Title

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Journal

Pediatrics, 114(5)

ISSN

0031-4005

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Publication Date

2004-11-01

DOI

10.1542/peds.2004-1231

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Pediatrics 2004;114;1316-1320
DOI: 10.1542/peds.2004-1231

SPECIAL ARTICLE

Providing Life-Saving Health Care to Undocumented Children: Controversies and Ethical Issues

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ABSTRACT. Pediatricians and hospitals with special pediatric expertise are facing the dilemma of rationing care to uninsured, undocumented children, especially for expensive life-saving care such as transplants, chemotherapy, and dialysis. This article reviews a relevant case history and provides a review and discussion of the ethical and policy issues associated with this problem. ***Pediatrics*** **2004;114:1316–1320;** ***life-saving health care, undocumented children, child health policy.***

Latinos have become the largest minority population in the United States, making up 13% of the total US population. Approximately 40 million Latinos in the United States are citizens or documented residents, along with a large and growing number of undocumented Latinos.[1] In 2000, it was estimated that ~4.8 million undocumented persons from Mexico were living in the United States.[2] Almost every community in the United States faces the challenge of providing care to this population, because the federal government has left much of the funding of health care for uninsured undocumented persons to individual states, local governments, hospitals, and clinics. Emergency Medicaid was established in 1986 by the federal government to help pay for health care expenses when certain defined groups of persons, including any uninsured documented and undocumented children, are sick enough to be hospitalized with a specifically defined "emergency medical condition."[3] The Medicaid Act defines an emergency medical condition as: "a medical condition manifesting itself by acute symptoms of sufficient severity (including extreme pain) such that the absence of immediate medical attention could reasonably be expected to result in any of the following: (1) placing the health of the individual (or, with respect to a pregnant woman, the health of the woman or her unborn child) in serious jeopardy, (2) serious impairment to bodily functions, or (3) serious dysfunction of any bodily organ or part."[3] Individual states administer the program and are allowed to broadly interpret eligibility requirements and benefits set by the federal government.[4] The states are reimbursed for part of the costs of the emergency Medicaid program. In the vast majority of cases, if a child receives emergency Medicaid in the hospital, it will not cover the costs of out-of-hospital ongoing care. Furthermore, undocumented children cannot qualify for state Medicaid insurance to cover ongoing treatment for a given illness. Increasing health care expenditures for this population in an environment of widespread state budget deficits are adding to the already severe financial and resource problems for public safety-net hospitals and clinics as well as not-for-profit community hospitals. Pediatricians and hospitals with special pediatric expertise are facing the dilemma of rationing care to uninsured undocumented children, especially for expensive life-saving care such as transplants, chemotherapy, and dialysis. The following case history and discussion illustrate many of the ethical and policy issues associated with this problem.

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Accepted for publication Jul 30, 2004.
doi:10.1542/peds.2004-1231

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THE CASE

LC is a 10-year-old Mexican boy who was living and attending school in the western United States for the past year. He moved with his mother to a state farther east to be closer to grandparents and other family members. Just before coming to this state he was hospitalized for "acute renal failure" and was discharged on a phosphorus-binding agent (PhosLo) at 3 tablets every other day. At discharge, his hematocrit was 24%, his serum urea nitrogen was 70 mg/dL, and his creatinine was 6.9 mg/dL. His electrolytes were normal. Two weeks after moving, he presented to a community health center at which a physical examination revealed a pale, small boy whose weight and height were both at the 5th percentile for his age. He reported a normal urine output and did not appear to have edema. His heart rate was 100 beats per minute, his blood pressure was 130/90 mm Hg, and laboratory findings included the following results: sodium, 140 mmol/L; potassium, 4.1 mmol/L; chloride, 105 mmol/L; bicarbonate, 18 mmol/L; calcium, 9.5 mg/dL; phosphorus, 5.0 mg/dL; alkaline phosphatase, 609 U/L; hematocrit, 24% with a normal mean cell volume; serum urea nitrogen, 70 mg/dL; and creatinine, 7.0 mg/dL. His urinalysis was unremarkable. After a telephone consultation with a pediatric nephrologist, a renal ultrasound was obtained and showed hyperechoic, small kidneys bilaterally, consistent with chronic renal failure. A C3 level at that time was normal (150 mg/dL).

The pediatric nephrologists informed the primary care pediatrician that they would provide telephone consultation to help manage her patient medically

but that the hospital had a policy to neither provide dialysis nor kidney transplantation to undocumented uninsured end-stage renal-failure patients. LC was started on calcitriol at 0.25 μg every other day and renal vitamins (nephron-FA) at 1 tablet every other day, in addition to continuing on PhosLo at 3 tablets every other day. LC was also begun on erythropoietin at 6000 units by subcutaneous injection every week. Arrangements were made to have erythropoietin donated through the manufacturing company (equivalent to a donation cost to the company of $243 per week). During the next several weeks, his serum bicarbonate decreased to 15 mmol/L, and he was started on bicitra at 30 mL 3 times per day.

The primary care pediatrician explained to the family that LC had chronic end-stage renal failure and would need dialysis while awaiting a kidney transplant. LC's mother did not want to go back to Mexico to seek care for her son, as was suggested by some pediatricians, because she had no health insurance in Mexico, was uncertain that he would receive the needed care, and did not want to leave her extended family, who now were living with her. The primary care pediatrician discussed the case with several pediatricians in administrative leadership positions at the hospital, including a member of the hospital's ethics committee. She tried to convince them to make an exception for LC. However, the hospital administration felt it should not make an exception to its policy, noting that it was already covering the chronic dialysis costs of 2 other undocumented children who had started dialysis before establishing the policy. After making several inquires, the primary care pediatrician contacted a pediatric nephrologist in another state willing to dialyze LC. This nephrologist suggested that the family move to get care at his hospital, which did not have a formal policy of limiting care to undocumented children. One month after their visit with the primary care pediatrician, LC and his mother moved >1200 miles to this state (using bus tickets donated by a charity fund in the local hospital), initially living in a homeless shelter. LC started peritoneal dialysis 1 month after arriving. Later, other family members, including grandparents, also moved. Subsequently, several local Latino community and religious groups, the local children's hospital, and area newspapers spearheaded a fundraising campaign to raise the $75 000 needed for his kidney transplant. Fourteen months after settling in this community, the family had raised sufficient funds for the transplant, and arrangements were being made to have the mother donate 1 of her kidneys to her child.

DISCUSSION

This case highlights the following important but complex questions:

1. Should hospitals with special pediatric expertise have formal policies on providing expensive lifesaving care to uninsured children who are undocumented? If so, how should these policies be developed?

In this case, a not-for-profit community hospital had a policy to neither perform transplants nor carry out chronic dialysis for uninsured undocumented children but was more flexible in its approach to uninsured documented children eligible for Medicaid. Dialysis is the only chronic therapy for acute renal failure that is covered by Medicare regardless of the patient's age. In the case of noncitizen children, developing standardized policies that are disseminated to hospital staff and the public may be more just and equitable than making individual arbitrary decisions by a poorly defined process. However, deciding which therapies are too costly can be extremely difficult and seemingly arbitrary, not only from a monetary standpoint but also from an ethical one. For example, in some hospitals, chronic dialysis is not allowed, whereas more expensive cancer chemotherapy is provided. In certain situations, expensive interventions such as a transplant ultimately may be more cost-effective by reducing the need for frequent emergency department visits, hospitalizations, and expensive chronic care therapies. However, both the hospital administration and physicians must be willing to provide the transplant as well as the patient's chronic posttransplant management, including life-long medications and follow-up. In addition, the hospital may have to accept the full cost of the transplant, whereas emergency Medicaid may only pay for a portion of the hospitalization costs. Implementing a uniform policy for care to undocumented children is likely to be restrictive and would probably fail to consider all possible outcomes such as risks and benefits of a given procedure for a given child, extenuating life circumstances, possible outside funding opportunities, and the hospital's current finances. Establishing a structured process with a panel of pediatricians and hospital staff who would assess these considerations and make a recommendation may be a more just and equitable approach. This approach could result in the formulation of a type of medical individual expense plan for uninsured patients that could include providing financial aid, discounted treatment, and payment plans as well as philanthropic support and active fund-raising for undocumented children requiring care. Potential sources of funding to help establish local health-coverage programs for undocumented children might include targeting financially successful immigrants in a given community as well as businesses that employ a significant number of immigrants.

2. To what extent can hospitals absorb the expenditures associated with providing expensive lifesaving care to undocumented children without compromising new and/or existing clinical programs?

Hospitals that traditionally serve large numbers of low-income families are facing many challenges to their financial stability as the numbers of uninsured increase, public insurance programs such as Medicaid and Medicare pay less than cost of care, and the ability to "cost shift" to commercial insur-

ance plans continues to diminish. Some safety-net hospitals in communities with substantial immigrant populations such as Los Angeles, California, Arizona, and Texas have become financially insolvent trying to serve large numbers of uninsured patients who are citizens/legal residents or undocumented. In Texas, which has the largest number of uninsured in the United States (~1 of 4 residents), ~170 000 children will lose health insurance coverage by 2005 because of state cuts in health-insurance subsidies.[5] In Arizona, the University Medical Center in Tucson wrote off more than $3 million for providing care to undocumented patients in 2000–2001.[6] Hospitals with pediatric expertise may be committed to supporting programs that are unable to generate the revenue needed to sustain these programs. Examples of such programs include those in child abuse, child development, metabolic disease, and genetics. Primary care clinics that serve uninsured and publicly insured patients also require substantial hospital subsidies. Many hospitals and pediatric departments rely on private philanthropy and/or government grants to maintain these programs. Providing expensive life-saving care to undocumented children over what has been budgeted may place these other subsidized clinical programs at risk. A difficult question that some hospitals might be forced to confront is where the balance lies in deciding whether to downsize a primary care clinic serving low-income children or to provide chronic dialysis and a kidney transplant to an uninsured child without documentation. To avoid such a challenging issue, creative financing mechanisms may have to be considered, such as developing a charity care pool for noncitizen children using a portion of revenue generated from each fee-for-service patient who pays out of pocket, international agreements from patients' countries of origin to subsidize their care, fund drives from immigrant communities, and donations from businesses frequently employing immigrants.

3. To what extent will hospitals that provide expensive life-saving care to undocumented children attract increasing numbers of these children from other hospitals and directly from Latin America?

   In this case, a hospital in another state was willing to absorb the costs of dialyzing LC and assist the family in raising funds for a kidney transplant. As fewer hospitals become willing to provide expensive life-saving care to undocumented children, increasing numbers of children will present to the remaining hospitals that will provide this care. Ultimately this shift may force those hospitals to also adopt more restrictive policies. This effect highlights the urgent need for a national discussion and a unified approach to the problem.

4. Will denying acute and chronic care to undocumented children result in higher expenditures related to preventable hospitalizations and more expensive therapies and have unintended public health consequences? In this case, failure to begin LC on chronic dialysis would have resulted in his hospitalization with hypertension, acidosis, and uremia. Although in the hospital (probably in the intensive care unit) he would qualify for emergency Medicaid and have in-hospital emergency dialysis, he then would have been discharged to wait to become ill enough to be readmitted, and his condition would continue to deteriorate. This cycle of preventable hospitalizations would likely be even more expensive than the dialysis and cause significant long-term morbidity and a high risk of early death. Recognizing this, states should attempt to redefine what conditions are eligible for emergency Medicaid, as was done successfully in a recent case in Arizona.[7]

   Failure to provide care could also have unintended public health and societal consequences. Undocumented foreign nationals are totally integrated in the social fabric of our lives. They harvest our crops, work in our restaurants, clean our houses, care for our children, work in our hotels and resorts, and shop with us. Their health status directly impacts the public health and economic well-being of entire communities. Failure to immunize their children or identify and treat communicable diseases such as tuberculosis and hepatitis places both their children and others at risk for vaccine-preventable diseases and infectious diseases. Failure to treat children with chronic diseases directly impacts the health of individual children, their ability to learn and attend school, and parents' ability to work. Promoting access to quality health care and avoiding new access barriers to care for these children and their families may provide the optimal mechanisms for reducing public health and societal risks and costs.

5. Can arrangements be made for these children to return to Mexico or other Latin American countries of origin to receive expensive life-saving care?

   In the majority of cases, this is probably not realistic. Mexico is a developing country with wide disparities in access to health care. Infant mortality, a good indicator of access to health care and the general health of the population, ranges from 103 deaths per 1000 infants in the poorest areas of Mexico to 9 deaths per 1000 in the wealthiest areas. Approximately 50% of Mexico's 100 million citizens are uninsured and live in poverty.[8] In Mexico, uninsured families qualify for an "essential health package," which includes funding for family planning; Papanicolaou (Pap) smears; prenatal, delivery, and postnatal care; basic child nutrition/growth monitoring; vaccines; ambulatory care of diarrhea, respiratory illnesses, and parasitic infections; and prevention/control of active tuberculosis, hypertension, diabetes, and accident prevention/first aid. Perhaps the American Academy of Pediatrics or subspecialty pediatric academies could help to establish formal relationships with children's hospitals in Mexico to share in providing care for undocumented children with chronic medical problems, which could involve providing some services in the United

States and then coordinating long-term care/follow-up in Mexico.

6. Is it ethical for a pediatrician and/or hospital to refuse to provide life-saving care to an uninsured child without documentation when it would provide the care to an uninsured child who is a citizen or legal resident?

   Should the decision to provide care to a patient be based on whether a child has the correct documentation rather than on the patient's need and the physician's ability to help cure or alleviate his or her problem? Should a child's place of birth determine if a patient will be treated and live? Many sectors of our economy benefit from the labor of undocumented workers, including agriculture, construction, the restaurant industry, and tourism. Is it ethical for our society to benefit from the labor of undocumented immigrants but refuse to save the lives of their children when we have the capacity to do so?

POLICY INITIATIVES

Currently, pediatricians often find themselves in an untenable situation when caring for an undocumented child needing expensive life-saving care. Their role as a physician and patient advocate often leads to conflict with the hospital administration, which is balancing the need to provide care with the need to remain financially solvent. "No margin-no mission" has become the bottom line for many institutions, yet there are significant ethical, public health, and expenditure consequences when we deny needed care to these children. The Supreme Court recognized these types of consequences when in 1982 it upheld the right for undocumented children to receive a public school education, arguing, in part, that denying education to undocumented children unduly penalized this group, whose parents and not their children had broken US law. As stated in the ruling, "the deprivation of education takes an inestimable toll on the social, economic, intellectual, and psychological well-being of the individual, and poses an obstacle to individual achievement."[9] Clearly, and perhaps more urgently, the same argument could be made against denying health care to these children.

The District of Columbia, Massachusetts, New York, and Rhode Island have developed initiatives to provide some health care for undocumented children by using nonfederal funding.[10] Other local initiatives include pooling county and city monies with funding and support from community grassroots organizations, businesses, and private foundations. Such an initiative was undertaken in 2001 in Santa Clara County, California. In this model, health care (including primary, specialty, inpatient, and emergency care) is provided to all children ≤18 years old, regardless of immigration status, who have family incomes ≤300% of the federal poverty line.[11] Charity care may be another approach. In 1998, Kaiser Permanente Northern California established subsidized care to low-income children, including those who are undocumented. As of 2002, 1891 children had been enrolled in their Child Health Plan.[12] Studies need to be done to address whether there is a true cost savings as a result of these initiatives, as evidenced by decreased emergency department use and severity of disease at presentation.

Arrangements should be established that spread the cost of care for undocumented children across all hospitals. The financial health of hospitals caring for large numbers of uninsured patients would be improved if hospitals with greater financial stability (because of their patient-payer mix) contributed to the care of the uninsured either directly or through payment transfers. A successful example of this model is the Uncompensated Care Pool in Massachusetts,[13] which provides medically necessary services to low-income uninsured and underinsured people. Another financing option to explore would be to consider revising Medicaid's Disproportionate Share Hospital Program[14] (designed to help safety-net hospitals that serve large numbers of Medicaid and uninsured patients) to include needed medical care for undocumented immigrants.

One new program, created as part of the 2003 Medicare law, allocates funding to hospitals that provide emergency services to undocumented immigrants (the most substantial funding will go to states with large immigrant populations including California [$72 million], Texas [$48 million], and New York [$12 million]). The initiative originally was praised by state officials and hospital directors as a significant step to help decrease the financial burden faced by states with large undocumented-immigrant populations, shifting the burden to the federal government. Recently, however, the federal government stated that for hospitals to receive this money, they must ask patients for proof of immigration status. Linking these funds to what many see as a way to identify and track undocumented immigrants for future deportation could deter many immigrants from seeking needed health care and potentially jeopardize the public health of many communities.[15]

Recently, the Bush administration proposed a guest-worker program, allowing millions of undocumented immigrants to work legally in the United States for a 3-year period. On return to their country of origin, these immigrants would receive monies set aside for Social Security and retirement programs.[16] Not mentioned in this proposal, but vital to its success, is the need for health care coverage for these workers and their families while in the United States. The federal government should share the costs of health insurance with employers who participate in this program.

Hospital administrators and physicians should consider lobbying their county, state, and federal governments to expand health care coverage to all children regardless of documentation. To help in this effort, more research is needed on health care disparities for undocumented children, including short-term and long-term morbidity and mortality and system and societal costs and adverse outcomes.

There is an urgent priority for discussion and research initiatives to take place at the city, county, state, and federal levels to address the delivery and financing of medial care to foreign national undocu-

mented children residing in the United States. Major adverse consequences for our health care delivery system will persist and perhaps worsen should we continue failing to address this issue rationally and equitably.

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THE DOCTOR IS ONLINE

"Lots of patients want to e-mail their physician, but few doctors are willing to communicate online. The problem: privacy and security issues—and the fact that insurers haven't been willing to reimburse doctors for their time online. That is changing as new secure message systems offer both secure communication and a system to reimburse doctors for online consults. . . . Reflecting the growing acceptance of online consults, the American Medical Association, which licenses the coding system most doctors use for billing, recently announced a new code for online medical communications. Once insurers regularly reimburse for online consultations, 40% to 50% of doctors will use such systems within 2 to 3 years. . . . Some online-consulting sites simply charge patients directly. Medem [a provider of secure Web sites for doctors] says the 11 000 doctors using its secure messaging system charge an average fee of about $26, but they end up charging only about 40% of the time because the query was easy to answer or didn't require much time."

Landro L. *Wall Street Journal*. September 3, 2004

Noted by JFL, MD