Planning for Children Whose Parents Are Dying of HIV/AIDS

ABSTRACT. Although the character of acquired immunodeficiency syndrome is changing into a chronic illness, it is estimated that by the end of this century, 80,000 children and adolescents in the United States will be orphaned by parental death caused by human immunodeficiency virus infection. Plans for these children need to be made to ensure not only a stable, consistent environment that provides love and nurturing, but also the medical and social interventions necessary to cope with the tragic loss. Pediatricians should become aware of local laws and community resources and initiate discussion early in the course of parental illness to facilitate planning for the future care and custody of the children. States need to adopt laws and regulations that provide flexible approaches to guardianship and placement of children orphaned by acquired immunodeficiency syndrome.

ABBREVIATIONS. AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus.

THE PROBLEM

Health care professionals caring for children of parents who are chronically or terminally ill with acquired immunodeficiency syndrome (AIDS) should consider raising the issue of planning for the future of these children at an appropriate time in the course of the parents’ illness. It is estimated that by the end of this century, parental death caused by human immunodeficiency virus (HIV) infection or AIDS will result in as many as 80,000 orphaned children and adolescents in the United States.1,2 For parents who face worsening illness and impending death, one of the most painful realizations is the inability to care for their children, plan their futures, and see them grow to maturity. In the context of HIV infection, both parents are likely to be infected and possibly ill or dying, and the mother may be quite isolated and not have assistance from the father of the children, who may have died or is unavailable. Future planning for the children can create peace of mind for parents by assuring that the children will be cared for according to the parents’ wishes concerning their future. Future planning is a difficult and complex process that requires considerable time and effort and should be initiated in a sensitive manner early in the course of illness. Parents often are reluctant to initiate such planning because of a sense of guilt, denial of the seriousness of the illness, or fear that others may learn about the diagnosis.

Planning for the future of a child or adolescent who will be orphaned includes creating a stable, nurturing environment providing love and stability. At the same time, the legal framework and social interventions necessary must be provided for the child to cope with the loss of their parents and to receive necessary medical, mental health, and educational services.

BACKGROUND

Children and adolescents who are orphaned by the HIV/AIDS epidemic are generally from families who have experienced the consequences of poverty, lack of access to services, discrimination, and family disruption. They are most often cared for solely by their mother, with or without the assistance of other family members such as a grandmother.3 It is, therefore, not surprising that parent(s) may be somewhat reluctant to discuss the issue of their own death and the planning for their children.4,5 Parents with HIV/AIDS may fear the potential stigmatization and isolation from family and community that is associated with revealing the diagnosis. In addition, they may fear losing custody or parental rights to direct their child’s future when they reveal concern about their future loss of capacity.6 They also may be concerned about the burden imposed on potential guardians such as a grandmother, sister, or aunt, and may be reluctant to raise the issue of planning for their children. Most poignantly, the parents may be reluctant to face their own potential death and be unwilling to discuss their child’s future with the child or with anyone else.7

A legal guardian is appointed by a court and is empowered, in lieu of a parent, to make day-to-day decisions for a child, including issues involving health care, housing, and education. Once a guardian has been appointed, that person assumes legal authority for the child even if the chronically ill parent and guardian have agreed informally that the guardian will not assume responsibility until the parent is no longer able. A parent can ask the court to designate a guardian for a child, but the other parent, if alive, must agree to the appointment or be judged to be unknown, unavailable, or determined to have relinquished parental rights. A parent can designate a guardian in a will, but the authority comes into effect only after the completion of the approval of the guardianship petition by the court after the death of the parent.8–10 Some states have created flexible laws and regulations that aid ill parents in planning for...
their children’s future. New York, New Jersey, Illinois, Florida, North Carolina, and California have instituted a stand-by guardianship law to authorize a guardian to be temporarily or permanently designated by a chronically ill parent to make decisions for the child at a specified time such as at the death of the parent or when the parent becomes physically debilitated or mentally incapacitated. This guardianship arrangement can allow the parent to resume custody if sufficient health returns. This approach allows maximal involvement of the parent while alive, and immediate clarification of guardianship for the child after the death of the parent.

Foster care agencies generally have not developed flexible policies for placement of children during episodes of parental illness and rapid return of the children to the parent when sufficient health warrants resumption of custody. This is particularly important as HIV infection becomes a chronic disease with multiple acute episodes of serious illness. Agencies also should make efforts to keep siblings from being separated or losing regular contact with one another when making foster care arrangements.

Children and adolescents who have experienced the death or face the impending death of a parent require sensitive bereavement counseling services including information, long-term emotional support, and preventive services. Pediatricians should be aware of community and financial resources to assist such children and families and should monitor the grief process and provide appropriate anticipatory guidance and referral when needed.

CONCLUSION

Because an increasing number of children and adolescents are being orphaned because of the death of their parents from HIV/AIDS, health care professionals should assist chronically ill and dying parents to plan for the future of their children. Creating loving and nurturing environments for such children by providing the legal framework; the counseling and other necessary social and financial services; and the stability of a clear, consistent family structure enhances the outcome for children while assuring that chronically ill parents participate actively in the planning process.

RECOMMENDATIONS

1. Health care professionals caring for the children and adolescents of chronically and terminally ill parents with AIDS should assist families to create a plan for the future care and custody of their children. This discussion should be initiated in a sensitive manner early in the course of parental illness and take place over an appropriate period consistent with disease severity and the course of the parents’ illness.

2. Pediatricians should refer families for assistance with planning for the future well-being of their children to social service agencies that provide these services. When pediatricians are not aware of such agencies, they should advise parents to contact the HIV Resource Center or the Pediatric AIDS Foundation.

3. Pediatricians should advocate for laws that include provisions to authorize flexible and stand-by guardianship and that provide specific funding to facilitate planning for children with parents with HIV/AIDS who will become ill and have limited life expectancy.

4. Pediatricians should ask state and local child welfare agencies to develop flexible policies that permit temporary placement of children during parental illness and return of the children if the parent regains sufficient health. Whenever possible, such policies should not separate siblings. For those children who are HIV-infected themselves, policies should address the special concerns about the continuity of health care during placement.

5. Pediatricians should advocate for and assist in the development of state-funded programs that provide economic and social support to family members who care for children orphaned by HIV infection. Permanent adoption should be encouraged through the provision of social services and by decreasing economic disincentives.

6. Pediatricians should advocate for state-funded model programs that provide comprehensive mental health care, social support, and legal services for chronically ill HIV-infected parents, their children, and future caregivers and guardians to enhance the well-being of the children and their families. Additional research is necessary and should be promoted by pediatricians to learn more about program effectiveness and the long-term outcomes of the children and their foster and adoptive families.

REFERENCES


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