Medical Treatment of Children with HIV Illness and the Need for Supportive Intervention: The Challenges for Medical Providers, Families, and the State

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ABSTRACT

Human immuno-deficiency virus (HIV) illness in children poses tremendous challenges to medical providers and families to work together to deliver optimal care. An alternative to filing "neglect" reports with the Department of Social Services is necessary to provide support and appropriate intervention to families and medical providers caring for HIV-positive children.

The creation of a neutral entity that could intervene and identify barriers to treatment and communication between the medical providers and the family would benefit all the parties involved. Knowledgeable mediators could help facilitate communication and identify appropriate support for the child and family.

Intervention would not be delayed until it is demonstrated that a child has been "neglected" or is at substantial risk of harm. Assistance could be made available without a finding that a parent was guilty of wrongdoing. Involving parents as full partners in medical decision making and monitoring would benefit children living with HIV now and in the future. The creation of an alternative process will also prove valuable in assisting providers and families caring for other medically at-risk children, e.g., children with asthma, diabetes, or mental illness.

riers to its success were not immediately recognized. However, after a couple of years of experience, the barriers have become clear.¹ HAART treatment holds out great promise for children with HIV illness. However, at the same time, it poses great challenges to families and providers because of the complexity and side effects of treatment and

I. The Problem: Barriers to Medical Treatment for HIV-Positive Children

AIDS is once again carving out new ground. When medical providers first began treating children with the new Highly Active Antiretroviral Therapy (HAART) regimen in 1997, it soon became apparent that an interdisciplinary approach to working with patients' families would be essential to assisting stressed families in dealing with this huge challenge. In the first year of treatment, medical providers were so happy to have a treatment that really seemed effective that all the potential bar-

riers to its success were not immediately recognized. However, after a couple of years of experience, the barriers have become clear.¹ HAART treatment holds out great promise for children with HIV illness. However, at the same time, it poses great challenges to families and providers because of the complexity and side effects of treatment and the need for unusually strict compliance to the medication regimen to avoid the later development of resistance.² This situation requires unusually good communication and trust between the child's physician and parent/caretaker.³ It involves complex decisions about when treatment

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should begin, and what treatment should be used. Most of the treatment is very new, and there is not yet data on long-term efficacy and side effects. And it demands all this in a setting where typically the patient and medical provider come from very different backgrounds. The majority of children with HIV are poor, African-American children living in the inner city. The majority of providers are affluent, White, and male.

As a result of their frustration in dealing with families who seem unwilling or unable to follow the necessary medication regimen to preserve their child's health, a number of physicians providing care for HIV-positive children have found it necessary to seek state intervention by filing neglect reports alleging that the child is not being given "proper care and attention." In some cases, the provider may be seeking removal of the child because the barriers the parent faces to providing adequate care seem insurmountable.⁴ More often, however, the provider really wants to find the necessary support to help the family be successful and avoid removal of the child. In a few cases, the provider may be trying to impose his view of essential treatment on a family that disagrees.

What is needed, and what physicians/social workers seek without success, is intervention to *prevent* "neglect" from occurring. Because state protective services systems typically focus on the issue of whether neglect has already occurred, i.e., is "indicated" or "substantiated," there is often no opportunity for preventive intervention.⁵ Voluntary intervention without the need for a "neglect" finding can and should be offered to families in crisis.

In addition, there is a need to empower families to be full participants in health care delivery to their medically fragile children. These families can help determine the optimal treatment for their children and future patients.

In the first appellate level decision addressing the issue of whether a parent may refuse to give her child HAART, the Supreme Court of Maine in 1998 found that such refusal was not neglect because of the still experimental nature of the treatments.⁶

The parent in that case clearly articulated her objection to the new treatments. Her older child had taken AZT and suffered numerous side effects until her death at the age of four. In most cases where medical neglect of an HIV-positive child is alleged, the unwillingness to comply is not so clearly articulated. Sometimes parents

or caretakers engage in passive resistance, indicating to a physician that they intend to follow the medical regimen, but then failing to do so effectively. This failure to comply may stem from a lack of conviction in the usefulness of the drug, a denial of the seriousness of the child's condition, a lack of trust in the medical professionals treating the child, or simply being overwhelmed by the day-to-day demands of caretaking. Other barriers to compliance include the parent's own illness, limited family support, the challenges of living in poverty, depression or drug or alcohol addiction, and the child's resistance to taking three types of drugs with often unpleasant or serious side effects.

A. Challenges Posed by Available Treatment for HIV Illness

Great progress has been made in the past three or four years in developing treatment for HIV illness that enables adults and children to remain healthier longer. New drug combinations are used to reduce the patient's viral load and protect the immune system from attack by the virus. The death rate from HIV has dropped dramatically as has the frequency of hospitalizations for people with HIV illness. However, the medication regimen is extremely demanding, e.g., three different drugs, two or three times a day, some to be taken with food, some without, etc. Many drugs are available only in capsules or tablets or awful-tasting liquids that are difficult to persuade children to take, especially two or three times a day. For the drugs to be and remain effective, the patient must be extremely compliant with the regimen. Anything less than 95% to 100% compliance will result in the drugs becoming less effective.⁷ In addition, and perhaps most important, being less than fully compliant will mean that the patient will develop resistance to one or more of these drugs (and the whole class of drugs to which this drug belongs), meaning that the drug will no longer work for the patient, dramatically reducing the patient's long-term treatment options.⁸

These drugs often have side effects that can interfere significantly with the patient's day-to-day sense of well being, including diarrhea, nausea, fatigue, neuropathy, etc. There is the possibility of serious long-term effects that are just beginning to be recognized, e.g., an elevation of cholesterol levels resulting in cardiac problems in some adult patients.⁹ And just within the last year, adults and

adolescents have died from side effects of medication, including lactic acidosis and pancreatitis.¹⁰

When HAART first became available for treatment of adults, physicians recommended a "hit hard, hit early" approach, hoping that the virus might be eliminated altogether by such treatment. As it has become apparent that this approach has not succeeded in eliminating the virus, and as it has become apparent that even the most compliant patient is likely eventually to develop resistance to one or more of these drugs, a new approach has emerged. The Department of Health and Human Services' (DHHS) recommendation for asymptomatic adults who are not AIDS-defined is that treatment should generally begin when the patient's cd-4 count is under 200 cells/ml. Treatment may be started with a cd-4 count in the 200-300 range, if their viral load is over 30,000 copies/ml.¹¹ This new recommendation takes into account the long-term side effects that may occur due to the toxic nature of these drugs, as well as the impact of day-to-day side effects (diarrhea, fatigue, etc.) on the patient's quality of life and willingness to maintain the treatment regimen.

Treatment recommendations for adolescents are the same as those for adults, but recommendations differ for younger children. Clinical trials are now in progress to identify optimal treatment protocols for adolescents. Immediate treatment is recommended for all children under one year of age because of the difficulty of determining which children are likely to be "fast progressors." In the average adult patient, HIV infection slowly wears down the immune system and major symptoms do not typically emerge until 10 years after the patient has been infected. Approximately 25% of infants, however, become critically ill within the first year in the absence of treatment. Treatment for older children is recommended if they are symptomatic, or if there is evidence of immune suppression, e.g., a low cd-4 count. For symptomatic children, treatment is also recommended, but can be deferred if risk for disease progression is low and other factors (e.g., concerns about the durability of response, adherence) favor postponing treatment.¹²

In 1998, the Centers for Disease Control published guidelines for HIV treatment for children recognizing this treatment as recommended therapy. There is data available showing the relationship between high viral load and risk of death in children.¹³

These new drugs have contributed significantly to the decline in illness and death suffered by HIV-positive children.¹⁴ However, the availability of bactrim and other prophylactic drugs to prevent some of the more serious opportunistic infections has also contributed to this trend. HAART can be very burdensome, with serious side effects to the extent that some adults choose not to accept or continue the treatment. In addition, many adult patients who have been most compliant with this treatment up to now are no longer able to take the new, more effective and palatable drugs as they come on the market because they have developed resistance based on their earlier acceptance of medication.¹⁵

As time goes on and physicians gain more experience with these medications, these recommendations are likely to continue to evolve. However, the above-described treatment is the current "standard of care." This treatment is experimental in the sense that long-term side effects and efficacy are not yet known. These drugs have been approved for children largely because of their demonstrated efficacy in adults over two or three years. Optimal dosing for children is in some cases still being determined. Clinical trials are now being conducted with children to ascertain the most optimal treatment regimen. All of this is in part a result of fast track approval by the FDA of new drugs for treatment of a terminal illness. Fast track approval was in large measure a response by the FDA to AIDS activists, e.g., ACT UP and others, who were desperately seeking a class of effective treatment in the early years of the epidemic. Fast track approval means that a drug is available to all patients before long-term efficacy and toxicity studies can be done.¹⁶ In effect, these studies are being conducted now with all patients who wish to participate.

This reality makes good communication and a trusting relationship between physician and child and family especially important in the context of HIV care.

B. Other Challenges Faced by Families Coping with HIV

Almost all the factors associated with poor medication compliance in children in other contexts are present in many families impacted by HIV.¹⁷

Often people diagnosed with HIV, or parents with a child diagnosed with HIV, are overwhelmed with a sense of powerlessness (especially when they first hear the

diagnosis) and believe nothing can be done. On the other hand, sometimes people who have been living with HIV for an extended period of time, but have experienced no symptoms, may be in denial about the seriousness of their condition. A parent or caretaker raising a child who seems perfectly healthy may resist the recommendation that she be administered drugs two or three times a day that often have unpleasant and potentially serious side effects, e.g. upset stomach, diarrhea, elevated cholesterol. The child feeling well will often understandably resist taking drugs that make her feel sick.

Most families impacted by HIV are poor and struggling simply to survive. They face incredible challenges: lack of income; unstable, dangerous (e.g., lead paint) housing; no transportation; disintegrating neighborhoods; poor, unsafe schools; no day care. HIV is only one issue these households face, and often it does not seem the most pressing one.¹⁸

Another barrier associated with HIV is fear of being stigmatized or mistreated if the illness is disclosed. Several studies have indicated that perceived social support for them and the treatment of their illness has a substantial impact on medication compliance in children. One of the major challenges posed by HIV is that often parents are concerned about disclosing the child's HIV status to the child. They are concerned not only about the impact of this knowledge on the child's sense of herself, but also about fear the child may disclose this information to friends in the neighborhood or children at school. Often they fear the reaction of the child's peers as well as the spread of this very personal information about both mother and child in the community or in the school setting. Because research has shown that both knowledge of his or her illness and perceived social support can have a major impact on children's compliance with medication regimens, the issue of disclosure must be addressed.¹⁹

Inadequate compliance with medication regimens is a major issue in health care generally, but it is particularly an issue with long-term or chronic illnesses. It is a challenge even for short-term treatment with antibiotics of ordinary childhood illnesses. In other contexts, such as treatment of heart disease, 80% compliance may be considered adequate. However, the HAART regimen is particularly demanding. To avoid development of drug resistance, a compliance rate of at least 95% is deemed

essential. This rate of compliance is seldom achieved in any context. This is another reason these families are so in need of support, and should not be judged "neglectful."

It is critically important that the drug regimen not be initiated until the family and the child are ready to wholeheartedly engage it. Compliance with the HAART regimen can be very challenging and wearing even to adult patients. The long-term side effects of the treatment are unknown, and research continues every day to find more effective and more palatable drugs. Children put on drugs available today may be precluded from using new and better drugs that come along in the future.²⁰ Parents or caretakers must be fully informed of the complex decisions that need to be made and engaged fully in the decision making process.

C. Communication Difficulty Between Medical Providers and Patients' Families

A common theme in the medical neglect cases in which we have been involved is an underlying distrust of the medical establishment that is recommending this treatment for their children. Parents fear, but do not always clearly articulate, that their children are part of an experimental treatment program. And in some ways, this is true, even for children not enrolled in an experimental protocol. The medical professionals treating these children are caring, dedicated people doing their best to deliver effective treatment. But long-term data on the efficacy of treatment and dangers of side effects are not yet available. Though the short-term efficacy of HAART has been demonstrated, the long-term effects are not yet known.

In addition, though medical providers generally feel they have spent more than enough time educating patients' families, the families often do not have even a basic understanding of HAART treatment. These families often do not feel that medical providers are responsive to their concerns and difficulties. This is true despite the fact that many pediatric HIV clinics have had some success in increasing compliance by including social workers, psychologists, nurses, and/or peer educators on staff. "Understanding the parents' major concerns and meeting their expectations from the medical visit are extremely important in achieving good patient compliance."²¹

"Patients who are dissatisfied with the way their

doctors explain their illnesses or treatments are less likely to adhere to their treatment than patients who are happy with the manner in which explanations are given."²² The inability of families and physicians to work together and develop mutual respect when caring for a seriously ill family member is, of course, not limited to the context of children with HIV illness.²³

In the cases in which we have been involved, the reasons for the neglect report varied dramatically, so the potential remedy also varied. In one case, the mother was depressed and feeling hopeless about her illness. She was struggling to extract herself from an abusive relationship. Her 8-year-old daughter resisted taking the prescribed medication. The doctors felt the mother's parenting skills were inadequate because she could not always succeed in getting her daughter to take the medication. However, our client proudly informed us that her daughter had received an award for perfect attendance at school. This did not fit with the picture of an inattentive, neglectful parent that had been presented to us. Clearly something else was going on.

In this case, the parent entered counseling for her depression, and mother and child met with a behavioral therapist to address difficulties with the drug regimen. However, the relationship between the physician and the parent was severely damaged by the neglect report. She removed her child from the HIV Clinic and took her elsewhere for treatment. She ended up at a medical provider who had much less expertise with HIV treatment.

The client doubted the efficacy of this drug regimen from the beginning and felt her choices were not adequately explained to her.

In another case, an HIV-positive pregnant woman sought our assistance when she feared her physician would take her to court to compel her to take AZT during her pregnancy and also to have AZT administered to her newborn at birth. She was highly educated in HIV care and had been dealing with her own illness for an extended period. She had taken AZT a couple of years prior, but stopped because she felt it was unhelpful and the side effects were troublesome. In recent months she had managed through her own efforts of reducing stress, watching her diet, and using herbal supplements to get her viral load down to an undetectable level without any medications. After discussing the situation with her, we consulted another physician who is an

expert in pediatric HIV care and issues of transmission from mother to child. This physician believed that she did not need to take AZT during her pregnancy because her viral load was undetectable and there would be no point in taking AZT or any other medication. He did recommend AZT just before and during the actual delivery process to provide as much protection for the newborn as possible. He also recommended AZT for the child at birth, but thought that the critical time to protect the child was during the delivery itself. We conveyed this information to our client. After discussion with a nurse from a similar cultural background whom she trusted, the client ultimately agreed to AZT just before and during the delivery process. She chose not to have AZT administered to her son after birth.

Of course, this case raises the additional question of whether a mother can be forced to take drugs for the benefit of the fetus, a different issue than what the parent can be forced to do with regard to health care for her child.²⁴ However, the underlying issue of patient/physician communication and trust is present. What this client really needed was the opportunity to get a second opinion. She wanted to be a partner in her health care, not simply to be told that she must follow whatever recommendations had been laid out. In fact, the compromise she was able to reach with her physician is now considered the standard of care in these cases.

An overarching issue that leads to difficulty in many of these situations is failure of communication between the medical provider and the patient's family. This failure may sometimes be attributable to differences in race, class, age, and cultural background that make trusting communication a challenge.²⁵ It can also be related to the physician's focus on treating the illness and lack of time/attention given to the family's concerns.

In a third case, medical providers reported a care provider for medical neglect when her two-year-old, Jessica, began to develop resistance to a variety of HAART medication. Ms. Robertson was a young African-American woman who found it very difficult to communicate with her child's physician. She volunteered to care for Jessica from birth, developed a strong bond with her, and was referred for assistance in adopting her. The medical providers believed that Ms. Robertson loved Jessica and was generally a good caregiver, but they felt she was immature and did not take seriously

the responsibility of medicating the child. However, Jessica, when first given these drugs at the age of 15 months, was sick every day for almost two weeks with vomiting and diarrhea. Thereafter, according to Ms. Robertson, the child frequently resisted attempts to administer medication. In the beginning, Ms. Robertson described her difficulty to the medical staff, who offered suggestions to help. But the child's unwillingness to participate continued. She refused to eat the foods that she believed contained the medication, would spit up the medication, etc. The Department of Social Services found the medical neglect report "indicated," but did not remove the child because they recognized that Ms. Robertson was otherwise a very good parent to the child. Medication compliance was the only issue, though a critical one.

Fortunately, Ms. Robertson was able to develop a good relationship with her child's case manager who helped to educate her about HIV and HIV medication in a way the medical staff had been unable to do. The case manager was an African-American woman who had social work training and was very knowledgeable about families and HIV. The case manager also identified that the primary issue affecting adherence to medication was the child's unwillingness to take medication, not the parent's willingness to administer it faithfully. She referred the client to a day care center for HIV-positive children, where the child was able to observe three-year-olds taking their medication and receiving positive reinforcement for doing so. In this supportive environment, she finally became a willing participant in her own health care.²⁶ Since the child's enrollment in this day care center, problems with adherence have disappeared.

In all three of these cases, the parent was an African-American woman and the physician with whom conflict arose was White. Two of the physicians were male, one was female. In each case, the impasse about treatment was resolved only after the parent developed a relationship with an attorney who helped give voice to her concerns, and she was connected to a social worker or medical provider she felt she could trust. In each case, connections were made with African-American women health care providers who were knowledgeable about HIV illness and related issues.

Our observations in practice are borne out by the study just released by the Institute of Medicine,

"Unequal Treatment: Confronting Racial and Ethnic Barriers in Health Care." The authors believe that overt, conscious discrimination in health care is rare, but they found significant differences in the quality of care received by people of color, particularly African Americans, even when economic factors are equal—e.g., type of health insurance.²⁷ Health care providers, like many people raised in the United States, are affected by the legacy of slavery, segregation, and racism. Health care providers may employ stereotyping, often in a subtle and even unconscious fashion that can impede optimal understanding of and communication with patients (Unequal Treatment, at 81, 82-86).

In addition, because of this same history of racism, segregation, and unequal treatment, as well as their own personal experience, many African Americans are less trusting of White physicians (14, 15).²⁸ Many African Americans have a significant skepticism toward the predominantly White male medical community. This stems, in part, perhaps from the syphilis studies conducted on African-American men in Alabama at Tuskegee. It also stems from the daily disparity in treatment that African Americans experience.²⁹

This history poses a tremendous challenge to health care providers seeking to provide quality care to the affected population. It requires tremendous sensitivity and dedication to overcome these barriers of trust created by the long history of racial segregation and discrimination in this country.

In addition, racial bias has been identified at all levels of the child welfare system, from the provider making the report to the caseworker investigating the report. African-American children are more likely to be found neglected and more likely to be removed from their families.³⁰ Medical providers are more likely to report drug use of African-American parents than White parents. For example, a study of women in Pinellas County, Fla., found little difference in substance abuse along either racial or economic lines. Yet, Black women were 72% more likely than White women to have their babies removed by protective services.³¹

II. Failure of Existing Legal Response

Historically, under common law, children were not viewed as individuals with rights separate from their parents. They were seen as the property of their parents, and

if a physician treated a child without the parent's consent, he could be found guilty of battery.³² Courts made an exception to this rule for emergency treatment. Eventually, courts turned to neglect statutes as a way to intervene when there was concern that a parent was not properly addressing a child's serious medical need.³³

A major problem with this approach is that intervention cannot take place unless there is a finding of neglect against the parent. Courts have no opportunity to examine the issue in a non-adversarial setting. The provider's goal is typically to persuade the court to order treatment over the parent's objection and/or remove the child from the parent's care.³⁴ The focus is shifted to whether the parent was guilty of neglect and shifted away from an even-handed analysis of the child's medical needs.

The way the CINA (Child in Need of Assistance) system is structured in most states, the Department of Social Services typically will not intervene in a child welfare situation unless there is an "indicated" finding of child neglect.

What this means in the context of compliance with HIV treatment is that typically the Department of Social Services will not intervene until the child has begun to develop resistance to one or more HIV medications. At that point, the child has potentially lost a whole of class of drugs that could have helped her stay healthy for years longer. Resistance typically develops due to a failure to strictly adhere to the medication regimen.

In addition, Department of Social Services protective services workers (and the courts) are typically not educated about the complexities and difficult decisions involved in the treatment of HIV illness. If the physician has recommended a treatment and the parent has not carried it out, the parent is found to be neglectful.³⁵ Interestingly, most HIV cases reported to Protective Services concern a parent who is "not cooperating" with the medical staff. In fact, hospital social workers have been told Protective Services will not take cases where the parent is at least trying to work with the medical staff.

This raises two issues. First, families who want to provide HAART for their child but are having difficulty due to obstacles at home, e.g., work schedule that interferes with drug administration, parent's own illness, resistance from child, etc., are unlikely to receive serv-

ices through the CINA system. They will need to find support elsewhere. In addition, families deemed "uncooperative" are apparently in conflict with their medical provider. Advocates, masters, and judges involved in this type of case must carefully investigate the underlying cause of this conflict, and see what steps might be taken to resolve it. The physician and family may have communication difficulties, as described above, that could be overcome by thoughtful intervention.

A middle-class family, faced with a disagreement or conflict with their doctor, will often simply go elsewhere. When faced with a difficult medical decision, many will seek a second medical opinion. Most poor families are unlikely to have such an option available.

Physicians, nurse practitioners, and social workers are often frustrated when seeking help from the child welfare system for children they believe to be at risk of harm due to their parent/caregivers' failure to properly medicate them. If intake workers do not perceive the harm to the child to be sufficiently imminent or severe, they will simply refuse to intervene.

What is needed is a system that does not require a finding of "indicated" neglect before some helpful action can be initiated.³⁶

In a recent article critiquing the overemphasis placed on making a finding of whether neglect has already occurred in child welfare cases, the authors argue for a focus instead on whether preventive services could prevent harm to a child.³⁷ They describe the emphasis placed by the current system on substantiation as a judgment made from a criminal justice adjudication paradigm which is of questionable utility for a social worker operating under a preventive services paradigm. Substantiation requires proof that neglect has occurred, when the real concern is trying to assess where neglect is likely to occur and offering services to prevent it.

A good example of the ineffectiveness of focusing on whether neglect can be substantiated is the Robertson case described earlier. In that case, Protective Services investigated a neglect report filed by the physician and found neglect "indicated." However, by this time the physician had stopped the child's medication. The Protective Services worker had no knowledge of HIV treatment and limited ability to ascertain what the real issue was about medication compliance. And when the

physician requested that Protective Services remain involved to provide services when the child was again beginning medication, Protective Services refused. The bottom line was that they made a finding of neglect, but did absolutely nothing to protect this child's welfare.

In addition, in many cases, there is a need for intervention by a neutral entity that can address communication difficulties. In several cases of alleged medical neglect in which we have been involved representing a parent/caretaker, failure of communication between the physician and the parent was a major obstacle to good care for the child.

The analysis courts have applied to other "medical neglect" cases is of limited usefulness with HIV treatment.

Typically, cases of alleged medical neglect involve a failure or refusal of a parent to authorize or to follow through with a time-limited treatment for a child's medical needs. They may include, for example, consenting to surgery or chemotherapy or authorizing a blood test. They generally do not raise the same issues that HIV cases raise, namely, that the mandated treatment must be administered daily for years, perhaps for the child's entire life. In HIV cases, if the family is unable or unwilling to provide this treatment, the court is faced with the difficult choice of having to remove the child from her home to ensure the child receives appropriate treatment.

In all cases in which a parent refuses to authorize or neglects to provide a certain course of treatment, the central focus is an evaluation of the risk of the procedure, including potential side effects, compared to its potential for success. So, for example, in *Newmark v. Williams*,³⁸ the Supreme Court of Delaware reversed a lower court order finding a child neglected when his parents refused to consent to a very invasive form of chemotherapy having a 40% chance of success. The child's parents were Christian Scientists, and chose to leave him in the hands of a Christian Science practitioner rather than subject him to dangerous, painful, and potentially life-threatening treatment.

The court felt it was appropriate to defer to the parents' judgment, especially given the dangerous nature of the proposed treatment and a likely success rate of 40%.

On the other hand, in *Custody of a Minor*,³⁹ the Supreme Judicial Court of Massachusetts ordered chemotherapy over the parents' objection. Treatment

involved an intensive three-year course of chemotherapy. The parents began treatment for their son, but became increasingly concerned about his discomfort in treatment and pessimistic about his chances for survival. Though short-term remission rates were high, and the child had gone into remission for a period of time, the long-term chance for a cure was 50%. Nevertheless, the court found that, because the treatment offered at least the possibility of a cure and the side effects of treatment had not been too burdensome (from the court's point of view, not the family's), treatment was in the child's best interest and could not be refused by the parents.

As these two cases illustrate, reasonable people may disagree about when a court should override parental decisions and how heavily to weigh the various considerations. In addition, the long-term prognosis for children receiving HAART is unknown. HAART is a treatment, not a cure. Because effective treatment for HIV illness has been available for only a few years, no data on its long-term efficacy and side effects are available. Ordering treatment may protect the child in the short term from disease progression, but there are insufficient data at present to indicate how long the treatment will remain effective. If a child's family is ambivalent about beginning treatment, they may not be compliant to the prescribed regimen with the required degree of consistency. This lack of compliance will likely limit the regimen's benefit and also lead to the child's developing resistance, potentially seriously limiting her treatment options in the future. Courts must therefore be cautious in overriding parents' decisions to defer treatment.

The impact of a child neglect finding on a parent/caretaker is severe: In many states, an indicated finding means that the parent/caretaker will be listed in the abuse/neglect registry. The registry does not distinguish between abuse and neglect. This would likely prevent this person from adopting a child or becoming a foster parent in the future. If she seeks work as a child care provider or teacher, she is likely to be asked to sign a waiver releasing this information. In addition, it makes the parent vulnerable to an action for termination of parental rights.

In the case of Ms. Robertson and Jessica, described above, Ms. Robertson was in danger of being listed on the statewide registry of parents guilty of child abuse/neglect. Such a listing would have prevented her

from adopting the child, despite the fact that all the parties, including the child's physician, agreed that adoption was in the child's best interests. The Law Clinic assisted her in persuading an administrative law judge to overturn the neglect finding.

There is a great need to treat these cases separately for what they are—parents or caretakers struggling under difficult circumstances to do the best they can to care for medically fragile children. The children's needs must be given first priority, but this need not be achieved at the cost of labeling the parent as bad or neglectful.

Once the physician files a neglect report, the relationship between physician/parent/caretaker may be irreparably harmed. This is certainly not in the child's interest.

Separating ill children from their family and placing them in foster care or group homes has its own costs. It is especially painful when part of the reason for removal is that the parent's illness prevents her from caring for the child.

III. Proposed Response

A. Physician/Patient/Parent Relationship and Compliance with Medical Regimen

The patient-physician relationship is a central factor in patient compliance with treatment, though this is just beginning to be acknowledged. It is recognized that the authoritarian model of compliance where the doctor gives an order to the patient and the patient carries it out is often ineffective. However, achieving compliance is still largely neglected as a topic in medical education, including pediatric residency training.

In his article, "Enhancing Patient Compliance in Pediatrics," Dr. Gregory Liptak⁴⁰ describes studies indicating that failure of communication between physician and parent/patient is often a cause of non-compliance. He makes a number of suggestions to health care providers that could help improve compliance. These include encouraging physicians to be aware of the different perspectives that they and the patient may have on a particular situation. Patients and their families tend to focus on the difficulties in their home life and the impact of the illness on their lives, while physicians tend to see the illness primarily as a patho-physiologic problem that affects the patient's physical body. Physicians tend to focus on the task of intervening with medication rather than relating to the patient. Dr. Liptak recom-

mends that the physician attempt to envision the impact the condition will have on the patient and her family. Attempting a true conversation with the client in which the physician ascertains the parent's belief regarding the seriousness of the condition is also important.

Care of HIV-positive children places a tremendous responsibility on physicians to develop a trusting partnership with the child and her family. It demands a model of health care delivery that is rare in our present health care system.

Traditionally, communication with patients has not been a focus of physician education. This situation is gradually changing, as it is recognized how important good communication is both in achieving good outcomes and in maintaining a positive relationship with one's patient.⁴¹ In addition, patients who have a trusting and open relationship with their physician are much more likely to forgive mistakes the physician may have made and less likely to file a malpractice suit. Developing an open and trusting relationship benefits the physician as well as the patient and improves the quality of care the patient receives. Taking the time to really hear a patient's concerns on a regular basis, and to explain in lay terms complex treatment options, is time well spent. Different patients/families will have different levels of interest in detailed communication, and the physician must be attuned to this difference.

The communication difficulties that may exist between patient and provider are often compounded when they are from different racial or ethnic backgrounds.⁴² As described in the case examples above, lack of trust is often an issue in the context of pediatric HIV care, where the physicians tend to be White male and upper middle class and the patients are predominantly African American or Latino and poor.

Providers must become sensitive to the skepticism with which many patients will hear their advice. They must take the time to really hear the families' concerns and demonstrate respect for the parent/caregiver role in decision making. They must work extra hard to bridge the communication gap.⁴³ They must honestly examine their own attitudes and become aware of the racial stereotyping that is often done unconsciously.

When a child's immune system remains relatively healthy, most physicians are willing to postpone treatment if this is the family's decision. However, when the

child's immune system begins to deteriorate, hard decisions may no longer be postponed. At this point, it is critically important that there be open, trusting communication between physician, child, and family. The physician must be able to assess the likelihood that the child/family can comply with a demanding drug regimen. This assessment must include an assessment of the child's/family's beliefs about the illness, belief in the efficacy of the treatment, and understanding of how the drug works and the impact of failing to take it *exactly* as prescribed. The physician, working with the family, must identify potential barriers to compliance and supports that would help the child/family be successful in treatment.

B. An Alternative Resource for Medical Providers: Supports to Children and Families

Families raising a child with HIV illness need at least two kinds of support. At some juncture in their child's care, most parents and families need and desire more information. A middle-class family dealing with a life-threatening illness such as AIDS or cancer undoubtedly often finds it helpful to seek a second opinion about certain treatment options. Poor families should also have that option available to them.

In each of the case examples described above, what resolved the conflict between the provider and the parent and enabled good medical care for the child to go forward was an opportunity for the parent to consult with someone they trusted about HIV treatment options. In all of these cases, this opportunity did not happen until either a neglect report was filed or until the parent felt so threatened by possible legal action by the treating physician that she found it necessary to seek legal advice. In addition, having access to an attorney who could counsel her about her rights in making decisions about medical care, as well as how to respond to threatened legal action, facilitated resolution of the dispute. In each case, it was also important to the parent to be able to speak to a knowledgeable person with similar values and background to help her assess her options and the efficacy of her choices.

Parents differ concerning how actively involved in decision making about their child's medical care they want to be. Some patients and families prefer simply to have the physician tell them what is best and they will

do it. However, for parents and families who want to be fully engaged in decision making, the option must be provided. It is important not only for decisions to be made for the children of these families but also to the progress of research in HIV care.

There is a need to have someone who can help facilitate communication between the physician and the child's family if in-house staff is not able to do this. This person must be someone knowledgeable enough to speak with the physician from a position of mutual respect.

The family must have access to legal counsel who can describe to them their rights and obligations, and help give voice to their concerns.

The second area of support that is essential for families coping with HIV illness is day-to-day support to enable the family to successfully administer medication to children. The specific support needed will vary from family to family. However, one kind of support that has proved helpful to many families is daily home nurse visits to ensure that a child receives timely and correct medication. This option may seem expensive, but it is actually inexpensive when compared to the psychological costs of removing a child from her home and the economic costs of providing foster care.

This supportive entity must have an experienced facilitator with in-depth knowledge of HIV illness and treatment, and the training to assess requests from medical providers or families for assistance and to decide what intervention would be most helpful.

The kinds of services that are necessary vary dramatically depending upon the issue. In some situations, as described above, the issue might be simple failure of communication and trust between physician and the patient's parent. In other situations, the barrier to compliance might be the parent's work schedule and care responsibilities for several children interfering with the medication regimen. In that case, a visiting home nurse to provide medication might be a solution. Another situation, as described above, might involve the parent's difficulty in coping because her depression would need to be addressed. An interim plan could be put in place while the parent sought help for her depression.

What is needed is a neutral entity to intervene either at the request of the medical provider or the family to help identify and address barriers to medical care for the HIV-positive child. The goals of intervention

would be to support the family in meeting the child's medical needs and to identify and address any communication issues between the medical provider and the patient and the patient's parent or care provider. There would be no need for a finding that neglect was "indicated" before service could be provided. The parent would receive counseling about his or her legal obligation to provide necessary medical care to the child and the possible consequences of a neglect report.

When a physician has a concern about a child, he or she could request intervention. The agency would be knowledgeable about the pros and cons of HIV treatment and able to determine the real issue. Is the caregiver simply overwhelmed and unable to cope with this demanding medication regimen? Is the child resistant to taking the medications? Is the parent distracted by other issues—e.g., domestic abuse, the needs of other family members? Or does the caregiver have questions or misgivings about the medication but feel unable to take these up directly with the child's physician?

This system has several advantages. A family could be successfully referred for support and assistance as soon as a potential problem is identified, without need to prove that harm had already occurred or even that the child was at imminent risk of significant harm. Permitting early intervention would provide more protection for at-risk children than the current system.

This referral to a neutral agency would avoid the damage to the physician/patient/parent relationship that occurs when a physician reports a parent for alleged "medical neglect."

The agency would act as a mediator between the physician/patient to ascertain the issues that were posing a barrier to care and try to help resolve them. They could help provide additional education to the parent about HIV, or assist the parent in advocating his or her experience and perspective with the physician.

The primary disadvantage to this proposal is that participation would be voluntary. The parent/care provider could not be forced to participate. However, he or she could be informed that a medical neglect report would be the likely next step if problems could not be resolved informally.

From the physician's point of view, being willing to engage in a conversation with a third party about recommendations for a patient's care requires some sense of relinquishing control.

On balance, however, this proposal's strengths outweigh the possible disadvantages. In addition, the entity created in response to this crisis in pediatric HIV care could also respond in other contexts where compliance with a care plan proves difficult for children and their families. Asthma, diabetes, and cancer are examples of chronic and potentially life-threatening health conditions where families might benefit from additional education, support, and help in negotiating a care plan for their child.

This concept of providing services to prevent a child's removal is fully consistent with the statutory framework for neglect cases. A parent could be informed that if she did not avail herself of the offered services, a neglect report would be the likely result. But it should not be necessary for a neglect finding to take place before services could be offered to prevent removal. It is critically important, however, that the investigating worker be extremely well educated about the medical aspects of HIV treatment, the impact of poverty on families, the psycho-social aspects of coping with HIV illness, and communication problems that may arise between the medical provider and the patient's family.

C. Supports to Children/Families: Lessons Learned from other Contexts

Studies of adult HIV patients have shown that the more patients understand about the purpose of their therapeutic regimen and the reasons for the restrictions required by the medication, the more likely they are to be compliant in taking them. In a study of 202 patients receiving anti-retroviral therapy for six months or more, adherence was greatest among those who understood the purpose of anti-retroviral therapy.⁴⁴ Education is thus a critical component that must be in place before a patient and family can be expected to adhere to a medication regimen. A study of children suffering from cystic fibrosis found that, particularly for younger children, knowledge about their disease and the treatment they were asked to undertake significantly increased compliance with the medication regimen.⁴⁵

At least one major study has shown that having an interdisciplinary team that can provide primary health-care, support, coordination, patient advocacy, and education to clinically ill children and their families increased the child's psychological adjustment to his or

her condition, lessened the mother's psychiatric symptoms, and improved the family's satisfaction with care overall. In this program, home visits were conducted to teach the patient and his family in the situation to which the care is given as well as to evaluate the family's medical, psychological, and social needs. The care providers included a pediatric nurse practitioner, a generalist pediatrician, and a social worker. A consultant psychiatrist and physical therapist were also available. Most families involved in this setting were either Hispanic or African American, the families were predominantly low-income, and less than half had two parents present in the home. The children had a variety of illnesses including asthma, seizure disorders, cancer, diabetes, and heart disease.⁴⁶

Studies from other contexts also indicate that children benefit from education and training in how to handle the reactions of others to their illness.⁴⁷ Children enrolled in the Varni study (see note 47) were taught to problem-solve cancer-related interpersonal difficulties

that they had confronted with peers, teachers, parents, and siblings. They were taught how to effectively express their thoughts, wishes, and concerns to others and were helped in coping with verbal and physical teasing associated with the illness. In this study, children who received this training reported a perception of higher support from classmates and teachers, and parents reported a decrease in behavior problems at school and an increase in school performance.

Conclusion

This alternative to using the CINA system in medical neglect cases has many advantages. It will prevent injury to children, rather than attempting to rescue them after harm has occurred. It will avoid the costly placement of children in foster care who do not need to be there. It will empower families to become partners in their children's health care, benefiting both these children and the progress of treatment for all children living with HIV.

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END NOTES

¹ "Guidelines for the Use of Anti-retroviral Agents in Pediatric HIV Infection," developed by the Working Group on Anti-retroviral Therapy in Medical Management of HIV Infected Children convened by the National Pediatric and Family HIV Resource Center, the Health and Resource Services Administration and the National Institutes of Health. The Jan. 7, 2000 publication of these guidelines specifically states, "Effective management of the complex and diverse needs of the HIV infected infants, children, adolescents and their families requires a multi-disciplinary team approach that includes physicians, nurses, social workers, psychologists, nutritionists, outreach workers and pharmacists" (p. 3). The guidelines go on to say, "Participation by the caregivers and child in the decisionmaking process is crucial, especially in situations for which definitive data concerning efficacy are not available" (p. 13).

² The difficulty of compliance with the drug regimen of HAART has been a major challenge for adult patients as well. See: Senak, Mark, "Predicting Antiviral Compliance: Physicians' Responsibilities vs. Patients' Rights," *Journal of the International Association of Physicians in AIDS Care* (June 1997). Adherence problems are common across all disease types. Adherence problems have been studied primarily with adults. Studies that have addressed such issues in pediatric populations have estimated adherence to be 50%. Gudas, Linda, Koocher, Gerald P., Wypij, David, "Perceptions of Medical Compliance in Children and Adolescents with Cystic Fibrosis," *Journal of Developmental and Behavioral Pediatrics*, Vol. 12, No. 4 (August 1991).

Compliance of 70% in children with asthma has been reported. This is similar to findings with children taking long-term drugs for epilepsy, diabetes, and the prevention of recurrence of rheumatic fever. Matsui, Donna, "Drug Compliance in Pediatrics," *Journal of Pediatric Clinics of North America*, Vol. 44, No. 1 (Feb. 1997). Children with life-threatening conditions such as cancer were also found to be at risk for treatment failure due to non-adherence to a medication schedule. For example, random urine assays in children suggested that 33% of patients who were supposed to be taking prednisone were not complying. Self-reported compliance in children and adolescents with cancer was 60.5%. Significant non-compliance was also reported in pediatric renal transplant patients, Matsui at 2-3.

³ Williams, Ann, "Anti-retroviral Therapy: Factors Associated with Adherence," *Journal of the Association of Nurses in AIDS Care*, Vol. 8, Supp. (1997), p. 18-23. As the author describes, the AIDS epidemic has a history of raising challenges that cast light on larger issues in our society. In the first decade of the epidemic, the focus was primarily on the dynamic of intimate human relationships and the impact of poverty, exclusion, and vulnerability in facilitating the spread of the epidemic. "In the second decade, the focus will be on the dynamics of relationships between health care providers and patients as we try to understand and then influence once again, human behavior and social conditions" p. 18.

⁴ For example, in a recent case, a 12-year-old's physician filed a neglect report due to her concern that the child's mother was not properly supporting the child with dietary restrictions, medical appointments, etc. Both mother and child are diagnosed with AIDS, both are receiving dialysis, and both have end-stage kidney disease. The mother's illness occasionally interferes with her ability to assist her daughter, take her to medical appointments, etc., but the daughter desperately wants to stay with her mother and was very depressed when she was removed to the home of a relative. She is very clear about her desire to return to her mother's home. Surely it should be possible to create a system that would be able to support her in this desire.

⁵ Drake, Brett and Johnson-Reid, Melissa, "Substantive and Early Decision Points in Public Child Welfare: A Conceptual Reconsideration," *Child Maltreatment*, Vol. 5, No. 3, (Aug. 2000), p. 227.

⁶ In Re Nikolas E., 720 A.2d 562 (Maine Sup. Ct 1998).

⁷ In other contexts, e.g., compliance of 80% is often considered good.

⁸ Interestingly, the language surrounding this issue has evolved over the last few years. In the beginning, providers spoke in terms of "compliance" with the regimen. Now the language more often used is "adherence" to the regimen.

⁹ Lucas, Gregory, "Antiretroviral Toxicities Take Center Stage at the 9th Conference of Retroviruses and Opportunistic Infections," *The Hopkins HIV Report* (March 2002).

¹⁰ Bartlette, John G., Gallant, E. 2001-2002 Medical Management of HIV Infection, Johns Hopkins University School of Medicine, p. 85.

¹¹ *Id.*, p. 46.

¹² 47 *Morbidity and Mortality Weekly Report* 4, Table 7 (1998). See also: "Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection" (see note 1).

¹³ 47 *Morbidity and Mortality Weekly Report* 4, Table 4 (1998).

¹⁴ De Martino, Maurizio, et al., "Reduction in Mortality with Availability of Antiretroviral Therapy for Children with Detrimental HIV-1 Infection," *JAMA*, Vol. 284, No. 2 (July 12, 2000).

END NOTES

15 Gallant, Joel. "Antiretroviral Therapy: Coping with Failure, Planning for Success," *Positively Aware*, (May/June 1998).

16 *In re Nicholas E.*, 720 A.2d 562 (Maine Supp. Ct. 1998). The Supreme Court of Maine decided that a parent's decision to delay experimental drug therapy known as HAART did not constitute serious neglect sufficient to warrant a child protection order. The Court recognized that HAART had been officially approved as the standard of care six months after. However, the Court also appeared to be influenced by the opinion provided by Dr. Kenneth McIntosh, head of the AIDS program and chief of the Division of Infectious Diseases at Children's Hospital in Boston, Mass., and professor of pediatrics at Harvard Medical School. Dr. McIntosh recommended HAART treatment for the child, but felt that no child should be started on the program unless his parents were fully accepting and in support of the treatment. Because of stepped-up FDA approval, all AIDS treatment programs (especially for children), when compared to traditional methods of approving medical drugs, are experimental. No one can predict how long the drugs will be helpful, or the long-term effects of the drugs.

17 Reasons given by parents in other contexts for failure to give medication as prescribed include side effects, misunderstanding of instructions, child's resistance, and simply forgetting. Taking medication for asymptomatic conditions or the prevention of disease tends to be more difficult, Matsui, *supra*, p. 5. The more complex the regimen, the higher the rate of non-adherence. Palatability has been found to be a major issue for children, p. 6. Other factors include: Condition perceived as not being serious; individual not perceived as being at risk; treatment/preventive measure not perceived as beneficial; lack of social support; learned helplessness; adolescence; lack of continuity of health care; difficulty of the treatment or prevention program (Liptak, Gregory, "Enhancing Patient Compliance in Pediatrics," *Pediatrics in Review*, Vol. 17, No. 4, 128, 131, April 1996).

18 As Marsha Garrison stated in her article, "Child Welfare Decisionmaking: In Search of the Least Drastic Alternative," 75 Geo. L.J. 1745 (August 1987), "The need for child welfare services and the difficulty of providing them successfully—springs largely from the chronic stresses and deprivations of poverty. It is no accident that virtually all of the children in foster care come from families that are impoverished or that children who stay in foster care seem to fare better than those who go home. If we, as a society, are not willing to give families sufficient support to avert the extreme stresses that produce abuse, neglect and family dysfunction, then we must expect a population of damaged children with diminished potential. And given our limited therapeutic abilities and commitment to rehabilitation, we must expect that child welfare services will fail to help many of these children."

19 The American Academy Committee on Pediatric AIDS encourages disclosure of HIV status to school-age children. Disclosure of the diagnosis must, of course, be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances. Preliminary data suggests that children who know their status have higher self-esteem than children who are unaware of their status. Parents who have disclosed their status to children tend to experience less depression than those who do not.

20 Gallant, *supra*, note 15.

21 Matsui, *supra*, note 2, p. 5.

22 Fotheringham, M.J., and Sawyer, M.G., "Adherence to Recommended Medical Regimens in Childhood and Adolescence," *Child Health*, Vol. 31 (1995), p. 72.

23 See, e.g., Levine, Coral, and Zuckerman, Connie. "The Trouble with Families: Towards an Ethic of Accommodation," *Annals of Internal Medicine*, Vol. 130, No. 2 (Jan. 19, 1999). The authors describe the conflicts that often arise between physicians and family members of a patient who is terminally ill.

24 See: McGovern, Theresa, "Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal and Unsound Approach," 28 Columbia Hum. Rts. L. Rev., 469 (Spring 1997).

25 "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," Institute of Medicine (2002), p. 109.

26 *Id.*, p. 32-62.

27 One arena that pediatric clinics have begun to explore to encourage adherence is behavior management, with positive reinforcement for participation in properly taking the necessary medicine. See: Varni, James W., "Clinical Behavioral Pediatrics: An Interdisciplinary Biobehavioral Approach" (1983) Pergamon Press. Varni describes techniques that were used to encourage compliance with dietary mandates for children with end-stage renal disease.

28 Nearly one-third of African Americans report having experienced discrimination in health care at some point in their lives, and 16% report having such experiences in the last year. Unequal Treatment, p. 109. The study found that people of color are less likely to be offered certain procedures, e.g., cardiac catheterization, and more likely to be subjected to severe treatment for disease, e.g., amputations in context of diabetes.

END NOTES

Unequal Treatment, p. 108. It found that people of color generally have less access to state-of-the-art HIV treatment. Pediatric HIV patients who are predominantly Black and Latino generally do have access to state-of-the-art treatment. The issue in this context is not necessarily one of access but of education and decision making in an area that is in many ways still experimental. A related difficulty is that for most pediatric HIV-positive patients, their treating physician and the researcher are the same person.

²⁹ Unequal Treatment, p. 109.

³⁰ Roberts, Dorothy, *Shattered Bonds—The Color of Child Welfare* (2002), New York: Basic Civitas Books, p. 51-52.

³¹ Chasnoff, Ira J., Landress, Harvey J., Barrett, Mark E. "The Prevalence of Illicit Drug or Alcohol Use During Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida." *New England Journal of Medicine*, Vol. 322, No. 17 (1990), pp. 1202, 1204.

³² Pilpel, Harriet, "Minors' Rights to Medical Care," 36 Albany L. Rev. 462 (1972).

³³ Sher, Elizabeth, "Choosing for Children: Adjudicating Medical Care Disputes Between Parents and the State," NYU L. Rev. 157 (1983).

³⁴ It has also been criticized for permitting the state to intervene in situations where deference to the parent's judgment would be more appropriate. See: Goldstein, Joseph, "Medical Care for the Child at Risk: On State Supervention of Parental Autonomy," 86 Yale L.J. 645 (1977). Goldstein proposed to limit state intervention to situations where: (1) medical experts agree that the treatment is non-experimental and appropriate for the child; (2) the denial of treatment would result in death; (3) the anticipated result would be a chance for normal healthy growth. See also: Goldstein, Joseph, Freid, A. and Solnit, A., *Before the Best Interests of the Child*, p. 91 (1980). This approach was challenged as too limiting. See, e.g., Sokolosky, Wendy, "The Sick Child and the Reluctant Parent—A Framework for Judicial Intervention," 20 Journal of Family Law 69 (1981-82).

³⁵ This is generally true also with children and their families facing other serious illnesses. Courts typically will defer to the physician's opinion, unless the parent is able to bring in another physician with similar credentials who is of a different opinion. It is quite possible for two cases with virtually identical fact patterns to turn out differently due to the divergent testimony of doctors. Such was the case with *In Matter of Hofbauer*, 393 N.E. 2d 1009 (1979), and *Custody of a Minor*,

379 N.E. 2d 1053 (1978). Both cases involved parents who desired to treat their child's cancer with metabolic therapy, including injections of laetrile, rather than medically accepted chemotherapy. Yet, despite the similarities of these two cases, they were resolved completely differently.

In *Hofbauer*, the New York Court of Appeals held that the child was not a neglected child because the parent had the support of a duly licensed physician who testified that such therapy was a "beneficial and effective mode of treatment," *Hofbauer*, 393 N.E. 2d at 1012, thereby satisfying that state's "adequate medical care" standard, *Id.* at 1013 (explaining that the "Legislature has imposed upon the parents of a child the nondelegable affirmative duty to provide their child with adequate medical care"). The *Hofbauer* court considered various factors to arrive at its holding such as the severe potential side effects of chemotherapy, *Id.* at 1012 (noting that side effects include "fibrosis of the body organs, swelling of the heart, impairment of the growth centers and leukemia"), a study which revealed beneficial effects of laetrile and the fact that the child was responding well to the alternate therapy. The court also described the parents of the child as "concerned and loving parents who have employed conscientious efforts to secure for their child an alternative medical treatment." Rather than completely adhering to the prevailing standard of medical care as a basis for whether the parents' actions constituted neglect, moreover, the *Hofbauer* court opined that as the parents are providing acceptable care "in light of all the surrounding circumstances" then they were providing adequate care for the child (*Id.* at 1014).

In contrast to the holding in *Hofbauer*, the court in *Custody of a Minor* (*Custody of a minor*, 379 N.E. 2d 1053, 1978) concluded that the evidence sufficiently established that metabolic therapy for the child was useless and dangerous. The parents in this case initially consented to treatment of their child's illness with chemotherapy but, without the physician's knowledge, they gave laetrile and other nutritional therapies. When the child's physician learned of the parent's actions, he implored them that such "metabolic therapeutics" were potentially dangerous (at 1058). The parents then withdrew their child from standard therapy (*Id.* at 1064). The mother testified that her decision to cease chemotherapy for her son did not stem from a belief that a more effective treatment existed. Rather, she was deeply concerned over the child's discomfort in the chemotherapy program.) She was upset that the child's physician filed a petition seeking the child's commitment to legal custody of the Department of Public Welfare for the limited purpose of providing chemotherapy (at 1057.) According to the medical testimony, after one year of treatment, 90% of children are disease free. In the second year of treatment, 70% are in remission. By the third year, 65% are still in remission and in the fourth year, the survival rate of 50%. Other courts, such as the court in *Newmark v. Williams*, 588 A.2d 1108 (1991) also tend to rely on the chances of recovery. In *Newmark*, the court held that a child was not neglected when parents refused to permit their child to receive a radical form of chemotherapy when there was only a 40% chance of success. (*Id.* at 1110.)

END NOTES

The disparate outcomes in *Hofbauer* and *Minor* are reconcilable mainly by the fact that the doctor in *Hofbauer* supported the alternate treatment desired by the parents. It appears, therefore, that when parents choose an alternate form of therapy prescribed by a duly licensed physician, courts will not override the parents' wishes. Giving strong weight to the testimony of physicians is expected, particularly in cases involving a parent's refusal or failure to properly administer medication. Yet, in listening to the opinions of the medical community, it is very important for courts to consider the nature of the treatment at issue. As is demonstrated by the *Nikolas* court, with some treatments, especially AIDS treatment, the standard of care is always changing and there are many uncertainties about the recommended drugs. While the *Nikolas* court took this into consideration, other courts do not adequately consider this factor.

³⁶ The abuse and neglect statutes are inadequate and unhelpful in cases involving disputes between parents and medical providers over care for ill children. They provide no guidance and focus the Court's attention on the parent's alleged misconduct rather than on the child's medical needs and how they could be met. Sokolosky, Wendy, "The Sick Child and the Reluctant Parent—A Framework for Judicial Intervention," 20 *Journal of Family Law*, 69 (1981-82).

³⁷ Drake, Brett, Johnson-Reid, Melissa, "Substantiation and Early Decision Points in Public Child Welfare: A Conceptual Reconsideration," *Child Maltreatment*, Sage Publications, Inc., Vol. 5, No. 3 (Aug. 2000), p. 227-235.

State agencies vary dramatically in the degree to which they provide voluntary services to at-risk families (secondary prevention) or to families in which maltreatment has occurred but can not be formally substantiated (tertiary prevention). For example, in Pennsylvania and West Virginia, about 65% of children in unsubstantiated reports received services, whereas in many other states, less than 5% of children in unsubstantiated cases receive services. A national consensus on these issues has yet to emerge.

³⁸ 588 A.2d 1108 (Del. 1991).

³⁹ 379 N.E. 2d 1053 (1978).

⁴⁰ Liptak, *supra*, note 18.

⁴¹ Epstein, Ronald M., Campbell, Thomas L., Cohen-Cole, Steven A., McWhinney, Ian R., Smilkstein, Gabriel, "Perspectives and Patient-doctor Communication," *Journal of Family Practice*, Vol. 37, No. 4 (Oct. 1993), p. 377. The authors describe approaches to patients that involve an emphasis on truly listening to the patient and developing a better rapport between patient and physician.

⁴² So, for example, a 1996 study of 103 patients with AIDS found that the majority had not discussed treatment preferences with their physicians. Black patients were half as likely to have discussed their preferred approach, even when controlled for education income, age, etc. Black patients were more likely to want to continue with active treatment, as opposed to adopting a palliative care approach. "Communication of Preferences for Care Among Human Immunodeficiency Virus-Infected Patients," Mouton, Charles, Teno, Joan M., Mov, Vincent, Pume, John. *Arch. Fam. Med.*, Vol. 6 (July/Aug. 1997).

⁴³ Medical professionals, particularly nurses, have begun to examine the importance of understanding and addressing cultural differences in developing successful relationships with patients and their families. See, e.g.: Jones, Mary Elaine, Bond, Mary Lou, Carson, Carolyn L. "Where Does Culture Fit in Outcomes Management?" *Journal of Nursing Care Quality*, Vol. 4, No. 1 (Oct. 1998).

The authors suggest that health care workers can best be educated to appreciate the impact of culture by integrating this learning into their day-to-day practice with patients. They point out the limitations of classroom education (p. 5).

See also: Newman, Julliana, "Managing Cultural Diversity: The Art of Communication," *Radiologic Technology*, Vol. 69, No. 3 (Jan.-Feb. 1998), p. 231.

⁴⁴ Eldred, Wu, Chaisson and Moore (1997) as quoted in Williams, Ann. "Anti-Retroviral Therapy: Factors Associated with Adherence," *Journal of the Association of Nurses in AIDS Care*, Vol. 8, Supp. (1997), p. 18-23.

⁴⁵ Gudas, Linda J., Koocher, Gerald P., Wypij, David. *Perceptions of Medical Compliance in Children and Adolescence with Cystic Fibrosis, Developmental and Behavioral Pediatrics*, Vol. 12, No. 4 (Aug. 1991).

⁴⁶ Stein, Ruth E.K., and Jessop, Dorothy Jones. "Does Pediatric Homecare Make a Difference with Children with Chronic Illness? Findings from the Pediatric Ambulatory Care Treatment Study," *Pediatrics*, Vol. 73, No. 6 (June 1984).

⁴⁷ Varni, James W., Katz, Ernest R., Colegrove, Jr., Robert, Dolgin, Michael. "The Impact of Social Skills Training on the Adjustment of Children with Newly Diagnosed Cancer," *The Journal of Pediatric Psychology*, Vol. 18, No. 6 (1993), p. 751-767.