

PERINATAL

FAMILIES AT RISK: Quality of Life in Technology-Dependent Children and their Families

by Dennis J. Baumgardner, MD

When children require medical technology, most families focus on issues of survival. Medical technology also impacts on the quality of life of the child and all those involved with their care. Medical technology is an enormous physical and emotional commitment. Many of these children receive medical services, including home nursing visits through Medicaid. These services would be severely effected by cuts to this program.

I found few articles in the medical literature describing these issues, so I undertook an informed study with our parent support group to explore these issues. The group includes parents of children between the ages of 3 and 19 who are dependent upon technology (tube feedings, tracheostomies, ventilators, complex assistive devices, and therapies). We also gathered information from focused discussion groups with parents, siblings, and healthcare workers (home- and hospital-based nurses and social workers).

What is "quality of life" for a child who is dependent on technology?

Parents express concerns that healthcare professionals, in particular the initial treating physicians, do not discuss quality of life issues and the long-term outlook with them. Both groups felt that the physicians initially focus on survival rather than on quality of life without an adequate discussion of the effects that caring for the child will have on the rest of the family.

Families complain that their religious beliefs were ignored when decisions about life support were made and that they were not included in discussions about discontinuing support. Some viewed technological support as experimentation. Healthcare workers felt that physicians made decisions about technology and support based on fears of liability suits. Overall, our group felt that our ability to use technology exceeds the sociological and ethical understanding of its impact.

The parents and healthcare workers involved in our study considered quality of life in terms of physical comfort and the ability to function. This includes:

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- the child's basic needs are met (e.g. food, shelter, education);
- the child is living at home comfortably (e.g. positioning and medical care);
- any pain is being managed;
- the child's need for happiness, dignity, respect, and self-esteem are being met;
- the child is capable of social and has an opportunity for interaction;
- the child has an opportunity to achieve as much independence as possible, considering his or her particular disabilities.

What is the family's "quality of life?"

One parent emphasized that, "life was more than breathing." The needs of a child who is dependent on technology becomes the focus of the family. The parents and siblings have a right to have their needs for comfort and independence met. Our group agreed that the following can interfere with these needs:

- physical and mental anguish including exhaustion, burnout, resentment, grief, depression, and suicidal thoughts;
- fear of divorce and disordered aging;
- inhibition of normal family functions and loss of mobility issues.
- isolation from traditional family and social circles;
- lack of respite care;
- injuries resulting from providing care.

Positive aspects of parenting a child with a disability include improved acceptance of other persons with disabilities, personal growth, and intangible rewards such as feelings of accomplishment derived from providing a good quality of life for the child. Healthcare workers fear that parents will make overly optimistic interpretations of the initial information provided by medical professionals.

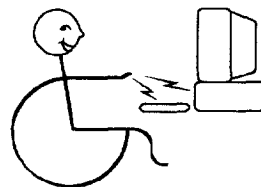
Concerns

Home nursing increases time available for family activities and optimizes the child's medical care, often avoiding hospitalization, but there were concerns voiced as well. Parents noted frustration when promised a particular level of

service at the time of hospital discharge planning, only to have these services pulled away at intervals once home. Parents felt the need to become comfortable moving in and out of the medical role depending on whether a nurse is

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present. They must accept variable quality and inconsistent availability in nursing services, and the lack of privacy that having a stranger in the house creates.

Quality of life—more than survival

Parents and healthcare workers agree that cuts in Medicaid services would decrease quality of life for both the child and the family. The resulting lack of nursing services would lead to increased fatigue, frustration, and sleep deprivation, as well as further erosion of family activities. Parents also worry that fatigue-induced error could affect their child's overall health, as could the lack of input from profes-

sionals. Any cuts in Medicaid would result in family responsibility and expenditure for care. These stresses can weigh heavily on all family members, even the siblings, who voiced fears of poverty and divorce.

Parents, for their part, feel it is unrealistic to expect that they can provide proper nursing care for the child while parenting other children, working, maintaining marital relationships, and performing household duties.

Conclusions

This medically and psychosocially fragile population is in need of ongoing forums for discussing quality of life issues in addition to receiving respite services and

advocacy from their healthcare team. **EP**

Dennis J. Baumgardner, MD, is the parent of a 5-year-old son who has multiple disabilities and spent his first 4 1/2 years on a ventilator. Dennis and his wife, Mary, are the parents of seven children and actively participate in a support group for parents and caregivers of technology-dependent children. This article is adapted from: "Quality-of-Life in Technology-Dependent Children Receiving Home Care, and Their Families—A Qualitative Study" by D.J. Baumgardner and E.D. Burtea, published in the Wisconsin Medical Journal, 1998(3):51-55.



This column is prepared in collaboration with the National Perinatal Association (NPA, 3500 E. Fletcher Ave., Ste. 209, Tampa, FL 33613-4712). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time of birth) issues from preconception through infancy.

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