Medical Neglect of Children

Reporting Issues for Nurse Practitioners

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ABSTRACT

Neglect is the most commonly reported form of child maltreatment, yet the reports raise difficult issues for advanced practice nurses. While federal law defines child neglect and sets minimum guidelines, advanced practice nurses are bound by their state laws, where specific definitions vary and reporting standards involving imminent harm to the child may be difficult to interpret. Ethical issues around reporting of medical neglect and the unintended consequences of intervention to protect vulnerable children are explored using a case study of one seriously ill toddler. A framework for approaching medical neglect is discussed.

Keywords: Child abuse, child maltreatment, cultural competence, ethics, medical neglect, neglect

More cases of neglect are reported every year than any other form of child abuse,[1] yet this area can be challenging for advanced practice nurses. Child neglect is defined under federal law[2] as any act of omission or failure to meet the basic needs of a child, including clothing, education, food, emotional needs, medical attention, safety, shelter, sleep, and supervision. While federal law sets minimum guidelines, advanced practice nurses are bound by their state laws, where specific definitions vary, and which may or may not include exemption from medical care for religious reasons.[3] In contrast to physical and sexual abuse, where a single act must be reported, neglect may be manifested as a series of omissions over time.[4] As acts of omission accumulate, is one skipped health care appointment too few? Are six too many? What constitutes appropriate supervision? When does a disagreement with a family over the best treatment for the child become grounds for a neglect report? Do some families get a break or another chance before we report? And what about cultural differences?

In this article, I will address 2 of many critical issues in the area of medical neglect: the decision to make a child abuse report the decision to remove a child from a parent's care because of medical neglect, which is often made by child protection staff in consultation with health care providers. I will illustrate how these issues presented themselves in the case of Manuel*, a toddler with acquired immune deficiency syndrome (AIDS), whom I met as an RN and whose story continues to challenge and inform me in my current expanded roles as pediatric nurse practitioner (PNP) and educator.

*The names of Manuel and all family members have been changed to protect confidentiality.

I first met Manuel when I was working for a nonprofit community clinic in the San Francisco Bay Area, and my job involved connecting clients with human immunodeficiency virus (HIV) infection to early intervention services. Approximately 20 months old, he had been diagnosed with AIDS when he was hospitalized as an infant with pneumocystis pneumonia. Until this hospitalization, his mother had no idea that she was also infected and was already pregnant with her third child.

The year was 1992; we did not yet have highly active antiretroviral therapy (HAART), and many cases of HIV progressed rapidly to AIDS, with almost 100% mortality. Community services were overwhelmed, and although special housing for HIV-infected families was under construction, it was not yet locally available.

I learned that Manuel's mother, Graciela, had most likely been infected by a boyfriend who had since deserted her and the children, leaving her with a broken heart and a large unpaid phone bill. Her lack of a working phone rendered her ineligible for most in-home support services. A recent immigrant from Mexico, she had low literacy skills in Spanish, spoke no English, and seemed to have some cognitive impairment — we could not tell if it was from HIV, from intense grief, or was pre-existing. Graciela struggled to keep her own and Manuel's many appointments and to give his medications correctly.

While my role at the time was to work primarily with Graciela herself, I was part of a care team that included our clinic social worker (SW), the SW from the pediatric infectious disease clinic where Manuel received his care, and the public health nurse (PHN).

One day the PHN called to consult — she had been to the house, and when she knocked on the door, 6-year-old Belinda had opened the door, not knowing who was there. She was alone with Manuel. Ten minutes later, Graciela came back with the baby, having gone to the store to buy milk and diapers. She explained to the PHN that she did not have the energy to take all 3 children to the store with her and there were no neighbors who could watch the baby. The PHN's dilemma: should she make a child abuse report?

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Although Graciela came from a small village in Mexico where young children were routinely entrusted with sibling care and neighbors were readily available to help, her current neighborhood was not a safe place to leave a 6-year-old child with a seriously ill toddler, especially a child who would readily open the door to strangers. The PHN filed a child abuse report for neglect. While the first report resulted in no action, Graciela continued to struggle to meet her children's needs, and subsequent reports prompted Child Protective Services to assign a bilingual bicultural social worker in a family preservation unit to the case, who was able to arrange in-home support and respite care.

Manuel continued to deteriorate, starting to lose weight. He always had a look of apprehension on his face, and none of the providers involved in his care had ever seen him smile.

On a subsequent visit, his SW realized that Manuel's 6-year-old sister was often entrusted with measuring and administering his medications. A conference was held with the pediatric infectious disease providers and SW, nursing and SW staff from the community clinic, and the PHN and Manuel's child protective service worker. Graciela was not at this conference. A decision was made, reluctantly, to remove Manuel from Graciela's care and place him in a therapeutic foster home, several towns away.

The foster mother welcomed Graciela and her other children to visit as often as they liked, but they were dependent on rides from clinic staff. The infectious disease clinic reported that Manuel was transformed: gaining weight, playful, and smiling. However, 2 weeks after he was placed in foster care, Manuel died in his sleep, of AIDS-related complications. The clinic SW rushed Graciela down to the foster home so she could hold Manuel before he was removed from the home, and social services paid all expenses for a religious funeral and burial. Shortly after Manuel's death, Graciela moved with her remaining children to Southern California to stay with relatives, and we lost touch with her.

When I tell this story in trainings, participants are split between those who think that it would be a terrible punishment to file a child abuse report about this struggling mother and those who advocate reporting as a way to encourage more services. The reporting opponents raise the issue of the potential stigma of a child abuse report, and their heart goes out to Manuel's