

Home Health Care for Children who are Technology Dependent

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by Juanita W Fleming, PhD, RN, FAAN

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This is an outstanding new book which brings both pride and sadness to an ethics reviewer.

The pride comes from examining the outstanding work of a nurse colleague who has taken her career pattern of research and developed a guidebook on such an important topic. Fleming conducted several national studies on the needs of technology dependent children and is well grounded in her presentation. She examines all aspects of home care for technology dependent children, based on her own research and that of others. Fleming states that there are 45,000 children on apnea monitoring, 6,000 children on dialysis, 8,000 on long-term intravenous therapy, and 2000 children living at home on ventilators. She concludes both nurses and families will have significant needs in order to make home care work.

The book is provided as a reference for health care professionals caring for technology dependent children who live at home. Fleming lays out what nurses will need to provide these home care duties and what families will need to make it work.

Nurses, states Fleming, must understand the characteristics of such children and families, have the technical knowledge and skills to provide the mechanical care needed, and support parents who prefer to care for their children at home. Families, she continues, will need adequate training and preparation, appropriate and well-maintained equipment, adequate social and psychological support services, proper transportation, availability in the community of emergency facilities, competent case management services, and high quality respite care services (p. 11). Fleming provides information on how to obtain financial assistance, how to obtain social support, and how to obtain respite care. The book presents the perfect setting for caring for an acutely chronically ill child at home. Pediatric nurses would do very well to purchase this book for all pediatric or neonatal intensive care units that discharge technology dependent children.

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The fact that this book is necessary at all is sad, however. Why are there so many seriously ill children living at home, is this the appropriate place for them, and are we certain that the benefit of their care is greater for them than the burden? After conducting a comprehensive integrative review of research on technology-dependent children and their families, Wang and Barnard (2004) were not sure. They found many difficulties in the emotional, financial, and social costs of bringing medical care and machinery into the home. Wang and Barnard concluded that "the appropriateness of current social and public policies in home health care for technology dependent children and their families should be reexamined and reevaluated, based on the findings of sound research studies... and warrants urgent research attention and consideration from policy makers, professionals, and society." (p. 43).

One hopes that the families will have access to the needed services Fleming sets out for us. One hopes that there will not be repetition of the Kelso and Kelso case, in which Richard and Dawn Kelso delivered their son, his toys, ventilator, clothes and supplies to the Alfred I duPont Hospital for Children in Wilmington, Delaware, stating that they had given up. Despite means and access to nursing services, the Kelsos were unable to secure enough help to maintain their child at home, and surrendered themselves into custody for child abandonment.

Fleming presents us with the very best in her text. She paints a world of services, security, and social support. One should purchase this text with the hope that this book, full of support and respect, is the harbinger of social policy for chronically ill children in our country.

Reference

Wang, K. W. K., & Barnard, A. (2004). Technology dependent children and their families: a review. *Journal of Advanced Nursing, 45*, (1), 36-46.

Also of Interest

Aras, John. (1995). *Bringing the hospital home: Ethical and social implications of high-tech home care*. Baltimore: Johns Hopkins Press