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Disclosure of HIV Status to an Infected Child: Medical, Psychological, Ethical, and Legal Perspectives in an Era of "Super-Vertical" Transmission

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INTRODUCTION

More than a quarter century after the discovery of HIV we are still finding our way through thickets of confidentiality, stigma, and access to treatment. In fact and on balance, one could make the case that for all the progress made in the *medical* treatment of persons with HIV/AIDS, we have made a hash of it when it comes to clinical or applied ethics management of HIV cases, particularly in mother-child dyads when either or both is of questionable mental capacity. This is especially troublesome, given the recent appearance of a new and extraordinary population: children who acquired the virus from mothers, who themselves acquired the virus from mothers. In other words, we are now seeing cases of "super-vertical" or grandmaternal transmission. In the presence of high-quality treatments that allow affected children to live long enough to reproduce, HIV has become a malady that is inherited without being genetic.

Against this background, it is still the case that parents are often reluctant to disclose the diagnosis of HIV-1 infection and/or AIDS to an infected child. There are several reasons for this reluctance, most prominently denial, fear of the child becoming depressed or being ostracized because of the stigma, and parental guilt.¹ In states that have enacted strict laws governing the disclosure of HIV-related diagnostic information (often known as "super-confidentiality laws"), these issues are magnified because the disclosure of the HIV status of a child generally involves the simultaneous disclosure of the parents' HIV status. Decisions in this area require a balance among the child's right to know and ability to comprehend the information, and the emotional well-being and privacy rights of parents; in some cases we must take into account the competence

of parents to make best-interest decisions for their children. Despite an evolving literature on disclosure of HIV status to children, the clinical and ethical problems raised by this type of case are largely unresolved.

This report describes a dramatic, albeit not entirely unfamiliar, case that resulted in a change in hospital policy and identified a need to change state law. The case involved an HIV-infected mother who refused to disclose the diagnosis of HIV to her infected child. After its presentation we will discuss the medical, behavioral, ethical, and legal aspects of the case. The case warrants such review because of what it reveals about the problem of HIV disclosure in an era in which we are still sorting out the ethics of access, stigma, and information exchange, and in which children can acquire a dangerous and fraught malady indirectly from their grandmothers.

CASE REPORT

The patient was an adolescent with perinatally acquired, advanced HIV-1 disease marked by profound immunosuppression and multiple medical problems. Both the child and her mother were identified as being HIV-1 infected when the child was two years old. The child then endured recurrent pneumonias, chronic skin infections, failure to thrive, and HIV-1 encephalopathy associated with severe cognitive impairment. The mother, who was the child's only guardian, was in apparent denial regarding both her own and her child's diagnosis. She persistently refused all medical therapy for HIV, and insisted that God would care for her family. She did not belong to any church that prohibited seeking medical care.

As the child's health was failing, the mother finally agreed to start highly active antiretroviral therapy (HAART) — but she did not adhere to the recommended medication regimen and follow-up medical visits despite repeated counseling regarding the consequences of failing to do so. Previous attempts to involve Child Protection Services had failed, apparently because of an evolving trend at the time to support a parent's right to refuse HIV treatment for a minor child. At the same time, legal interpretation of the state law regarding the super-confidentiality of HIV status raised significant legal concerns about disclosure of the child's diagnosis without the mother's consent.

The child was admitted yet again for fever, wasting, and worsening skin ulcerations. The mother adamantly and repeatedly refused permission to disclose the diagnosis to the child, stating that her daughter would be "too sad" if she were to know. Physicians discussed this case with the hospital risk management staff, who opined that the mother's conduct constituted child neglect. After communicating this sentiment to the mother, she agreed to disclose the diagnosis — but not while the child was hospitalized. The mother agreed to bring her daughter in for a follow-up clinic visit so that disclosure could occur. However, mother and daughter missed both this and subsequent clinic visits.

The child was admitted for the last time eight months later, because of recurrent fevers and continued wasting. The mother repeatedly denied to the emergency room staff that her child had AIDS, even though several members of the staff had previously cared for the child. The mother had been given a prescription for a prophylactic antibiotic to prevent *Mycobacterium avium-intracellulare* (MAI) bacteremia the previous year, but she later admitted she was not giving the child the medications. This child had MAI. When asked to bring the medications from home, the mother brought in more than 30 bottles of pills, the majority of which had never been opened. The case was then referred to the state Child Protection Services agency for an investigation of medical neglect. After obtaining judicial authorization, the child was informed of the HIV-1 infection status in a manner that was regarded as appropriate for her age and degree of cognitive impairment. Under court order, the child was then placed in the custody of a relative.

The child's clinical status initially improved once regular antiretroviral therapy began. Despite this initial success, progressive HIV-1 disease complicated by advanced neurological impairment overwhelmed the child. She was transferred to hospice, where she died six months later. She had become a teenager (in conjunction with other facts of the case, any more precise age or even age range could serve to identify her, and so we therefore withhold this datum). Mother, too, later died of AIDS-related complications.

STATEMENT OF THE PROBLEM

Decisions about disclosure of HIV status to children are complex. There is a growing consensus, supported by the American Academy of Pediatrics (AAP), that the benefits of disclosure outweigh the risks.² However, in clinical settings, disclosure occurs in a complex context that involves evaluation of the child's medical condition, consideration of (a) medical and psychological effects of disclosing versus not disclosing, (b) a child's cognitive and psychological capacity to comprehend and act upon the information, and (c) the parents' cognitive and psychological capacity to comprehend and act upon the information. These clinical factors are further influenced by statutory law, case law, and institutional policy developed in light of the law. In most states, disclosure of HIV status is controlled by laws written to apply to adults; caregivers are left to deal with the consequences of insufficient consideration of the effects on decision making related to children and adolescents. Pediatricians inevitably confront cases that simultaneously involve complexities in all of these dimensions, leading to uncertainty about how to proceed medically, psychologically, ethically, and legally. This case illustrates the complexity of this issue.

While this discussion focuses primarily on the mother, and it is usually the mother with whom the medical team interacts, the reasons commonly cited for nondisclosure may come from the father and/or the mother. As was the case here, the mother may be in denial both in regard to her own as well as her child's infection status. If she refuses to accept her own or her child's diagnosis, then she can perhaps avoid having to cope emotionally with this reality. The extent of the mother's denial in this case is evidenced by her repeated refusal in the face of extensive evidence to admit that her child had AIDS. Denial may also be prompted by the stigma associated with AIDS. Because of this stigma, many patients and/or their families adopt denial as their primary means of coping with their infection.

Many mothers refuse to disclose because they fear repercussions from their sex partner and/or (other) family members. These repercussions may assume several forms. The mother might be subject to emotional and/or physical abuse, or she may suffer economic deprivation if her sex partner, who may be a primary source of income, abandons her. Mother might also be afraid of being socially ostracized by her partner, her family, or other support systems (schools, churches, et cetera), or being criminally prosecuted if she knows her infection status and fails to disclose it to her sex partner. She might also suffer from guilt about having infected her own child. Further, as expressed in this case, a mother might have a genuine fear of the child becoming severely depressed by the knowledge of its infection status. Alternatively, the mother might refuse to disclose because in doing so she thereby discloses her own HIV status. In all these respects, HIV is truly a family disease.

MEDICAL COMMENTARY

The American Academy of Pediatrics Committee on Pediatric AIDS recommended in 1999 that the "disclosure of the diagnosis to an HIV-infected child should be individualized to include the child's cognitive ability, developmental stage, clinical status, and social circumstances."³ The committee "strongly" encouraged the disclosure of HIV-infection status to school-age children, and that symptomatic ("particularly those requiring hospitalization") children and adolescents should be informed of their diagnosis. There are several medical reasons why disclosure of this diagnosis to an infected child should be promoted once a child reaches a certain age, the most prominent being the need to optimize compliance with HAART. While adherence to HAART is demanding, it pales when compared to the regimens required to treat the complications of AIDS if the disease is allowed to progress. In our experience at a major pediatric HIV treatment center, a number of children treated for advanced disease have required 25 or more different medications.

When a regimen becomes this complex, compliance becomes extremely difficult. The critical need for compliance should be emphasized at the start of HAART. Despite some current controversy as to when to start therapy, HAART is most effective when begun before the development of profound immunodeficiency. Continued effort must be made to optimize compliance to minimize the risk of developing HAART resis-

tance and treatment failure. Disclosure remains one of the most useful means of achieving this once a child is sufficiently mature.

Once aware of the diagnosis, a child can assume greater responsibility for her or his own care. This may be essential for children in dysfunctional families or whose caretakers are incapacitated by their own illness. It is important that a child be educated and emotionally accept the diagnosis before being unable (that is, if she or he develops severe cognitive encephalopathy, as was partly the case here) or unwilling (that is, because of issues related to adolescent psychological development) to participate in his or her own medical care. As a greater number of perinatally infected children live longer and enter adolescence, they must be informed of their status before they become sexually active or engage in other high-risk behaviors (intravenous-drug use, for instance). They must be given the time and the opportunity to make informed and responsible decisions.

The care team must also attend to confidentiality regarding a parent's infection status. At the same time, team members must remember their primary role as advocate for their child patients, and not elevate the rights and needs of the parent over those of the child, especially when life is in the balance. It is a sad perversion indeed when a parent's demands for confidentiality result in a diagnosis of HIV being withheld from a child or adolescent.

The advent of HAART therapy, coupled with the development of a reliable surrogate marker of disease activity (viral load), radically altered our conception of HIV management. Gortmaker and colleagues⁴ demonstrated that the use of HAART is associated with a reduction in mortality among HIV-1 infected children and adolescents, duplicating findings previously reported among adults.⁵ While such therapy did not exist when the child in our case was diagnosed at age two, the benefits of HAART were readily apparent by the time of death.

What has happened is no less than a major shift in the expectations of treating physicians. While HIV cannot be cured, neither can juvenile onset diabetes (at least without a pancreatic transplant). Like diabetes, HIV infection is a treatable condition. The survival of HIV-infected children is, in some cases, already measured in decades rather than years. These accomplishments underscore the need to make children aware of their status when they are mature enough and before they are neurocognitively impaired.

BEHAVIORAL HEALTH COMMENTARY

As this case demonstrates, disclosure of HIV status to a child who was vertically infected raises a number of complicated issues, including (a) whether the child should be told, (b) what effect disclosure might have on the child's psychological functioning, and (c) whether there are factors associated with the disease in children that may negate any benefits of disclosure and bring into question the capacity of the child to understand and act upon the diagnostic information in a way that benefits his or her health.

Whether disclosure of diagnostic information to a child is helpful or harmful has been, and continues to be, a potential source of conflict between parents and healthcare providers. This is particularly true when the illness is potentially life threatening. Parents feel a need for secrecy and fear their child will experience greater distress when provided this information. Parents often believe their child needs to be "ready" for the information.⁶ In the case of vertical transmission, disclosure of the diagnosis to the child represents concurrent disclosure of the mother's diagnosis, something we have seen a mother may disdain out of fear of increased stigma or social isolation⁷ for her and/or her children. Factors related to greater parental willingness to disclose to children include recognition of more severe disease-related symptoms⁸ and parents' appreciation of their limitations in dealing with the situation.⁹

Research on the effects of disclosure on children's psychological functioning suggests that there are clear benefits for children who know their diagnosis. Reports indicate that as many as 66 percent of children infected with HIV have received either full or partial disclosure, but this disclosure usually occurs two to eight years after initial diagnosis.¹⁰ When disclosure occurs, it has been associated with children's use of more active coping strategies,¹¹ lower levels of behavior problems,¹² lower levels of aggression, and higher

levels of self-esteem.¹³ There are developmental issues that may argue for or against disclosure at specific points in time, including the ability of the young child to make discriminating decisions about whom to tell about the disease.¹⁴ For adolescents, decisions about sexual activity and protection of partners are closely related to knowing their diagnosis.¹⁵ Finally, adherence with HAART regimens may be improved if the child knows the reason for the therapy, particularly given the many challenges this treatment presents.¹⁶

After considering the relative risks and benefits of disclosure for children, the American Academy of Pediatrics recommended disclosure, but also that the disclosure process take into consideration the child's age, maturity, and developmental challenges.¹⁷

An issue that is not addressed in the literature, but which arises in this case, is that of the competence of the child, and possibly the parent, to understand and be able to act upon diagnostic information once it is disclosed. One of the known consequences of HIV infection is central nervous system (CNS) disease. AIDS-related dementia in parents who are infected may dramatically affect their ability to make informed decisions on behalf of their children. In addition, the CNS effects of HIV on the cognitive functioning of children have been documented in the school-age years, with particular effects noted in the areas of memory, processing speed, social-emotional regulation, attention, and executive functions such as problem-solving, planning, and organization.¹⁸ As children reach adolescence, more severe cognitive impairment consistent with AIDS-related dementia in adults can be anticipated.¹⁹ Progressive cognitive impairment may work against maturity associated with age in children, creating a situation in which children may be "old" enough to be told, but impaired enough for this information to be meaningless and have no influence on their behavior. In this case report, the child's lack of cognitive capacity added to the complexity of the decision to disclose diagnostic information against the parent's wishes.

While there is substantial evidence that disclosure may be beneficial for children, there are a number of legitimate concerns to be considered when evaluating the risks and benefits of this action. Models are being developed and tested to determine the optimal way to provide diagnostic information to children.²⁰ Research is clearly needed that addresses the relationship between providing diagnostic information and the cognitive capacity of the child to understand and act upon that information. It may be the case that providing diagnostic information to the "incompetent" child may have no effect at best, and may in fact be harmful. This is a question that should be answered by data, not opinion.

ETHICS COMMENTARY

Of the many ethical issues that arise here, two call for the greatest attention:

- When, if ever, can a claim of parental confidentiality trump a child's right or need to know an HIV diagnosis and treatment plan?
- When, if ever, can a parent's (purported) desire to protect a child from onerous medical news supersede those rights and/or needs?

CONFIDENTIALITY

While privacy and confidentiality are often accorded pre-eminent status in any itemization of the duties of health professionals, they are not absolute. Indeed, there is a well-supported suite of events, circumstances, or situations in which the violation of confidentiality is not only morally permissible — it may be morally obligatory. The instances in which health professionals are morally (and generally legally) required to notify authorities are well known: gunshot wounds, child and elder abuse or neglect, and certain epidemiologic data. There are powerful utilitarian reasons for this: generally, expectations of medical confidentiality are inadequate to override expectations of life, physical safety, necessary public health practice, and so forth.

The case at hand, however, does not involve informing authorities of a case or diagnosis, but informing a *patient* of her diagnosis. Here, any ethical justification to violate the mother's confidentiality and disclose the child's diagnosis must appeal both to public health and to rights of personal self-determination. Note also

that the issue is often cast as a duty to warn an innocent third party who faces ongoing or repeated exposure. Even in such cases, it is reasonable to insist on more evidence, more research, and more structured ways of trying to manage decision making in the face of a paucity of empirical data.²¹

The public health argument is based on the fact that adolescents who are unaware of their HIV-positive status might themselves be or become a source of contagion. If adolescents know their HIV status, then, with adequate counseling and other interventions, they will be able to avoid being the source of additional infection. For a generation, policies and laws regarding the disclosure of HIV status have been based on the well-motivated belief that when HIV-positive individuals know their status, they tend to change their behavior in appropriate ways.

The self-determination argument is somewhat more difficult to make in the case of an adolescent, particularly one whose capacity is in question. For instance, it is not unreasonable to doubt (at least a little) the ability of some adolescents to make generally sound decisions about a variety of matters. Still, many pre-adolescents and even children are able to achieve insight and understanding about a variety of maladies and health issues, especially health problems with potentially severe or catastrophic consequences. Moreover, making patients — including pediatric patients — partners in their care is known to improve compliance and a variety of outcomes.

This being the case, the values attached to self-determination and good outcomes should be regarded (all other things being equal) as adequate to set aside the primacy of confidentiality. The law recognizes this in the "privilege to warn" principle, most famously invoked in a California case, *Tarasoff v. Regents of the University of California*, in which a therapist chose to honor the therapist-patient obligation of confidentiality and did not alert his patient's girlfriend of his serious homicidal intentions. Finding the therapist liable, the California Supreme Court invoked an exception to the obligation of confidentiality when necessary to prevent undue hardship and cruelty.²²

THERAPEUTIC PRIVILEGE

In our case, the mother stated that she wanted to protect her child from the awful news of an HIV diagnosis. This (provisionally) compassionate position must be addressed. It is part of a long tradition in pediatrics and adult medicine to invoke the "therapeutic privilege," or notion that deception may be morally permissible if truth-telling will cause a negative outcome. This belief enjoys more support than evidence permits; indeed, much such "evidence" is anecdotal and episodic. But the price it demands is steep: the erosion of trust, which might be long standing; the loss of an engaged ally in care; and the generally unhappy stance that deception is better than truth-telling, which wears on clinicians as heavily as any professional burden.²³ This is not to suggest that there are no circumstances under which it will be appropriate to deceive children about aspects of a malady. Rather, it lends support to the AAP policy on disclosing HIV to children — namely, a strong recommendation that clinicians undertake such disclosures while simultaneously admitting the possibility of exceptions.

We must take care not to make a virtue out of interpersonal necessity, or even difficulty. It can be quite a challenge to communicate bad news to patients. It would be perverse if we were to allow that difficulty to be used in support of a policy that just happened to free clinicians of the duty to communicate bad news with compassion and understanding. While the literature shows a high prevalence of nondisclosure of HIV status to children, it is not entirely clear if this nondisclosure is for the patients' sake or the clinicians'.²⁴

It is difficult to say whether or how a patient's diminished capacity should alter communication strategies. In the absence of outcomes data to guide us, even a little, the best course should be shaped by a "deference toward the standard." That is,

- If there is expert opinion and broad consensus on an issue (and here we have such with the AAP statement and a general movement by psychologists and psychiatrists to make all patients partners in their care); and
- If there is no compelling reason to the contrary (perhaps shaped by the facts of the case); then

- In case of uncertainty, defer to the evolving standard. In this case, that points to greater rather than lesser communication.

From or near the beginning of the HIV/AIDS epidemic it was clear that there was plenty of duty to go around: from patients and parents to clinicians and public health authorities, all parties should adopt stances characterized by trust, candor, and sexual responsibility.²⁵ What a happy coincidence that values we independently prize would be precisely those needed to impede the transmission of an awful malady.

LEGAL COMMENTARY

The law frequently lags behind what ethics and perhaps best medical practice would suggest. This case illustrates the short time within which even the most innovative legal efforts become dated. Within a mere 12 years, improved medical treatment has created a new and largely unanticipated class of patient: adolescent survivors of perinatal HIV infection. These patients may well require certain legal rights and protections as individuals, not as minors whose best interests are supposed to be protected by their parents.

Florida enacted one of the very first comprehensive statutes intended to protect rights of HIV-infected individuals. Passed in 1988 and amended several times thereafter, the Omnibus AIDS Act²⁶ is founded on the notion that "this illness can best be controlled through an informed public that knows how to avoid contracting and transmitting the disease and that voluntarily agrees to be tested."²⁷ The Florida State Legislature held that this goal would best be achieved by creating strong privacy and confidentiality rights for the patient.

Florida law's requirement for patient consent before both testing and disclosure of test results is almost absolute, with very limited exceptions, largely for public health reasons. So informed consent for testing is not required when federal or state law require a test for sexually transmitted diseases, when a party has been convicted of prostitution or related offenses, for release from prison, or for purposes required by a medical examiner.²⁸ Other exceptions to the informed consent requirement include specific situations such as organ donation, "bona-fide medical emergencies," autopsies, certain sexual battery cases, anonymous epidemiologic research, to protect medical personnel, and by court order.²⁹

Significantly, the Florida State Legislature imposed a heavy burden on any court contemplating overriding the right of a patient to confidentiality of HIV test results. The court must find that there is a "compelling need" for test results that "cannot be accommodated by other means."³⁰ Further, the legislature instructs courts to "weigh the need for disclosure against the privacy interest of the test subject and the public interest which may be disserved by disclosure which deters . . . future . . . testing or which may lead to discrimination."³¹ Indeed, the primacy of patient privacy is further underlined by a provision of the Omnibus AIDS Act that amends a variety of civil rights laws to prohibit discrimination against persons within its ambit. Consequently, Florida was one of the very first states to forbid discrimination on the basis of HIV status in employment, housing, public accommodations, and health/life insurance.³²

No doubt, the heavy weight of legislative and judicial concern in Florida, a trend-setting state in enacting comprehensive HIV legislation, is squarely in favor of giving the patient control over healthcare information and the right to veto disclosure — in most instances. In the case described here, the mother's dual role as guardian of her adolescent child, HIV infected from birth, and guardian of her personal HIV status, created a conflict of interest that was probably not contemplated by legislators when they attempted to balance patient rights against public responsibilities. The Florida Legislature did not foresee the survival of HIV-infected infants into adolescence and did not provide independent legal protection for them. Accordingly, the law in Florida gives no clear permission to a treating physician to disclose HIV status to an adolescent when so doing would *de facto* result in disclosure of parental status — unless that parent has consented. Hence, in our case, a court order was required when the mother refused to give her permission; this is the last resort for physicians caught in legislative limbo.

Have other states protected adolescent HIV patients, ensuring that they receive adequate and complete information about their status without having to resort to a court order? California and New York, states with

comparably comprehensive legislation concerning the privacy and confidentiality of HIV status, reflect some interesting variations. Worth noting is that California specifically provides that the results of an HIV test may be disclosed to a person believed to be the subject's spouse or sexual partner, the subject's hypodermic needle-sharing partner, and/or the county health officer.³³ As long as this disclosure is done according to statutory specifications, the person making such disclosure may not be civilly or criminally liable.³⁴ Similarly, New York permits disclosure of HIV status to a limited group of "contacts" that does not extend to children or minors.³⁵ Both statutes reflect the privilege-to-warn principle identified earlier, but neither state would permit physicians in the case under discussion to disclose to the child, as children are not within the protected group. That the nation's three most comprehensive legislative schemes do not explicitly permit disclosure of HIV status to adolescents, in situations such as these, indicates the state of the law at this time.

It is worth noting, however, that the California statute may afford an alternative avenue to physicians in such a predicament, although research reveals no case law on the issue.

Addressing consent to be tested for HIV status, California law provides that "when the subject of an HIV test is not competent to give consent for the test to be performed, written consent for the test may be obtained from the subject's parents, guardians, conservators, or other person lawfully authorized to make healthcare decisions for the subject. *For purposes of this paragraph, a minor shall be deemed not competent to give consent if he or she is under 12 years of age*" (emphasis added).³⁶ This provision raises the possibility of giving an adolescent older than the age of 12 years the right not only to consent, but also to receive information — rights not available under Florida law.

It is important, however, to underscore that the age, experience, intelligence, and maturity of a child may be factors in balancing rights and responsibilities. For example, a judge in Bangor, Maine, allowed a mother of an HIV-infected son to refuse treatment for the boy because she feared the powerful drugs would "kill him rather than extend his life . . ." ³⁷ Whether that would be the same outcome were the child an adolescent and able to understand the risks and benefits is an unanswered question.

In a discussion of this issue on a more global level, Hartman³⁸ suggests that a federal law titled The Younger Americans Act is necessary to protect the emerging and strong interests of adolescents in medical decision making. The scope of her analysis is broad — ranging from fertility to end-of-life issues — but her solution is a more long-range approach that will not resolve immediate and serious medical issues such as the one confronting the physicians in this case. Instead, attention must be focused on the particular and thorny public policy issues presented in the HIV/AIDS arena, in which the task of balancing confidentiality and the right to be informed has a peculiar immediacy.

At the very minimum, this case points to the need for creating a clear and specific statutory exception to the patient's strong right to confidentiality of her or his HIV status. In a circumstance when a patient's refusal to permit disclosure triggers serious health concerns in a person who both has a right and a need to know his or her medical situation, the therapeutic privilege discussed here should be translated into law. Obviously, it must be carefully drawn to prevent abuse and unwarranted breaches of confidentiality. Years of effort to create a public policy that respects private healthcare information must not be undermined by hasty attempts to remedy a serious, apparently unanticipated consequence of this strong policy. Nonetheless, public policy requires nothing less than a remedy in fact to the conundrum presented by this case.

CONCLUSION

This case began when there was no effective treatment for AIDS and the primary focus of HIV-related legislation was to both insure patient confidentiality and protect against discrimination. The treatment and monitoring of HIV disease has since undergone a radical transformation. This change occurred because of the availability of effective antiretroviral therapy and continuing advances in the understanding of the pathophysiology of this disorder. That the child in this case was not able to be treated more effectively was largely due to two factors: the mother's denial and our inability to gather more support for disclosure at an age when the child could have assumed primary responsibility for medical care and before extensive cognitive impair-

ment occurred. These failures stand as sentinels at a gate through which this patient, had she passed, might very well be facing the challenge of telling *her* children of this unhappy diagnosis.

As the clinical realities have changed, so must we work to change the common misconceptions regarding this disease. Adopting a pro-active stance toward disclosure should further this goal. A written policy has been instituted in our hospital that actively fosters disclosure.³⁹ This policy describes what procedures should be followed should a parent or legal guardian persistently refuse (permission) to disclose the diagnosis of HIV to a child over 12 years of age. It requires that each case be reviewed individually. If there is evidence of medical neglect as evidenced by the parents refusing or failing to comply with HAART despite repeated counseling, then the case must be referred to the Child Protection Services. If not, then the case is presented to the Pediatric Bioethics Committee for review, with the opportunity afforded to the parent or legal guardian to present their arguments for nondisclosure. If the committee concurs that disclosure is in the best interest of the child and the parent still refuses, the case is referred for further legal consultation. If the adolescent is or is about to become sexually active, then he or she can be informed of the HIV diagnosis despite the parent's refusal. At the end of the day, in both law and institutional policy, public health holds the strongest hand.

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39. Copies of the policy regarding disclosure can be obtained by contacting the corresponding author at cmitchell@med.miami.edu.