Nonadherence With Pediatric Human Immunodeficiency Virus Therapy as Medical Neglect

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ABSTRACT. Objective. To examine the results of an interventionist approach applied to human immunodeficiency virus (HIV)-infected children for whom caregiver nonadherence was suspected as the cause of treatment failure.

Methods. The medical records of a cohort of 16 perinatally HIV-infected children whose care was managed at the Arkansas Children’s Hospital Pediatric HIV Clinic for an uninterrupted period of ≥3 years were reviewed through July 2003. Data collected included date of birth, dates of and explanations for clinic visits and hospitalizations, dates of laboratory evaluations, CD4+ T cell percentages, plasma HIV-1 RNA levels, antiretroviral medications, viral resistance tests (eg, phenotype and genotype), and physician-initiated interventions to enhance adherence to the medication regimen. A stepwise interventionist approach was undertaken when patients continued to demonstrate high viral loads, despite documented viral sensitivity to the medication regimen and caregivers’ insistence that medications were being administered regularly. Step 1 was prescribing a home health nurse referral, step 2 was administering directly observed therapy (DOT) while the patient was hospitalized for 4 days, and step 3 was submitting a physician-initiated medical neglect report to the Arkansas Department of Human Services.

Results. The results for 6 patients for whom this stepwise approach was initiated are reported. Home health nurse referrals failed to result in sustained improvements in adherence in all 6 cases. Viral load assays performed before and after DOT provided an objective measure of the effect of adherence, with 12 hospitalizations resulting in a mean ± SD decrease in HIV RNA levels of 1.09 ± 0.5 log₁₀ copies per mL, with a range of 0.6 to 2.1 log₁₀ copies per mL. Four families responded to DOT hospitalization, and sustained decreases in the respective patients’ viral loads were noted. In 2 cases, medical neglect reports were submitted when DOT did not result in improved adherence. These patients were eventually placed in foster care, with subsequent improvements in their viral loads and CD4+ T cell percentages.

Conclusions. Nonadherence with antiretroviral therapy can be established on the basis of persistently elevated HIV RNA levels that decrease with DOT. Nonadherence poses a danger to the child that is grave and potentially irreversible. Caregivers should be offered all available resources to help them adhere to a sound treatment plan. In cases of demonstrated inability to provide needed care, it is necessary to consider seeking child protection, even for apparently healthy children. Pediatrics 2004;114:e346–e353. URL: http://www.pediatrics.org/cgi/content/full/114/3/e346; adherence, HIV, pediatric, neglect.

ABBREVIATIONS. HAART, highly active antiretroviral therapy; HIV, human immunodeficiency virus; HHN, home health nurse; DOT, directly observed therapy; DHS, Department of Human Services.

Highly active antiretroviral therapy (HAART) is effective in suppressing human immunodeficiency virus (HIV) replication, preventing opportunistic infections, reducing mortality rates, and improving the well-being of children and adults with HIV infection.1–4 Stepwise reductions in morbidity and mortality rates occur with increased intensity of antiretroviral therapy (particularly protease inhibitors).5 Inadequate suppression of HIV RNA replication by HAART can result from several problems, including 1) low potency of the antiviral regimen, 2) viral resistance, 3) inadequate drug exposure, and 4) poor adherence to therapy.6 Nonadherence is a leading cause of treatment failure.7–9 Incomplete suppression of HIV RNA replication in the presence of antiretroviral medications can select for resistant strains of virus, compromising future therapeutic regimens.

Although HAART has had tremendous effects on improving morbidity profiles, reducing mortality rates, and delaying death among HIV-infected children,10,11 some potential side effects of treatment are not benign; these include lipodystrophy, hyperlipidemia with associated diabetes mellitus and cardiovascular complications, lactic acidosis, and mitochondrial toxicity.12–15 The Centers for Disease Control and Prevention and the Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children acknowledge controversy regarding the treatment of asymptomatic infants and children and of children with mild or moderately advanced disease, in light of potential short-term and long-term side effects.16 The group currently recommends treatment for children <12 months of age for whom the CD4+ T cell percentage is <25%, regardless of the viral load, with the stipulation that...
many experts recommend therapy for all children <12 months of age, because HIV infection progresses more rapidly among infants. Treatment is also recommended for children >1 year of age for whom the CD4+ T cell percentage is <15%, regardless of the viral load, and treatment should be considered if the CD4+ T cell percentage is 15% to 25% or if the viral load is >100 000 HIV RNA copies per mL, with many experts recommending therapy at viral loads of >50 000 HIV RNA copies per mL. Therefore, according to national and international authorities, the potential benefits of HAART outweigh the potential side effects.

If a pediatric patient is not responding to therapy and problems intrinsic to the medication regimen are ruled out, then nonadherence by the caregiver must be suspected. Interventions to encourage adherence include education, counseling, behavioral contracts, electronic pill monitors, simplified medication regimens, gastrostomy tube placement, and home health nurse (HHN) visits.17-19 Since the late 1980s, 25 perinatally HIV-infected children, on average, have been cared for in the Pediatric HIV Clinic at Arkansas Children’s Hospital, and many have been monitored for extended periods. Of this small cohort, 6 patients continued to exhibit high viral loads, despite documented viral sensitivity to the medication regimen and the caregivers’ insistence that medications were being administered regularly. For these patients, more intensive strategies were used to ensure adherence, including HHN referrals, brief hospitalizations for directly observed therapy (DOT), and, in 2 cases, medical neglect reports that resulted in placement of the child in foster care.

This is a retrospective analysis examining the attempts to improve the outcomes of 6 perinatally HIV-infected children whose therapy was failing, on the basis of elevated HIV RNA levels. There are currently no reports in the medical literature that document the medicolegal responsibilities of health care professionals who provide primary medical care to HIV-infected children. The objective of this article is to report the interventionist approach used in the Pediatric HIV Clinic at Arkansas Children’s Hospital, so that others faced with similar patient situations may benefit.

METHODS

Subjects

The medical records of all perinatally HIV-infected children monitored in the Pediatric HIV Clinic at Arkansas Children’s Hospital were reviewed retrospectively. Data collected from each patient’s record and entered into an Excel (Microsoft, Redmond, WA) spreadsheet included date of birth, dates of and explanations for clinic visits and hospitalizations, dates of laboratory evaluations, CD4+ T cell percentages, HIV-1 RNA levels, antiretroviral medications, viral resistance tests (eg, phenotype and genotype), and physician-initiated interventions to enhance adherence to the medication regimen. Interventions recorded included HHN referrals, hospitalizations for DOT and intensive education, and medical neglect reports. This study was reviewed and approved by the University of Arkansas for Medical Sciences Human Research Advisory Committee.

For this study, we selected from the larger population 6 patients for whom physicians intervened because of suspicions that caregivers were being nonadherent with the treatment regimen. In each case, there were 1) viral genotype and/or phenotype findings that indicated viral sensitivity to the patient’s medication regimen, 2) evidence of treatment failure, as indicated by HIV-1 RNA levels of >4 log10 copies per mL in 2 consecutive laboratory evaluations, and 3) caregiver insistence that medications were being administered regularly. The criterion and threshold for increased viral loads of >4 log10 HIV RNA copies per mL were chosen because of 1) robust evidence in the medical literature that HAART results in an expected decrease in the viral load with time, with a decrease to <50 HIV RNA copies per mL expected after 4 to 8 weeks of therapy20,21 and 2) the 2002 recommendations for HAART for asymptomatic patients with viral loads of >4.7 log10 HIV RNA copies per mL, regardless of the CD4+ T cell counts.22

All of our patients received HAART (>2 nucleoside analog reverse transcriptase inhibitors and ≤1 protease inhibitor or nonnucleoside reverse transcriptase inhibitor) since its availability. Patients were scheduled for clinic and laboratory evaluations at least every 3 months, with more frequent visits scheduled at the physician’s discretion. At each clinic visit, the patient’s medication regimen and its effects on the lifestyles of the patient and the caregiver were discussed. Written instructions for medication administration were frequently reviewed with the caregiver, and suggestions were made to enhance adherence. Refrigerator calendars listing the daily medicines and pillboxes, when appropriate, were frequently given to caregivers as reminders. Every effort was made to prescribe the most palatable and convenient regimen possible, with gastrostomy tube placement if caregivers indicated that patient medication administration was a significant barrier to adherence with the regimen.

Physician-Initiated Interventions

When nonadherence was suspected, physicians intervened with a stepwise approach. Step 1 entailed providing a HHN referral for the patient, which consisted of nursing visits at the patient’s home at least 2 times per week for at least 2 weeks. Nurses were instructed to monitor the child’s health status, to provide emotional support to the patient and family, to familiarize the caregivers with the medication regimens with the primary caregivers, and to monitor caregiver administration of prescribed antiretroviral drugs to the patient. The nurses had pediatric training but no special training in HIV or HIV management. If the patient’s viral load continued to be high despite HHN visits, step 2 was initiated.

Step 2 was to administer DOT while the patient was hospitalized for 4 days. Viral load measurements were performed within 2 weeks of admission and on day 4 of hospitalization, before discharge. During the hospital stay, patients and caregivers received education from physicians, nurses, the HIV pharmacologist, and the HIV social worker. A clinic visit was scheduled approximately 2 weeks after hospital discharge. If hospitalization resulted in a marked decrease in the patient’s viral load, then this indication of nonadherence was discussed at length with the caregivers, and education and encouragement were again provided.

Step 3 entailed submitting a physician-initiated medical neglect report to the Arkansas Department of Human Services (DHS). The HIV treatment team made a report of medical neglect when it became clear that the caregiver was not going to be adherent with therapy, despite efforts made in steps 1 and 2, as described above. Medical neglect was strongly suspected when the patient’s viral load rebounded and remained elevated after a marked decline was observed during DOT. The HIV team physicians, nurses, and social worker were available for legal testimony regarding the need for foster care placement because of apparent medical neglect of the patient by the caregiver.

Data Analysis

Excel version 4 spreadsheets were imported into SPSS version 6.14 (SPSS, Inc, Chicago, IL). For purposes of calculation, HIV-1 RNA values reported in the Excel file as less than some amount were changed in the SPSS file to 1 less than that amount. For example, a viral load determined via a standard reverse transcriptase-polymerase chain reaction assay was reported as <400 HIV-1 RNA copies per mL and a viral load determined via an ultrasensitive reverse transcriptase-polymerase chain reaction assay was reported as <50 HIV-1 RNA copies per mL; in our Excel file, these values were reported as 399 HIV-1 RNA copies per mL and 49 HIV-1 RNA copies per mL, respectively. Viral loads of...
\[ \geq 750 \ 000 \text{ HIV-1 RNA copies per mL were reported as 1 000 000 HIV-1 RNA copies per mL. To analyze the effects of a specific intervention on adherence, viral loads and CD4+ T cell percentages recorded before the intervention were compared with those recorded after the intervention, up through the time of the next intervention, by using Student’s t test when conditions of normality and equal variance were met; otherwise, the Mann-Whitney rank sum test was used for comparison. The values obtained at the time of discharge from the intervention were not included in either of these groups. To analyze the acute effects of hospitalization for DOT on the patient’s viral load, paired Student’s t test was used to compare the patient’s viral load (log_{10} HIV-1 RNA copies per milliliter) recorded at the last clinic visit before hospitalization for DOT with that recorded at the time of discharge. Values of } P < .05 \text{ were considered statistically significant.}

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RESULTS

Records of 16 perinatally HIV-infected children whose care was managed at the Arkansas Children’s Hospital Pediatric HIV Clinic for an uninterrupted period of \( \geq 3 \) years were reviewed through July 2003. Ten patients have been maintained for an average of 6 years (range: 4–9 years) on 1 or 2 HAART regimens, with low viral loads (<3 log_{10} HIV RNA copies per mL) and good general health. For 6 patients, viral loads remained elevated, despite documented sensitivity to the drug regimens and insistence by the caregivers that medications were administered regularly. These patients received referrals and hospitalizations for DOT. Figure 1 demonstrates the effects of the interventions on each patient’s viral load and CD4+ T cell percentages.

All 6 patients sustained high levels of HIV-1 RNA for several years, despite the primary caregivers’ insistence that medications were being administered regularly. The caregiver for patient 1 requested that the child undergo gastrostomy tube placement when the child was 7 years of age, after the caregiver admitted to having difficulty administering some of the patient’s medicines. Signs of treatment failure continued despite a functioning gastrostomy tube. For patients 1, 2, 5, and 6, viral loads observed at the end of HHN referrals were not significantly different from those noted in the previous months. However, hospitalizations for DOT resulted in a dramatic decrease (>0.7 log_{10} HIV-1 RNA copies per mL) in each child’s viral load (mean ± SD decrease: 1.0 ± 2.0 log_{10} HIV-1 RNA copies per mL; range: 0.7–1.3 log_{10} HIV-1 RNA copies per mL). After 2 DOT hospitalizations and after being informed that a medical neglect report would be made if evidence for nonadherence with the regimen continued, the caregivers of patients 1 and 2 responded; although the patients’ viral loads have fluctuated, they remain at <30 000 HIV-1 RNA copies per mL (<4.5 log_{10} HIV-1 RNA copies per mL). In addition, the CD4+ T cell percentage for patient 1 increased from a median of 1% before DOT to a median of 22% after DOT (\( P < .001 \)) (Fig 1), and the child’s general health has markedly improved; symptoms of heart failure have resolved, and the patient has progressed from being wheelchair- and home-bound to walking with a walker and attending school. The median CD4+ T cell percentage for patient 2 increased from 11% before DOT to 19.5% after DOT (\( P < .001 \)). The caregivers of patients 5 and 6 responded after 1 DOT hospitalization with increased adherence, as evidenced by sustained decreases in both patients’ viral loads (Fig 1). The median CD4+ T cell percentages before and after DOT were not different for patient 5 (20% and 19%, respectively). For patient 6, a significant increase in the median CD4+ T cell percentage was noted after DOT (before DOT: 23%; after DOT: 30%; \( P < .001 \)). A comparison of the viral loads for these 4 patients in the months before DOT and after DOT revealed that all 4 patients experienced decreases of \( \geq 0.7 \) log_{10} HIV-1 RNA copies per mL, with a range of 0.7 to 1.3 log_{10} HIV-1 RNA copies per mL (\( P < .001 \) in each case).

Patient 3 experienced a complicated course. The child’s primary caregivers were the mother and the maternal grandmother, who lived in separate households in the same small town. Both stated that they administered medications to the child regularly and missed very few doses. However, the child had persistently elevated viral loads, and the CD4+ T cell percentages by the age of 2 were persistently <5% (Fig 1). The maternal grandmother remarked that the child had intermittent loose stools; therefore, different medication regimens were tried in attempts to overcome possible gastrointestinal absorption problems. When the child was almost 2 years of age, a HHN referral was made, which resulted in a decrease in viral load of 0.8 log_{10} HIV-1 RNA copies per mL. The nurses reported that the mother and grandmother administered the medications correctly when the nurses were able to observe them, but the nurses also reported extreme difficulties with ongoing follow-up monitoring because of the caregivers’ frequent absence from the home. The child’s HIV-1 RNA levels rebounded after discharge from HHN care, and the child was noted to have developed high phenotypic resistance to 1 of the medications in the regimen. On the basis of the phenotype, the regimen was changed when the child was 2.5 years of age; at the request of the mother and maternal grandmother, a gastrostomy tube was placed to allow easier medication administration. The viral load decreased dramatically, by 1.4 log_{10} HIV-1 RNA copies per mL, during the brief hospitalization for gastrostomy tube placement. However, the viral burden rapidly increased after the patient returned home. Boosted saquinavir therapy was instituted to allow twice-daily administration, and a subsequent hospitalization for DOT resulted in a significant decrease in the patient’s viral load, of 1.3 log_{10} HIV-1 RNA copies per mL. However, after the patient returned home again, the viral load rebounded to pre-DOT levels.

A medical neglect report was made to the Arkansas DHS. Despite our recommendations for foster care placement, the attorney from DHS recommended that the mother and maternal grandmother continue as the caregivers, with directives for HHN staff members to provide extensive assistance to the family. Although the viral load did not increase to 6 log_{10} HIV-1 RNA copies per mL, as had been seen before HHN involvement, it slowly increased in the next 6 months, and the child was again admitted for DOT. Interestingly, during the time of intensive
HHN intervention, despite increasingly elevated HIV-1 RNA levels, there was a steady increase in the CD4\(^+\) T cell percentage from 3% to 8%. A 4-day hospitalization for DOT resulted in a decrease in viral load of 0.6 log_{10} HIV-1 RNA copies per mL. After the patient returned home, however, the HIV-1 RNA level returned to its pre-DOT value, and the child was subsequently placed in foster care (Fig 1). By that time, multiple resistance mutations to all classes of medications had developed; when the patient’s HIV-1 RNA level remained unchanged after 6 weeks in foster care, the DHS attorney dismissed the case and recommended that the child be returned to his mother. We appealed to the chief attorney at DHS, and the case was reopened. It was actually the mother’s attorney who recommended to the judge that the child remain in foster care. The paternal grandparents requested that they be named as the primary caregivers and, after their request was approved by DHS, the child was placed in their home. The paternal grandparents were to be solely responsible for medication administration, with the mother having limited visitation rights. This recommendation was based on evidence of maternal nonadher-

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**Fig 1.** HIV RNA levels (log_{10} copies per milliliter) and CD4\(^+\) T cell percentages detected over time among perinatally HIV-infected patients monitored in the Arkansas Children’s Hospital Pediatric HIV Clinic for whom interventions were undertaken to improve adherence. Black circles represent values obtained when the child was living with the primary caregiver, gray circles represent values obtained at the end of a HHN referral, open circles represent values obtained at the end of hospitalization for DOT, and squares represent values obtained while the child was living in foster care.
ence, including decreases in the patient’s viral load with past DOT hospitalizations and the recent increase in the patient’s CD4+ T cell percentage while in foster care. The child’s regimen was changed on the basis of viral phenotype testing performed during the foster care placement, although a regimen without resistance was no longer feasible. The CD4+ T cell percentage increased to 18% and the viral load decreased by 0.9 log10 HIV-1 RNA copies per mL after 5 months. When the child’s HIV-1 RNA levels in the months before DOT were compared with those after DOT, no statistically significant difference was seen (5.65 ± 0.5 log10 HIV-1 RNA copies per mL vs 5.43 ± 0.5 log10 HIV-1 RNA copies per mL, P = .36).

Patient 4 maintained elevated HIV-1 RNA levels and decreasing CD4+ T cell counts despite the mother’s insistence that medications were being administered regularly (Fig 1). A HHN referral was unsuccessful; the mother demonstrated hostility toward the nursing staff and on occasion would not allow the nurses to enter her home. The child was admitted to the hospital for DOT at 8 years 9 months of age. A dramatic decline of 2.1 log10 HIV-1 RNA copies per mL during hospitalization was followed by a rebound to pre-DOT levels in follow-up monitoring. The caregiver failed to keep multiple appointments and repeatedly provided false information regarding filling the child’s prescriptions at the hospital pharmacy. Therefore, after 1 hospitalization for DOT, a medical neglect report was made, and the authorities
placed the child in foster care. An immediate decrease to ≤50 HIV-1 RNA copies per mL was maintained while the child was in foster care, with a coincident increase in the patient’s percentage of CD4+ T cells (8% at entry into foster care and 16% at discharge). The mother regained custody when the child was 10 years of age. The child’s HIV-1 RNA levels increased rapidly and the CD4+ T cell percentage decreased. Although a HHN referral when the child was 10 years 6 months of age resulted in a decrease in the HIV-1 RNA level (−1.1 log10 RNA copies per mL), nurses refused to continue to see the patient because of the mother’s uncooperativeness. As a result, foster care was reinstated (Fig 1). The child’s viral RNA level has been maintained at ≤50 HIV-1 RNA copies per mL except for the months, when the child was 11 to 12 years of age, when the courts allowed weekend visits of the child with the mother.

DISCUSSION

The complexity of HAART, with multiple medications, formulations, and dosing intervals, makes adherence challenging. Despite these challenges, the majority of our pediatric HIV patients’ caregivers are able to remain adherent, and the patients’ regimens have remained effective for many years. However, in this relatively small cohort, 6 patients exhibited sustained elevated viral loads, despite documented viral sensitivity to the drug regimen and the caregivers’ insistence that medications were being administered regularly. In an attempt to provide standard-of-care medical therapy to these perinatally HIV-infected children, an aggressive interventionist approach was taken.

In all 6 cases, HHN referrals failed to result in sustained improvements in adherence. Five of the 6 families cooperated with the visiting nurses. Many of the nurses had no specialized training in HIV therapy, however, and frequently did not directly observe medication administration by the caregivers to the children. Logistic problems were the primary reason this intervention repeatedly failed. The primary caregivers changed residences frequently and often were absent from the home at the time of the scheduled visit or insisted that medicines had already been given. The failure of HHN visits to increase caregiver adherence has also been documented for patients with asthma.23

Three studies noted associations between reported adherence and virologic responses among children.7,24,25 For the 6 patients described here, the caregivers and the children reported adherence but positive responses to HAART were not seen, despite viral sensitivity. For these patients, hospitalization for DOT was very effective for assessment of adherence. Twelve 4-day hospitalizations for DOT were undertaken, resulting in a mean ± SD decrease of 1.09 ± 0.5 log10 HIV-1 RNA copies per mL (P < .001), with a range of 0.6 to 2.1 log10 HIV-1 RNA copies per mL. Extensive education took place during DOT hospitalization. Viral load assays performed before and after DOT provided an objective measure of the effect of adherence. These data were used to show the family that therapy not only is effective but also is essential to the well-being of the child with HIV. In 3 of 4 cases in which the families responded with increased adherence after DOT, the median CD4+ T cell percentages increased significantly after hospitalization, indicating positive immunologic and virologic responses.

In 2 cases, the families did not respond with improved adherence after hospitalization for DOT. As a result, patients 3 and 4 were eventually placed in foster care, with subsequent improvements in their HIV-1 RNA levels and CD4+ T cell percentages. Unfortunately, viral resistance mutations that had developed for patient 3 rendered multiple medications ineffective. Possible factors that might have contributed to the development of resistance mutations for patient 3 included our delay in pursuing DOT in the presence of extremely high patient viral loads (multiple examinations during the first 2 years of life revealed HIV-1 RNA levels of >750 000 copies per mL) and partial nonadherence, rather than complete nonadherence, during prolonged HHN intervention.

For patients with elevated viral loads, early hospitalization for DOT should be pursued when viral resistance testing indicates sensitivity to the medication regimen. This intervention allows relatively rapid determination of nonadherence as the most probable cause for treatment failure. The patient’s viral load will not decrease with hospitalization if problems with the regimen (eg, poor bioavailability or decreased viral sensitivity) are contributing to treatment failure. Two hospitalizations for DOT give the caregivers ample opportunity to develop an understanding of and respond positively to treatment recommendations. It is important to note that the child’s clinical condition is not considered in our approach, because a child with HIV may appear quite healthy despite the presence of a significantly elevated viral load and an associated increased risk of developing acquired immunodeficiency syndrome or dying.26

Physicians and staff members are obligated to report suspected medical neglect. Repeated failure to adhere to health care recommendations is appropriately considered a form of neglect.27 Standards for neglect are less clearly defined than those for abuse (which refer to specific medical findings such as multiple unexplained fractures or retinal hemorrhage) and are still evolving. We think that those evolving standards should include parental inaction of the kind described in this report. Current antiretroviral therapy can significantly, perhaps even indefinitely, delay the onset of clinical symptoms and, with proper adherence, can prolong the life of infected individuals.1,2,9,28 In its policy statement on Religious Objections to Medical Care, the American Academy of Pediatrics states, ‘‘The AAP believes that all children deserve effective medical treatment that is likely to prevent substantial harm or suffering or death.”29 Because failure to adhere to the HIV treatment regimen is life-threatening, we think it should be considered medical neglect. When the probable outcome of neglect is death, there is a compelling...
argument for taking legal, if not physical, custody of the child.

Reporting parents for medical neglect because of nonadherence is not unprecedented. Published cases involved children with asthma, eating disorders, diabetes mellitus, and HIV infection. Clearly, there may not be malice on the part of a caregiver who medically neglects a child, making the decision to report the case very difficult for the clinician. If the final result is a dead or permanently damaged child, however, then the potential risk of psychologic difficulties with an out-of-home placement is more acceptable. When the home environment fails to meet the child’s basic needs, foster care can potentially improve the child’s functional outcome. Favorable and stimulating environments for infants and young children decrease the adverse effects of prior negative environments.

The Arkansas Child Maltreatment Act requires the immediate reporting of medical neglect by a caregiver when there is reasonable cause to suspect that it has occurred, and it is a criminal offense for medical personnel to willfully fail to make a report. The laws in other states are likely to be similar, and it is important that medical workers familiarize themselves with the statutes that relate directly to their duties. Physician-initiated intervention is an effort to identify nonadherence and to correct potential causes through education and encouragement, before the nonadherence reaches a level that might reasonably be suspected to constitute medical neglect.

Every reasonable effort should be made to help caregivers overcome barriers to providing proper treatment for their children. Special care should be taken to ensure that caregivers of children with HIV infection have been afforded all available assistance. These caregivers often are social victims themselves and almost always have HIV infection. As a result, they may have HIV dementia or secondary psychologic problems, such as depression, that limit their abilities to manage not only their own illness but also their child’s illness. All of these barriers to adherence with a child’s treatment regimen must be explored and corrected by the medical team or, when necessary, by state agencies. When educational and social assistance fails, however, it is in the child’s best interest that others seek to remove custody from the recalcitrant caregiver.

CONCLUSIONS

Nonadherence to antiretroviral therapy can be established on the basis of persistently elevated HIV RNA levels, which decrease with DOT. Nonadherence poses a danger to the child that is grave and potentially irreversible, and there is a theoretical danger to other members of society as this child matures. Caregivers should be offered all available resources to help them adhere to a sound treatment plan. In cases of demonstrated inability to provide needed care, it is necessary to consider seeking child protection, even for apparently healthy children. It is vital that we, as specialists in children’s health care, educate the courts and protective services about these issues and convince them that the harm of inadequately treated HIV infection may outweigh the potential harm of protective custody.

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REFERENCES

CMAJ. 1999;160(59–66)
JAMA. 1998;279:450–454
JAMA. 1997;277:874–875
JAMA. 2000;283:205–211
7. Watson DC, Farley J. Efficacy of and adherence to highly active antiretroviral therapy in children infected with human immunodeficiency virus type 1. 
8. Bangsberg DR, Perry S, Charlebois ED, et al. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. 
AIDS. 2001;15:1181–1183
New York City Pediatric Surveillance of Disease Consortium. 
Pediatr Infect Dis J. 2001;20:511–517
JAMA. 2000;284:190–197
AIDS Res Hum Retroviruses. 2001;17:1117–1123
17. McDonald HP, Garg AX, Haynes RB. Interventions to enhance patient adherence to medication prescriptions: scientific review. 
JAMA. 2002;288:2868–2879
JAMA. 2002;288:2880–2883


34. Arkansas statute of child neglect: definitions, §12-12-507(b)–(c).
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