adherence. We refer to that as our adherence team. That might be made up of the provider, the medical personnel, the nurse and maybe a counselor who all work together to help the family with the issues related to taking medication.

It's also important as a provider to know what our resources are. Are there treatment coaches or buddies in the community we can rely on to help family members with the complex issues related to the medication?

I think most importantly, what we need to realize is that we need to become a partner with the families that we work with. Because what we're asking them to do, when it comes to giving medication to their child, often requires us to really develop an understanding of each unique family, and to work with them in terms of what they know will be the issues that will be most difficult or most easy for them, in order to achieve good adherence.

And now let's talk about that. What is involved in adherence? Well, the parent or caregiver must give the medication to the child. That's the first step.

So what is involved there? Sometimes parents themselves are ill. They might also be living with HIV or other health problems, and so they're dealing with their own health concerns as well as taking medication. So when we're thinking of a parent giving medication, we really need to understand: what issues do the parents have that might get in the way of them being able to then attend to the needs of their child?

Parents might have job obligations that keep them away from home at the time when we would like them to be giving the medication to their child. So who else might there be in the family, or a relative? Maybe the child is in daycare, or at school, or with a babysitter. We really need to understand all of those pieces as we think about who is giving the medication to the child.

We also have to understand other family responsibilities. For example, there might be five other children in the home, and in addition to caring for the child with HIV, this parent or caregiver might also have all of the other daily routines that must happen for all of those other children. So we have to understand what those issues are for the family.

And finally, it's really important for us to understand the myths, or the lack of understanding, that a family member might have about HIV. In particular, do

they have any health beliefs or other thoughts about medication which might get in the way of them understanding the regimen, and to be adherent to the medication?

Now I first mentioned that parents have to give the medication to the child, and then the second and more complicated issue is that the children have to take it. This becomes really tricky, especially when we think about the child that you have sitting in front of you in clinic -- who looks like a perfectly agreeable child when they're sitting there with you. But when they go home with their parents, they might be a very different story. So there's some things we need to think about.

First of all, what is that child's experience with taking medication in the past? If they had a difficult time -- perhaps they were in the hospital and there were some challenges around taking medication -- we really need to understand those issues before we start talking with the family about providing new medication and a potentially different regimen.

Now the ability for a child to swallow pills or tablets would be really complicated, because some children who are younger aren't able to do that. And some children who are older might in fact be nervous, or have worries or concerns, about taking pills or tablets and swallowing them. If they're taking liquid medications, sometimes the taste of those medications can be rather difficult for children to tolerate. When children are taking liquid medication, sometimes the volume of that medicine is such that it's really difficult for them to take it all at the time and the requested way that we have prescribed it for them.

Then there's the developmental stage. It's kind of easier for someone to give medication to a baby, because they can't really get away from you, so you can hold them and get the syringe or the spoon in their mouth or a cup. But once children start walking and running around, it's much more complicated.

And those of you who have children at home probably know that different age children have different issues, and come up with different strategies for how to take their medication, or how they don't want to. They might refuse, they might fight, they spit it out. Think about all the issues related to the child's developmental stage, and the way the child has had experiences before we start to plan giving medication to the child.

In research that has been done in the United States, the three most common reasons that have been reported for children and families having difficulty taking their medication were: how complex the regimen was, if there were too many pills or the volume was too high, or if the doses had to be with or without food. So how complicated the regimen is.

The second were the side effects. Family members reported that when the child became ill because of taking the medication, like diarrhea, headaches or some of the symptoms that are often associated with taking medication -- the side effects -

- that children would refuse to take it. And so one of the things as providers we can do is to make sure that we are able to coach families about the types of side effects they might experience, prior to the taking of the medicine, so they could plan for those things and be prepared to treat them.

And finally, just forgetting. Sometimes it's just hard to remember in the course of a day. I'm sure all of us have taken medication at some time for something where it was even only prescribed for a week, but we get busy and we might forget. So forgetting is often the third most popular reason for why people have trouble remembering to give their medication.

We all know that treating with ARV is rarely an emergency. We should never start ARV on the first clinical visit. However, opportunistic infection treatment can be an emergency, and for that we need to start treatment. But in order to treat with ARVs, we really need to focus on adherence assessment, counseling, and patient education before we start treatment to maximize the effectiveness of our treatment and to ensure successful and long-term suppression of the virus, which is the goal of adherent treatment.

So, what's the first step? What do we need to think about first? Well, the first thing we want to do is we want to really understand what the caregiver knows and believe about HIV, their beliefs about medication and what do they know. What we have found in our work in our clinic is that until we really explore those issues, we can't really move ahead, because a lot of times, patient's worries or concerns are the largest barriers to giving their medication to the child. Once we've carefully gone over those issues with the family, which might take a few visits, and really understand what they believe about medication and what they think the outcomes will be that we can really become successful. So, you really need to make sure that you've covered the knowledge of the family members and their beliefs before you move further.

So, once you've established that, we still have still have some other important aspects of adherence assessment that we need to do. For example, we want to look at one of the potential barriers to adherence. For example, if no one else in the family knows about the diagnosis of the child, and therefore, the medication has to be kept in a secret place in the home so that no one else will be able to see it, is that going to be a barrier if the child's medication time comes when many family members are present? So, we need to understand that barrier, which would be, potentially, the disclosure issue, which could interfere with our ability to work with the family on being adherent.

It's also important to find out what other adherence strategies have been used in the past, maybe not even with this child. But, if the caregiver is on medication, what have they tried, and what's worked and what hasn't worked? Sometimes you can end up prescribing or recommending something that the family has already tried, and it didn't work, and they might not have as much confidence in you because they know that it hasn't worked in the past.

So, you really need to check in and say, "What have you tried before, and what happened on those occasions, " and not just with HIV medicine, so that you really know for sure what they've tried and what their success has been.

We also want to carefully assess the home life and the routine of the family. When we're prescribing medication, if you know that there are certain routines that happen in the family, we like to think of checking those out first to see if it's possible to build into that routine the taking of the medication. One of things we found is that if you start to develop a habit or behavior that you do everyday, and you attach the medication to that routine or behavior, what we find is that it's easier to remember because you have a few other things that you do all the time as well. So, we call that an "anchor" for the treatment. We hook the treatment together with other routine events in the family, so it's really important to be able to get a full understanding of what's happening in the family.

Sometimes, what I'll say is: "In the morning, who wakes up first? Tell me about that? Then, what happens next? When does child wake up? Does the child have breakfast then? Does the child bathe in the morning or in the evening? Who does that?" Just walk through the entire day with the family and get an understanding of what a typical day is like.

Sometimes, it's also helpful to ask what a weekend day is like, because often what we do Monday through Friday is different than what we do on the weekends. So, what we would want to make sure is that we have a full picture of the family's routines and activities before we start to prescribe how the regimen would fit best for that family.

You also want to know about who cares for the child. Is the child in a daycare situation? Does the granny come over, if the mom goes to work, to watch the child? If we're going to do some education about medication, who else do we need to talk to make sure everybody understands what's required in order for the child to successfully take their medication?

Again, like I mentioned earlier, disclosure: who knows the diagnosis in the home? If we've made sure that we've established who in the family can also provide medication, we need to be sure that those people also know about HIV and about the child's infection status. So, we want to make sure we understand about what are those issues, because that can be a huge barrier.

And finally, for some of the medications that need to be kept cold, does the family have access to a refrigerator, or are there other methods they can use, like a clay pot in the yard where they can keep things cold? You really want to be certain about, before you prescribe a medication, that the family would have the resources and ability to maintain the medication as you need it to be kept.

Now we've assessed the caregiver and the home, we also need to assess the child. We just don't want to make an assumption that because we've got the parent and

the home ready that the family will be ready because the child still needs to be part of the team. So, we want to talk about the child: does the child know how to swallow a tablet? If not, can we teach them how to do that? We've been able to, and I'm going to talk with you in a few moments about ways that we have taught children as young as three and four years of age to swallow tablets. So, if the medication comes in a tablet, we need to know if the child can swallow a tablet.

It's really important to never assume that a child is too young or too small to be able to swallow a tablet, or that if a patient is big enough or old enough that they must be able to swallow the tablets. I've known adults who still mash up their tablets into apple sauce or other things in order to take them. You just can't assume that by a certain age everyone is able to, just as well as you wouldn't want to assume that someone is too young to try.

Then, there's disclosure. Does the child know their diagnosis? The way you talk about the medication with the child will be different if they understand why they're taking it. Which doesn't mean that automatically everyone should be disclosed, and we'll be talking in a separate lecture about disclosure issues. But, it's important to know about the family's wishes and desires related to disclosure as you begin to explore medication.

Now, patient education is another important component. Whether or not the child is part of the patient education is dependent upon the child's age and disclosure status. But, what you do want to do is make sure that with the parent, as well as any other adults who care for the child and administer medication, you've discussed the proposed medication and proposed program for taking it with all those people.

The first thing that's really important to emphasize are the goals of therapy. It's important for people to know that ARVs are not a cure for HIV, but they can treat HIV successfully so that a person can have a long and healthy life. So, in that way, we need to expressly talk about adherence, and how important adherence is to have a long and healthy life.

It's important to talk about side effects before they start taking the medication. What patients have reported is that when they didn't know what to expect, and they had a difficult side effect, that in fact that was more difficult for them to understand what to do next. But, to be prepared for the side effects and have a treatment plan for them, actually made the side effects easier to manage.

It's also important to talk about following up with a schedule about when they'll come back. We find that when we start people on medication in our program that it's good to see them frequently in the beginning, because most of the side effects and the barriers will come up in those early months. We want to make sure that we address those quickly so that they are able to establish a good adherent routine.

Also, you want to make sure that you use the specific name of the medicine, the dose, and the requirement for each medication. Either write that out, or for patients who are unable to read, we use color coding or other types of instructions that would be easiest to understand for them.

Like I mentioned, many times clinicians are afraid of talking about side effects because they're worried that by mentioning the side effects, the patients will develop them. But in fact, we have never seen that to be true.

In fact, what we see is that patients trust us more when we're as up front as possible, and we prepare them for all the possible side effects or problems they can encounter.

As I mentioned earlier, one of the things that's really helpful as you develop your plan is to identify your activities of your daily life that helps you, a trigger reminding you to take your medication, like brushing teeth, eating meals, or some regular activity like prayer or listening to a specific radio program. All of those types of activities are important to identify so that you can pair them up.

Also, remember that you should plan for changes in the normal routine, to help adherence. For example, if there's going to be a holiday and the families going to a village to visit other relatives. What you want to do is make a plan, now that you won't be at home, what kinds of things to do you need to think about so you won't change your adherence routines even though you're not in the same environment. So it's best to plan for those things in advance, rather than to experience a potential period of non-adherence which can compromise a person's health.

And here are some other things that can help with reminders, providing tools. For example, pill boxes, or charts, color coding as I mentioned, especially for family members who have literacy issues that are unable to read the labels, using reminder phone calls from your clinic staff, or developing a treatment buddy that can help the family members remember. Sometimes patients like having a diary or something they can write the routine down or even using an alarm on a cell phone to help them take their medication.

Now I mentioned that we can teach children very young to swallow tablets, and what we don't want to do when we teach the children is bargain with them or bribe them or trick them, or even threaten to punish them, because this is a lifelong pattern of behavior that they're going to have to establish. So instead of thinking of it from a negative point of view, which often times when parents or caregivers get frustrated they scold the children for not taking their children for not taking their medicine, what we're trying to do is be praiseful repetitive in developing positive behaviors related to taking medication.

I frequently will tell children, do you remember that there was a time when you've probably seen pictures when you were a baby and you couldn't walk?

And the children say yes they remember. And then you say: Now you're older, and you can walk and you can talk and you didn't used to be able to do that, right? No.

And then I tell them well there are other things that you didn't know how to do and once you practice you can learn how to do, and swallowing tablets is one of those things. And we start practicing with smaller tablets, sometimes even with pieces of candy, and teaching them how to swallow those first, as a way of practicing before we start the medication. And by using short commands and praising them for trying hard, and even if they're not able to do it, just for the fact that they're trying, over time we've been able to teach the children how to swallow their tablets as young as three and four years of age.

Now, nothing is perfect, so it's really important for us to anticipate the types of problems that might happen ahead of time. For example, if there's a time of particular stress in the family, you might anticipate some changes in medication. Taking behaviors, for example, if there was a death in the family, or if a family member that had been staying in the home moved away, so you want to talk about those problems, and think about solutions to them before they might occur, so that the family can be prepared.

And we want to be flexible with our treatment and change things if we think it will make it easier and more successful. And most importantly, we want to be consistent. Our most important message for the family is that we want to work with them to be able to make them feel successful about taking medication, which is a hard thing for them to do.

And one of the things that you can do when you're trying to understand how the family is doing is to think about how you ask your questions. And it's really helpful to focus those questions in a very specific way.

In the last three days, tell me how it's been to take your medicine. In the last week, since the last time you've come to see me in the clinic, how has it been? And don't be judgmental because if you're judgmental the family is going to tell you they've taken all their medicine because they don't want to disappoint you.

But if they want to check with you, and see if you're going to be accepting of the fact that this didn't go well. If you're open, and able to listen to them, and listen and be supportive, they're often able to tell you about times when things have been more difficult.

It's easier to get information if you ask the questions in a more open way. So say something "How many doses did you miss, " instead of "Did you miss any doses?" You get more information. "What dose is the hardest to give or to take?" Or perhaps, "Tell me about a time when it was really easy to remember and take your medication." Because I think you'll be able to elicit much more information

by acknowledging that it's challenging and that some times are easier than others.

We need to recognize that almost all families will not be able to adhere to their regimen at some time. Some of those difficulties can last for a short term, and some of them can last for longer periods of time, depending on what's going on. Sometimes, when we think about it, families don't think they've been really adherent, and when you sit down with their diary, they really only missed one dose out of the past three weeks. So, we want to see that actual adherence versus the things that they're worried about or they're concerned about adherence.

Try not to take it personally. It's really, really hard sometimes, when you've spent a lot of time working with a family, and they're trying their best, but they seem unable to do it, for you not to feel, somehow, you haven't done something right, or that you're really concerned about what you might have said differently. This is a really challenging aspect of care that you and the family, as a partner, will be working together on. Both sides of that partnership, both the provider side in the family side, are trying to do their best, and we have to really try, with both sides, not to take it personally when things get really hard.

It's really important to try to identify what the problems are when things aren't going well. Ask specific questions about the medicine, and if you ask the right question, you're more likely to get the right answer.

Now, I'm using this photo to help remind myself, and remind you, about the times when, possibly, we've all made decisions, even with the best information possible. This is a photo of a friend of mine and I in South Africa. We had gone to a game preserve, and we're on a safari. We had seen lions, we had seen rhinoceroses, and all kinds of other big, scary animals. We were very amazed; they were very beautiful.

Then, we saw this sign, and the sign said, "Warning. Please stay in your vehicle, there are dangerous animals." The first thing that we did upon seeing the sign, and I might add both of us are psychologists who have good reading skills and understand the consequences of behavior, immediately asked the driver to stop the car so we could get out and take our picture with the sign.

So, even when we do our very best to educate, sometimes we just don't always meet the mark. So, we have to always keep in mind that we all do these things; we can make mistakes, but we can always get back on the boat, back on the track, and work hard to be able to get adherent again.

And so, I'm going to close with this little memory to all of that. I think all of us can work on, as a way of remembering, how important it is when we work with families about adherence, and that's to be proactive. The "P" standing for that **P**artnership, that we have to be partners with the families, and assess the family's

**R**eadiness to begin ART. Use reminders, for example, pill boxes, that I described, as a way of helping the family to increase or enhance their adherence.

Look at the **O**bstacles to adherence. Look at the barriers; they're going to be different for everyone, and address them explicitly.

**A**ctive, be active in the monitoring of adherence. Look at the side effects and treatment outcomes, and carefully monitor that in all of your visits.

Be **C**ompassionate. Adherence is very complicated for families living with HIV; there are so many different stresses that they're living at. Making sure that they can take medication, and administer the medication successfully to their child is really a challenge. For us to be compassionate and understanding and supportive is going to go a long way in fostering a good relationship and improving adherence.

**T**rust and respect. We want to nurture that patient/provider relationship. I know I'm emphasizing that a lot, but I really believe that if the relationship you've developed with the family is good, you're going to be able to gather more information about the things that are challenges, and be able to help them address them so they can be successful.

**I**nterventions. We want to look at interventions to enhance adherence. Like I mentioned, we would want to look at their family routine and see if there were some triggers or anchors in their day when it makes it most sensible that we would say that's the time of day we want to give the medication.

**V**igilance. We want to make sure that, over time, we continue to ask about adherence, and we continue to talk about the issues and barriers, which might change as time changes. We can sometimes see treatment fatigue, when after six months or a year of doing the same thing everyday, it gets harder instead of easier for a while because it starts to feel like it's never going to end. And sometimes, that is true, so we need to work on supporting the family through those challenging times so that they can feel good about doing this medication administration properly.

And finally, **E**valuate. You want to evaluate clinical outcomes, all of the available regimens, so that you're able to provide the best care and continued care to the families that you're working with.

I want to thank you all very much.