Transition of Severely Disabled Children From Hospital or Chronic Care Facilities to the Community

There has been an increase in the number of children with significant chronic illness requiring long-term care, as well as those with significant limitations of activities.¹⁻⁴ This increase is, in large part, the result of improvements in medical care and technologic advances. Among the groups of children with chronic conditions requiring long-term care are children with developmental disabilities and major congenital defects; survivors of major trauma with residual severe neurologic, neuromuscular, or orthopedic abnormalities; and children with low incidence and extremely costly chronic disorders ranging from those who are dependent on ventilators or have renal failure to children who may be hospitalized less frequently, such as those with cystic fibrosis or hemophilia. These conditions tend to be costly not only in economic terms but also in psychologic respects.⁵⁻⁸

TRANSITIONAL CARE

Many children with severe disabilities or long-term illness require special services to support home rather than institutional care. Transitional care may be defined as those services that support the move of the child from an institution to home and community. At times, special transitional care units provide such services, although, more typically, transitional care services refer to activities that directly strengthen the capacity of the family and community to care for the child at home. Transition to the community requires (1) careful planning and discharge efforts, (2) determination of special home equipment and service needs, (3) educational activities for family and community providers, and (4) development of an explicit plan to provide nursing care and other support services as needed.

SCOPE OF THE PROBLEM

In 1980, approximately 70,000 children younger than 17 years of age with chronic disorders were residents of health care-related institutions.⁴ More than 75% of these children lived in large institutions for the mentally ill or mentally retarded or they were cared for in smaller residential treatment centers, schools, or specialized homes. The remainder resided in a variety of homes and hospitals that were primarily oriented to providing care for the physically handicapped.⁹ The exact number of chronically impaired children residing in acute hospitals on a continuing basis is unknown. In addition, an estimated 75,000 children, the majority younger than 6 years of age, live at home and are classified as unable to conduct the major activities expected of other children their age.⁴

Although caring for such children at home is costly, providing care for children with severe and chronic disabilities in hospitals and long-term care facilities, including large institutions, is even more expensive. Thus, treatment of chronically ill children presents significant problems for the medical and, especially, the pediatric community. The social and economic consequences of providing this care are an issue of national importance.

CURRENT TRENDS IN CARE

Caring for those who are severely developmentally disabled in institutions and for those with chronic illness in long-term care facilities was, in the past, a socially, legally, and medically accepted practice. At the present time, however, an increasing number of parents and professionals have indicated a decided preference for home care. From a legal standpoint, care in the “least restrictive environment,” providing more normalizing experiences, has become a standard set by federal legislation, including Public Law 94–142, The Education for All Handicapped Children Act (1975), as well as other legislation for the developmentally and phys-
ically disabled (Public Law 93–112, Rehabilitation Act of 1973, and Public Law 94–103, Developmentally Disabled Assistance and Bill of Rights Act of 1975.) Severely disabled children are able to live in the community as long as the appropriate community support services are provided. Life at home, rather than in an institution, may enhance the child’s psychologic development, and, in most instances, is preferable for the family as well.

Improved technology has led to the development of sophisticated life-sustaining equipment and procedures. The increasing success in using such equipment at home has created an additional set of dilemmas in attempting to define (1) when a child can be transferred from the hospital to his or her home, (2) who will pay for home care, and (3) who is trained or qualified to care for such children at home or when they attend school.

Hospital care of all children is changing, primarily in response to financing and organizational development, such as Diagnostic Related Groups (DRGs), prospective payment systems, and managed care arrangements. For children with long-term illnesses, these trends tend to encourage greater substitution of out-of-hospital care for inpatient services.

COST FACTORS AND THE CHILD’S BEST INTEREST

The cost of chronic illness places a significant economic burden on the family. The Vanderbilt study reported that 8% of all children in the United States lack any form of insurance coverage or third-party reimbursement including Medicaid. Singer et al reported that 11% of children attending special education programs had no medical insurance; minority families had an even higher percentage of uninsured children. In addition, the pattern of Medicaid coverage, even when available, is variable from state to state, particularly for so-called “optional” services such as appliances, physical and occupational therapy, etc. Even when third-party insurers and Medicaid are relatively generous in their benefits, there is a strong bias toward reimbursing hospital and institutional care rather than care at home.

However, the most important consideration in providing care for the chronically ill child should be what is in the child’s best interest. Unquestionably, the focus must be on what is best for the child and family. As pointed out in the 1984 American Academy of Pediatrics statement on home care, “combining the benefits of home care with optimal medical treatment and support is a challenge requiring development of innovative programs between hospital, physicians, parents, and communities.”

Children with chronic illness have a right of access to necessary health care, regardless of cost. Comprehensive home care programs are expensive, but most studies suggest that there are considerable cost savings in home care, either institutional or hospital care. As the cost of medical care is more carefully scrutinized and regulated, it is evident that economical home care programs represent potential cost-saving approaches. The use of home care may be accelerated by the application of DRGs and similar fixed-cost systems that intend to limit prolonged or unnecessary hospital stays. Despite this trend, it is still difficult, although not impossible, for families to obtain financial assistance through Medicaid or private insurance to care for their chronically ill child living at home.

QUALITY OF HOME CARE

To a great extent, the quality of home care depends on the help offered to the family. The quality of this help is, in turn, heavily influenced by the quality of professional and paraprofessional staff available to provide the services. Successful home care requires the elimination of any remaining attitudinal barriers that have led professionals, especially physicians, to rely on hospital or institutional care as the easiest avenue for obtaining treatment for severely disabled children. Health care professionals, including physicians, nurses, psychologists, and social workers, as well as special educators, should be aware of the negative impact of long-term hospitalization on the social and emotional development of children and also the strain the hospitalization places on family relationships. Professional and institutional roles need reexamination, as do old assumptions about what must or must not be done in hospitals.

REQUIREMENTS OR PREPARATION FOR HOME CARE

A variety of models have been suggested to help achieve transition from an acute or chronic facility to a home environment. Preparation and training are essential for both the child and the family. Special arrangements include (1) proper schooling, (2) family counseling, and (3) necessary equipment or physical modifications for the home. All those involved with the child’s care at home or in the community require training in the use and operation of any specialized equipment that the child may need. This training is vital when caring for children who are dependent on ventilators or hy-
peralimentation. It is necessary to have systems for monitoring equipment, monitoring of the children, and substitute arrangements, including backup medical or residential facilities. Such systems are needed for both medical and psychological reasons. It is also essential to offer respite for families who are providing home care. The severely disabled child presents a continuous and demanding responsibility. Achieving transition to the community and satisfactory ongoing care requires effective community and regional planning, as well as the development of regional centers that can participate in all phases of care for chronically disabled children. It has been suggested that centers be created to serve a region and to deal with a variety of chronic disorders. These regional centers would have expertise in the diagnosis and management of these conditions and, as a result, could provide aid or directly participate in the planning and operation of programs, the training of the child and family, and the monitoring and coordination of care. These centers could also serve as the backup facility. Staff at these regional centers would not only aid in coordinating components in the service system, but also serve as advocates for children and their families.

There is no single model for delivering service in every community. Successful arrangements will take into consideration the resources in the community, community attitudes, and the cultural diversity of the population to be served. Long-range planning must take into account all of these factors, as well as the economic ones.

ROLE OF THE PEDIATRICIAN

Pediatricians who care for chronically ill children are in a critical position to help effect the transition to home care. Pediatricians’ medical judgment and rapport with such families are critical to determining the feasibility and timing of home care. As advocates for children, pediatricians must fully understand the technology and psychology of care at home, as well as the availability of resources in the community.

At the same time, tertiary and chronic care facilities must help clarify the expected role of the primary care pediatrician in the management of the severely disabled child who is being returned to the home and community. Although there will inevitably be problems at the interface between those providing primary care and the tertiary care specialist or facility, adherence to carefully constructed guidelines should enable successful implementation of these home care programs which should minimize the problems of communication.

CONCLUSION

Home care for chronically ill and disabled children is in the best interest of most of these children, their families, and society. The success of home care depends on smooth transition from hospitals, institutions, or chronic care facilities. Proper planning, financing, and training and provision of backup facilities are essential to the success of these efforts. There are a number of possible models for achieving these goals; flexibility is the key. Favorable results depend on each community's use of all its resources. The approach may vary and different mechanisms may be used in different locales, because no single program or center will assure the desirable objective of establishing effective home care models throughout the United States.

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