Adherence to Antiretroviral Therapy for Children, Youth and Families

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Note: This self-study module outlines issues pertinent to adherence to antiretroviral therapy (ART) in children and youth, and suggests intervention strategies that may be of help in supporting children, youth and families.

OVERVIEW

The Centers for Disease Control and Prevention (CDC) estimate that about 385,000 persons were living with AIDS in the United States at the end of 2002. Of these, more than 4,800 were children under the age of 15. (http://www.cdc.gov/hiv/stats.htm). The development of combination antiretroviral therapy (ART) has allowed individuals with HIV infection to live longer, healthier lives, often slowing disease progression and preventing opportunistic diseases.

Medication adherence can be defined as a complex health behavior that influences the extent to which an individual takes medications as prescribed. Many medications used to treat chronic illnesses remain effective with less than perfect adherence. Estimates of medication adherence in chronic illness range from 20 percent to 80 percent, averaging 50 percent, and decrease over time with length of treatment (Williams & Friedland, 1997). Antiretroviral drug regimens, however, require strict adherence to be effective. The potential consequences of non-adherence include viral resistance, antiretroviral regimens that are no longer effective, progression of HIV disease and increased morbidity and mortality.

In adult studies, high-level adherence to ART (>95 percent) has demonstrated dramatic reductions in viral load to undetectable levels, compared to smaller viral load reductions when doses were missed (Fischl, 2000, Paterson et al, 2000). Smaller viral load reductions have resulted in an increased risk of viral mutation and drug resistance. Estimates of adherence to antiretroviral therapy in adults are often reported to fall well below the 90% adherence recommended to maintain long-term viral suppression (Simoni, Frick, Pantalone, & Turner, 2003).

In recent studies in children and adolescents with HIV infection, adherence to ART, using varied definitions and assessment methods, has ranged from 97% to 25% *(Murphy, Wilson, Durako, Muenz & Belzer, 2000; Reddington et al., 2000, Steele, et al., 2001; Van Dyke et al., 2002; Dolezal, Mellins, Brackis-Cott & Abrams, 2003; Farley, Hines, Musk, Ferrus & Tepper, 2003; Gibb et al., 2003; Goode, McMaugh, Crisp, Whales & Ziegler, 2003)*.

Generally, the adult HIV literature has organized predictors or factors associated with adherence into the following:

- Characteristics of the individual and his or her environment
- Treatment regimen
- Healthcare provider and client-provider relationship
- Healthcare setting

It is possible to find conflicting research in the adult literature about the importance of one or the other of these factors in adherence to ART. The pediatric HIV literature is just beginning to identify and address factors related to adherence. It is clear that adherence is not easily supported in adults with one or two "cookbook" interventions that work for everyone, and this is particularly true for children, adolescents and their families. One size does not usually fit all.

While adherence problems in children and families are often multifaceted, the overriding issue is that children are dependent on caregivers for their medications. The psychosocial issues surrounding HIV/AIDS that affect the family/caretakers will have an impact on the child's care including how the child's ART is managed. The secrecy of the diagnosis within a family may limit who gives medications to a child and when they are given. Often the expertise of an entire multidisciplinary team is crucial in dealing with medical, nursing, social, psychological and nutritional aspects of adherence support.

This self-study module outlines issues pertinent to adherence to ART in children and youth, and suggests intervention strategies that may be helpful in supporting children, youth and families.

GOALS OF ANTIRETROVIRAL THERAPY

The pathogenesis of HIV infection and the basic virologic and immunologic principles for ART are similar in children and adults. The goals of treatment are to:

- suppress HIV below the limits of detection or as low as possible for as long as possible
- preserve or restore the body's immune function
- prolong life and improve the quality of life

UNIQUE ART ISSUES FOR CHLDREN AND YOUTH

There are key issues that make ART in children different from that in adults. These include:

- diagnosis of HIV infection in infants
- pharmacokinetics
- viral load levels
- psychological issues
- developmental issues

Diagnosis in Infants

Most children acquire HIV infection perinatally, during or near the time of birth. The diagnosis of infection can be made shortly after birth or within the first few weeks of life utilizing HIV DNA-PCR testing. Because the timing of perinatal HIV infection is relatively narrow, starting ART very early during the period of initial (i.e., primary) infection is possible. The goal of early treatment is to control HIV replication, thus allowing the infant and his/her immune system to develop as normally as possible. While experts recommend antiretroviral therapy for symptomatic infants with immune suppression, the decision to treat a young infant based on plasma HIV RNA levels is more complex. However, because HIV infection progresses more rapidly in infants than in older children or adults, some clinical experts recommend treatment of all infected infants under one year of age regardless of clinical, immunologic or viralogic parameters. (http://www.aidsinfo.nih.gov/guidelines/). It is important to recognize that starting a complex medication regimen in a newly diagnosed infant can be very difficult.

The diagnosis of HIV infection in an infant creates great psychological stress for a new mother and family. The mother may have learned of her own HIV infection during this pregnancy and may be dealing with the diagnosis of other family members as well. She may have taken ART to treat her own infection and/or to reduce perinatal transmission, and the infant may have become infected despite these interventions. The mother may have refused any antiretroviral drugs out of fear of harming her infant and may blame herself when the infant is infected. Starting and adhering to a complex medication regimen for herself as well as her infant will be very challenging for a new mother.

Adherence experts have identified the concept of readiness in behavior change as an important factor in adherence to therapy. The new mother may not be ready to give ART to her infant at the time the infant is first diagnosed. Multidisciplinary support and services may be needed to assist this mother and her family to accept the diagnosis of HIV infection and begin ART for the infant.

Pharmacokinetics

There are several issues related to the pharmacokinetics of antiretroviral medications (how they are absorbed, distributed, metabolized and eliminated) in children. Prior to 1997, it was not required that drugs be tested in children before medications were approved by the Federal Drug Administration (FDA). Therefore, pharmacokinetic data specific to dosing and toxicities in neonates, infants and young children as well as adolescents may be limited or not available for all antiretroviral drugs.

In general, drug pharmacokinetics change in children over time, beginning with the transition from the newborn period to childhood and then to adolescence. These changes require specific and ongoing evaluation of drug dosing and toxicity. Some physiologic changes that have an impact on drug pharmacokinetics follow.

- Infants and young children have greater total body water and increased body fat in relation to weight than older children.
- Young infants have limited ability to concentrate urine and have an increased renal excretion rate.

- Liver metabolism is immature in newborns - metabolic rate is highest in infancy and decreases with age.
- Gastrointestinal absorption is variable in infants and young children and may be affected by many conditions.
- Pharmacokinetics of some medications change during adolescence, especially hepatic enzyme inducers or inhibitors and protein-bound medications.
- Adolescent dosing for antiretroviral drugs is not based on age but on Tanner Developmental Stages of Puberty. Generally, adolescents in Tanner Stages I and II (pre- or early puberty) are prescribed antiretroviral medications using pediatric doses, and those in the middle of puberty, at Tanner Developmental Stages III and IV, are prescribed based on whether they have completed their growth spurt. Adolescents who have completed puberty should be given adult doses.

Viral Load Levels

Infants with perinatally acquired infection can reach and maintain very high HIV RNA copy numbers in the first several years of life. This high viral load declines very slowly without therapy until approximately age four to five, when a set point is reached. In contrast, most adults without treatment usually reach a set point or a stable, relatively low level of HIV RNA by six to 12 months after infection. The slow decline in children is thought to be due to an immature but developing immune system and possibly to a greater number of HIV-susceptible cells. For many infants and young children, viral load levels are higher than those seen in most adults. High HIV RNA levels in infants under one year of age have been associated with high risk of disease progression and death, particularly in symptomatic infants with CD4+ T lymphocyte percentages < 15%.

Psychological Issues

HIV infection in children represents a family and often a multigenerational disease. For a child with perinatal HIV infection, mother and child may both be on ART. Other family members may also be infected and on medications. HIV may be only one of many problems the family is dealing with. HIV may NOT be the most pressing problem. Substance use, poverty, inner-city stressors, denial of the diagnosis, secrecy, depression and mental illness may contribute to an unstable or chaotic home environment. A parent/caregiver and family may lack the understanding or parenting skills or be too ill to manage the complex care of a chronically ill child. In addition, because of the death of a parent or parents, many children and adolescents with HIV infection are cared for by elderly grandparents. While many grandparents are doing a wonderful job in caring for their chronically ill grandchildren, others may be struggling with grief and loss as well as with chronic illness problems of their own.

Managing a complex regimen of antiretroviral medications for a child is very difficult under most circumstances. Unresolved or complex psychosocial issues within the family only add to the difficulty of treatment adherence. However, a coordinated, comprehensive, family-centered system of care can often address many daily and long-term problems that face families and may affect adherence to complex medical regimens.

Developmental Issues: Childhood

Giving long-term medicines to a toddler is difficult and stressful for any family. In addition, many antiretroviral medicines are unpalatable and after a few doses, the child refuses the medication or vomits it after a battle. It is very important to prepare families for the need to "mask" the bad taste or texture of medicine, before the battle becomes a war. Healthcare providers need to be proactive in teaching families about the developmental needs of their children, especially regarding discipline and medications. Young children need ritual, consistency, and supervision. Making medication taking a ritual — the same time, same place and same way each day — is comforting for young children.

Many families do not realize that they need to supervise children and teens while taking medications. Often children are given responsibility far beyond their years for their HIV and other medications as well as for other family tasks. If this is the reality for these children and families, the most realistic and useful care-management intervention may be to provide supports for the older child so that he/she can manage medications safely.

Developmental Issues: Adolescence

The unique development of adolescents makes caring for them a challenge. The adolescent's approach to illness is often different from that of adults. The concrete thought processes of young adolescents makes it difficult for them to understand and accept the need to take lifelong medications when they are asymptomatic and feel well. This is especially true if the regimen includes many pills, needs to be taken several times a day and/or has side effects that make them feel sick. Denial is also common, particularly for adolescents who are recently infected. Having to take medications daily is a reminder that you have this frightening disease, that it is not going away, and you cannot forget that you have it.

Children with HIV infection who are becoming adolescents are adolescents nonetheless. Like all teenagers, they struggle for independence from parents and authority figures and want very much to be like their peers and not to stand out or be different. These needs often cause difficulty with treatment adherence. A child who had previously been cooperative and compliant can rebel against parents/caretakers and even against long-term healthcare providers regarding medications or care.

Adolescents who have perinatal HIV infection and have been linked to a health care/social service system since early childhood can be very different from those who acquired HIV infection as adolescents. However, some issues may overlap. Adherence to medication can be complicated by an adolescent's anger and depression about their HIV diagnosis, an unstructured and chaotic lifestyle which may include homelessness or limited access to proper nutrition or refrigeration, and a lack of family and social support. In addition, adolescents are often not covered by health insurance.

Many adolescents who are infected as teenagers face challenges in adhering to medication regimens for reasons that include:

- denial and fear of their HIV infection
- misinformation
- distrust of the medical establishment
- fear and lack of belief in the effectiveness of medications
- low self-esteem

Comprehensive systems of care are required to serve both the medical and psychosocial needs of adolescents with HIV infection who are frequently inexperienced with healthcare systems. The care needs to be provided in youth-friendly environments. A realistic assessment of what support systems the youth will need to manage adherence must be incorporated into plans for ART.

PLANNING FOR A GOOD START

Most problems with adherence happen in the first week, so it is important to plan for a good start.

Assessing Readiness Before Prescribing

Assessing readiness is an important step before starting an infant or child on antiretroviral medication. The family members need to be involved in and agree with the treatment plan for their child. It is important that the decision-maker of the family is part of the discussion. This may not be the family member who brings the child to appointments. Home visits can be helpful in getting the important members of the family involved in the plan.

Assessing family beliefs, lifestyle, environment and priorities, the ability and willingness of the child to take medications as well as prior success (or problems) with medications, can help plan strategies for successful adherence. You will not learn what the family members really believe about HIV/AIDS, its treatment and the value of treatment unless you ask them and are open to their answers. Again, it is important to obtain explicit agreement on the need for treatment and for adherence. (http://www.aidsinfo.nih.gov/guidelines/ [Table 5]).

Assessing capacity for adherence for both the caregiver(s) and the child is also important when making a change in medication regimen. One of the predictors of adherence is past adherence. If adherence is a factor in a failed regimen, non-adherence is likely to recur with a new regimen unless specific interventions are put in place to address existing problems.

Educating Families About Treatment and Options

It is very important to educate the family about HIV, the purpose of ART and the importance of adherence. Identify the adherence target of 95% of prescribed doses.

- Use multiple strategies to educate—peer groups, families sharing experiences, video programs—and be prepared to repeat information.
- Identify family, friends, health team members and others who can help support adherence.
- Use home visits to teach about medications. Home visits allow families to learn about medications in their own place, away from the distractions of medical visits;
  - offer an opportunity to assess the home environment (e.g., where medications will be stored, who knows the diagnosis, etc.);
  - often build trust and a stronger bond between families and providers through acceptance and recognition of the client as a whole person.
  - Do not assume a family knows what to do when a problem comes up. Tell families what problems they might run into, what to call about, who to call, where and when to call.
- Provider follow-up plans need to include more frequent appointments, appropriate home visits, and phone calls. Once the regimen has started (or for a change in regimen), follow-up with a phone call and/or home visit in the first few days; this is when most problems occur and families do not call.
- Develop as simple a schedule as possible - one that works with the child and family's schedule and lifestyle.
- Marking syringes for oral liquid medications is important.
- For families with low reading skills and other special needs, bottles and syringes can be color-coded to match the written schedule.
- Use pictures of pills or bottles.
- Plan a trial run for a week (including the weekend) using "dummy pills" (empty gel caps), low-dose vitamins, or liquids, and a real schedule.
- Do not use candy - children will willingly take candy as pills. Do not give the message that medicine is candy, especially for young children or if there are toddlers or other young children in the family. However, using candy of various sizes is acceptable for teaching the skill of pill swallowing.
- If possible, start the first dose under supervision.

Administration

Infants and young children eat frequently, making it difficult for families to coordinate giving medications with or without food. A family may not have regularly scheduled meal times or a lifestyle that fits a schedule for taking medications consistently. Work and school schedules also may not fit a medication regimen's requirements. Any deviation from routine, such as school holidays or vacation may throw a medication schedule off. A parent or family member may have a different drug regimen and schedule from the child's, causing confusion or an additional burden on the family.

Prepare the family for developmental/behavioral issues, especially for young children. Children do much better if medication taking becomes a ritual (the same time, same place, same way each day), and if parents are consistent. Discuss with the parent or caregiver the importance of supervising the child while taking medication, even school age children who are old enough to participate in managing their medications.

Side Effects

Prepare families for common side effects such as nausea, vomiting or diarrhea. Many families stop treatment when faced with unexpected side effects without informing the child's physician or nurse. Tell family members your plan to help them manage these effects if they occur. Tell them they need to seek advice before stopping any medication.

STRATEGIES FOR SUPPORTING ADHERENCE

Regimen-Focused Strategies

- Simplify the regimen whenever possible. Q.D. (once a day) is ideal; B.I.D. (twice a day) is better than T.I.D. (three times a day), especially for children who attend school. Twice-a-day dosing allows a parent and child with HIV infection to take medications at the same time. If possible, choose regimens with a low pill burden or volume, for liquid medications.
- Review all medications (not just HIV medications) with the family, and discontinue unnecessary medications.
- Home delivery of medications or mail order pharmacy, if available, can be helpful for families without transportation, with busy schedules, or chaotic lifestyles. Some pharmacies will package pills in customized unit doses for an entire week, according to the regimen for each day.
- Help families identify ways to mask bad tasting powdered or liquid medications. Some successful methods are: Have the child suck on strong tasting candy, especially sour candies that kids really like (e.g. Mega Warhead Sours®, Sour Patch Kids®, peppermint patties), before and after bad tasting medicines; to chew on ice or a flavored ice pop to deaden taste buds before and after taking the medicine, or mix medications with a small amount of pudding. Other masking strategies include peanut butter, chocolate syrup, cinnamon gum and others. It is helpful for families to hear what has worked for others.

- Teach pill-swallowing to children (see pill primer and pill swallowing video on http://bayloraids.org/resources). Children as young as 4 years old have been successful at learning how to do this. Crush pills if the child cannot swallow them, or put pills inside gelcaps (to make them easier to swallow) if the child can swallow pills. Note: it is important to identify those medications that should not be crushed because they are enteric coated.

Child-Family-Focused Strategies

- Use group teaching about medications and family-to-family or peer support. Many families are happy to share what works for them and their children.
- Share success stories of families that are doing a good job adapting to the challenges of medication adherence
- Employ anticipatory problem solving: Ask: "What will you do if your child vomits the medication or has diarrhea? What if you remember a dose 3 hours late? What will you do on weekends when family routine changes or if you are planning a trip away from home?"
- Show families how medications are working. A simple chart of falling viral loads and rising CD4 counts is positive reinforcement to keep families going for the long haul.
- Encourage family and child medication self-sufficiency. They can make the medication schedules, mark syringes, organize pillboxes and complete the assessment.
- Involve children in their medications. Include older children in adherence assessment. Use positive reinforcement and realistic incentives and rewards such as stickers or gift cards. However, because HIV medications will be needed for years, it is important not to get into the cycle of expensive or monetary rewards. A reward for taking all their medication doses for a week or a month does not have to cost money. Ask the child to suggest a reward. It might be a trip to the park, staying up late to watch a special TV show, or having a favorite meal at home.
- Teach families about developmentally appropriate medication administration to children. Many children are given responsibility beyond their years for taking medications. It is important to tell families that they still need to supervise school-age children while taking medications. When it is the reality that a child has been given responsibility for medications at too young an age, support may be needed to allow the child to take medications safely (e.g., school/camp nurse, medicine buddy).
- Utilize contracts with families, school age children and adolescents.
- Consult a behavioral psychologist or an adolescent specialist for behavioral issues in children and adolescents. Prevention is always better than trying to fix a difficult situation, especially regarding children taking medications. Behavioral modification programs are sometimes helpful and successful.

Provider-Focused Strategies

The client-provider relationship is important in creating a climate that encourages and supports adherence.

- Whenever possible, the same provider should see the child and family on each medical visit. Strategies that support a family in managing the child's complex regimen are based on trust, respect and collaboration. Building a trusting relationship includes working on communication and active listening.
- Being available and accessible to families becomes increasingly important as the medical regimen becomes more complex. A provider's commitment to follow up new regimens or a change in medications with phone calls and/or home visits may make the difference between success and non-adherence.
- Build a trusting relationship with a family of different cultural background by asking about a family's beliefs concerning medications and treatment, their cultural context, and family decision-making. This includes learning how decisions are made within the family and who makes them regarding medical treatment for the child. Providers who are culturally competent strive to understand the meaning of the client's perspective and advocate for policies or protocols that fit the context of the client's culture.
- Be aware and sensitive to your own culture as a provider (including the medical culture) and how your biases and values impact others. Within this framework, a provider can respect differences, share his/her own perspective, make recommendations for the child's therapy, and negotiate, offering alternatives to the family.
- Devise follow-up plans that focus on both short and long-term support for adherence. Adherence studies in adults have pointed to two critical time points for adherence: in the first week after a new regimen or change, and several months into therapy, when the long-term perspective of adherence becomes a heavy burden.

Other Supportive Strategies

Maintaining secrecy about an HIV diagnosis often makes adherence to ART difficult for individuals and families. If only one person in the family knows about the diagnosis, medications cannot be stored openly or taken in front of other family members. It is important that both providers and families recognize that disclosure is a process.

Supporting the family in disclosing to the uncooperative child, who cannot understand why he/she has to take medicines, may help family adherence. Disclosure to other family members or to peers may provide a supportive person to give medications to the child and/or to encourage the family to continue.

Many families are reluctant to disclose the child's diagnosis to school personnel because of fear that the child will be treated badly. However, a school nurse can be an important ally and an additional member of the child's care team. She/he can administer a mid-day dose of medications, making a three-times-a-day regimen possible.

Other referrals to support or correct adherence problems should include visiting nurses, home health aides, substance abuse treatment and mental health services. Other support or referrals may include child life specialists, social workers and daycare or after school programs, again respecting the family's decisions about maintaining confidentiality about the child's HIV diagnosis.

Pharmacists can be a key resource to families and the healthcare team. They can review medication profiles, discuss potential interactions, and provide medication consultation. They can also be an important support and source of information for the family, reinforcing instructions and masking the taste of unpalatable medications.

ASSESSING FAMILY ADHERENCE

What have we learned about adherence assessment from the literature?

The literature continues to reinforce the concept that no single method for assessing adherence is ideal and that multiple methods or at least two or more assessment techniques are needed.

Self report: The most common method of adherence assessment has been self-report of family/caregivers for young children, or of the older child or adolescent. The time frame for recall of medications or doses missed reported ranges from the previous two days, three days, one week, "since the last visit", and in an adolescent study, in the previous month. Some assessments have asked caregivers to name or describe medications as well. Several studies of adherence in clinical trails have utilized a standardized assessment tool that asks for recall of missed doses in the previous three days (Van Dyke et al. 2002; Farley et al. 2003) and previous week (Gibb et al. 2003). Dolezal, Mellins, Brackis-Cott & Abrams (2003) compared children's report to that of their caregivers. This study found low levels of agreement over the number of doses missed in the last two days, particularly in older children with responsibility for their own medications. This study was unable to identify whether the child or the caregiver's report was most reliable as no objective measure of actual adherence, such as electronic monitoring pill caps, was used. The authors recommend using more than one source for self-report.

Multiple measures of assessing adherence: Several studies have compared multiple measures. Farley et al. (2003) compared adherence using the Medication Event Monitoring System (MEMS caps), record of pharmacy refills, provider assessment, caregiver self-report (via the PACTG Pediatric Adherence Questionnaire) and appointment keeping. They found the best correlation to optimal viral suppression was with the combination of MEMS caps (although expensive and problematic) and pharmacy refill. Provider assessment and appointment keeping was also associated with virologic response. Caregiver self-report was not reliable in this study. Steele et al. (2001) examined the role of caregiver beliefs in adherence to ART in children, utilizing pill counts, caregiver reports and electronic medication caps and found that adherence was very different for each measure. Caregivers report of adherence (94%) and pill count (90%) indicated excellent adherence, while electronic pill cap measurement indicated poor adherence (45%). The study failed to find significant associations between measures of adherence and parents' perceptions of the vulnerability of their children or perceived barriers to adherence.

Working with the Family

Assessing how families are managing medications should be part of every clinic and home visit. It is an important part of treatment and can build trust and good provider-client communication. However, families may view on-going questions about "adherence" and efforts to develop adherence interventions as a "punishment" for non-adherence. Rather than focusing so much on adherence and non-adherence, identify family strengths and work with families in addressing treatment-related behaviors and family environmental conditions, rather than blaming the caregivers (and non-adherence) for rises in viral load. Early on, when first discussing antiretroviral therapy and the importance of adherence, ask the family how they would like you to assess adherence so that their child can get the very best benefit from their medications.

In the first several months of antiretroviral therapy, and after regimens have changed:

- Do not assume a family understands the child's medication or regimen.
- Tell families you will ask about how they are managing medications and be sure to do it.
- Ask for name, dose, time and reason for each medication.
- Display posters of medications in the office or clinic and use these to aid assessment.
- Review prescription medications brought to the medical visit. If possible, develop a system for monitoring prescription refills.
- Have the caregiver demonstrate drawing up liquid medications when there is possible confusion about the dose.
- Ask specific, but open-ended questions such as, "Tell me how you are giving the bedtime doses." Research has demonstrated that recall of recent events can be accurate.
- Ask about missed doses. For example, ask: "How many doses did Billy miss yesterday…in the last 3 days?"

Home visits can be very helpful in assessing family adherence. If planned around medication time, a great deal can be learned about how the family is coping with the regimen. Families are more relaxed in their own environment and are able to learn, discuss problems and identify possible solutions.

Perfect adherence is very difficult for anyone. Give permission for honesty by saying things such as: "Many families have trouble giving all the doses. Tell me how you are managing the medicines." This may help overcome the issue of social desirability — families telling you what you want to hear. Some families may also feel guilty if they have missed medication doses, especially since adherence is stressed as being so important. In particular, families who have a history with the child welfare system may fear losing their child if they admit to missed medication doses. Remember that the goals of assessment are to identify problems, provide support and help the family problem-solve.

Assessing Adherence in the Adolescent

Many adolescents **will** tell you what you want to hear, even if it is not the truth. They may not want you to be "mad" if you hear that they have been non-adherent. It is important to let adolescents know that you are concerned about them and that you want them to tell the truth, even if it is not what you want to hear. It is important to avoid blame and to use a problem-solving approach. For example, when an adolescent reports perfect adherence in the face of rising viral load levels, missed prescription refills and other indicators, he/she needs to be confronted matter-of-factly. You might say: "Do you want to rethink that answer so we can figure out what is going on? I have some information here that doesn't match."

Adolescents with HIV infection who were infected perinatally and are long-term survivors, in care for many years, may always have had a parent or other family member present during medical visits. As children get older, it is important to allow them some privacy and time away from the parent during the medical visit. Helping families to understand the need for privacy for youth is an important developmental intervention. Talking with adolescents about their goals (and about making goals) and how treatment and adherence fit into these goals is an important intervention for youth.

Assessment Methods

Adherence assessment methods may include:

- Self-report – most often used in clinical settings
- Direct observations – most often used
- Viral load level response
- Verifying prescription refills
- Pill counts/bottle checks
- Diaries

However, these assessment methods do not take into account other factors that may contribute to treatment effectiveness or failure such as:

- Strain of virus
- Immune functioning
- Resistance
- Concomitant viral or bacterial infections
- Poor or altered absorption of medications

Each method used to assess medication adherence has limitations. Some examples: the true self-report of a parent who states that she faithfully gives every dose of a medication to her school age child (who spits the pills out as soon as mom leaves the room); the discarding of untaken pills from the bottle prior to a pill count; electronic caps unavailable for liquid medication and inaccurate if multi-dose/multi-day pill organizers are used.

SUMMARY

Adherence to any long-term medication regimen is difficult for most individuals. While the issues of medication adherence for children, youth and families are complex and challenging, successful adherence is possible through the collaborative efforts of providers, families and their support networks. Interventions to support adherence should be tailored to meet the individual youth, child and family's needs and include a routine assessment at regular intervals.

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