

Health Affairs

At the Intersection of Health, Health Care and
Policy

Cite this article as:

L A Aday, D H Wegener, R M Andersen and
M J Aitken

Home care for ventilator-assisted children

Health Affairs 8, no.2 (1989):137-147

doi: 10.1377/hlthaff.8.2.137

The online version of this article, along with
updated information and services, is available
at:

[http://content.healthaffairs.org/content/8/2/137
.citation](http://content.healthaffairs.org/content/8/2/137.citation)

**For Reprints, Links &
Permissions :**

http://content.healthaffairs.org/1340_reprints.php

Email Alertings :

<http://content.healthaffairs.org/subscriptions/etoc.dtl>

Not for commercial use or unauthorized
distribution

To Subscribe :

<https://fulfillment.healthaffairs.org>

Health Affairs is published monthly by Project HOPE at 7500 Old Georgetown Road, Suite 600, Bethesda, MD 20814-6133. Copyright © by Project HOPE - The People-to-People Health Foundation. As provided by United States copyright law (Title 17, U.S. Code), no part of may be reproduced, displayed, or transmitted in any form or by any means, electronic or mechanical, including photocopying or by information storage or retrieval systems, without prior written permission from the Publisher. All rights reserved.

Not for commercial use or unauthorized
distribution

DataWatch

Home Care For Ventilator-Assisted Children

by Lu Ann Aday, Donna Hope Wegener, Ronald M. Andersen, and
Marlene J. Aitken

New technologies that help people with severe lung damage to breathe have extended the lives of a number of premature infants and children. Although the numbers of children supported by artificial ventilation technologies are relatively small (estimated at up to 2,000 nationally), they have become increasingly visible because of their long stays in intensive care units, the resultant high costs of caring for them, and the detrimental effects on their perceptual, motor, language, and educational development from long-term institutionalization.¹

Treating these children in the home received little consideration until the U.S. Surgeon General's Workshop on Children with Handicaps and Their Families held in late 1982.² The conference focused in particular on those children who were dependent on ventilators to breathe because of respiratory deficiency resulting from premature birth, trauma, or progressive neuromuscular disease as an illustrative case study of the issues surrounding technology-assisted children as a whole. As a result of the Surgeon General's conference, the Department of Health and Human Services (HHS) funded three demonstration projects to (1) develop and implement a regionalized system of services for ventilator-assisted children; (2) develop and implement a comprehensive, coordinated model of home care for these children; and (3) improve the well-being of patients and their families and reduce costs.

The Center for Health Administration Studies (CHAS) at the University of Chicago was funded to conduct an evaluation of the development, implementation, and impact of the three demonstration programs.³ This DataWatch reports selected findings from our evaluation based on both quantitative and qualitative data on the feasibility and success of devel-

Lu Ann Aday is an associate professor of behavioral sciences at the School of Public Health, University of Texas Health Science Center in Houston. Donna Wegener is a fellow at the Center for Health Administration Studies (CHAS) at the University of Chicago's School of Business. Ronald Andersen is a professor and director of CHAS. Marlene Aitken is a research associate at the University of Illinois at Chicago's Survey Research Laboratory.

oping home alternatives for these children—from the perspectives of the families and children the programs were intended to serve.

Background Of The Problem

The congressional Office of Technology Assessment (OTA) has defined a technology-dependent child as “one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability.”⁴ While this definition could include children with diverse technological requirements, the focus of our study is on children who require a ventilator for all or part of the day.

Little systematic, empirical research has been conducted on the impact of caring for these children at home. Small-scale case studies of ventilator-dependent children have documented positive benefits of home care for the families and the children: improvements in the child’s physical and psychological functioning; reduced costs compared to inpatient care; less travel to and from the hospital; the strengthening and normalization of the family unit; and the restoration of control of caring for the child to the family.⁵ There is also evidence of costs and stresses to the families of caring for these children at home: restrictions placed on the family’s activities because of the child’s unrelenting care needs; intrusion of medical professionals into the family’s privacy and parental decision-making roles; and the heavy financial burden resulting for families because of out-of-pocket costs for services or supplies that are not covered by private or public third-party payers.⁶ The data reported here are based on the most comprehensive and systematic effort to date to document the costs and benefits to the children and their families of having the ventilator-assisted child at home.

Methods

A total of 141 children (out of 216 eligible children), representing 138 families, participated in the evaluation, yielding an overall response rate of 65 percent. At the time of the interview, 80 percent of the children were at home; 7 percent were discharged from the hospital to alternative settings (such as a nursing home or foster home) or were previously at home but temporarily in the hospital. A total of 121 children had been discharged from a traditional inpatient unit. The percentage of children who were hospitalized, having never been discharged, was small (4 percent), and 9 percent of the children were deceased at the time of the interview. All but two of these children had been home before their

death. Semistructured telephone interviews, supplemented with mail questionnaires, were conducted with the families of these children during two periods (fall and winter of 1985–1986 and 1986–1987).

We focus on the 121 children who had been discharged to a home or homelike alternative. These interviews picture families at one discrete point in the continuum of their child's illness experience and ask retrospectively about the diagnosis, hospitalizations, and initial impact of the illness on the family. As a result, the comparisons are reflexive-comparing a family's experiences in having their child at home to when the child was in the hospital. Data from interviews with the families were supplemented with billing information obtained directly from hospitals in which the children were patients (when permission was granted by the parent); rental and purchase prices for equipment and hourly wage prices for health care professionals- who provided care to the child at home directly from vendors; and a consensus on the likely prognoses and anticipated development of the children from a panel of physicians involved in caring for this population,

Characteristics Of The Children And Families

The characteristics of all participating ventilator-assisted children and their families are summarized in Exhibit 1. The majority of ventilator-assisted children were white preschool-age boys, many of whom had been diagnosed with bronchopulmonary dysplasia (BPD), an iatrogenic condition resulting from prolonged exposure to mechanical ventilation as a premature infant. More than half of these children needed to be on a ventilator all or part of the day, and though half had medical conditions that were expected to improve over time, many had problems that would never get better (such as those resulting from spinal cord injuries) or, in fact, could worsen as they got older (such as muscular dystrophy or Werdnig-Hoffman). Their families were working people, with lower middle-class incomes, but many had become dependent on public third-party sources, such as Medicaid waivers or Crippled Children's Services programs, to pay for their child's care.

Characteristics Of The Care Plans

Many of the children in this study had been in the hospital long periods of time (ten months on average) before being discharged (Exhibit 2). Most were discharged directly from intensive care units.

The American Academy of Pediatrics' (AAP) Ad Hoc Task Forces on Home Care of Chronically Ill Infants and Children has developed an

Exhibit 1**Characteristics Of Ventilator-Assisted Children And Their Families**

Children (N = 141)		Families	
Mean age (years)	4.5 (.45)	Number in household related to child	
Mean age at ventilation (years)	2.1 (.38)	1-2	25%
Percent male	64%	3-4	62
Percent white	70	5 or more	13
Primary diagnoses		Birth order of child	
Bronchopulmonary dysplasia	42%	Only child	25%
Disease of the nervous system	20	Youngest	47
Congenital anomalies	18	Middle	8
Injuries	8	Eldest	15
Other conditions from the perinatal period	3	Twin, no other siblings	6
Other	9		
Hours per day currently on ventilation		Family income	
Never vented	5%	Less than \$11,000	15%
Technology discontinued	45	\$11,000-\$19,999	20
Fewer than 8 hours per day	1	\$20,000-\$24,999	16
8-12 hours per day	14	\$25,000-\$29,999	11
13-23 hours per day	12	\$30,000-40,000	18
24 hours per day	23	Over \$40,000	20
Physician's prognosis		Education/employment status of family	
Will get worse	18%	Mean number years schooling	13.2 (.22)
Will stay the same	29	One or more working full time	84%
Will get better	53	One or more working part time	5
		No family members working	11
Type of insurance			
Public only	40%		
Private only	41		
Public and private	19		

Note: The numbers in parentheses for the mean estimates are the standard errors of those estimates.

outline of the minimal requirements for a comprehensive discharge plan for chronically ill children.⁷ Questions regarding the elements of this plan were included in our survey to determine the extent to which these elements were a part of the discharge planning process. An average of 63 percent of the AAP elements were included in the plans for these children (Exhibit 2).

Many children had been home a long time (almost two years on average) at the time of the interview. They averaged four to five rehospitalizations during that period. The principal reasons for these rehospitalizations included surgery and respiratory-related problems, such as pneumonia or asthma. All of the children had a physician they could identify as their "principal physician." These included pediatricians, neonatologists, pulmonologists, or other specialists. Very few of the children had not been to a physician in the year prior to the interview.

Exhibit 2**Characteristics Of Care Plans For Ventilator-Assisted Children****Preadmission hospitalization**

Length-of-stay (mean days)	298 (37.3)
Type of unit	
Intensive care unit	69%
Regular ward	19
Stepdown/transitional unit	12

Elements in discharge plan^a

Medical or social conditions as outlined by physician	91%	Plan for periodic review of care plan	72%
Plans developed for emergencies	92	Plan for educational services	47
Trained while child still in hospital	97	Contract with vendors for service, maintenance	66
At least two family members trained	84	Arrangements for family socio-psychological support	19
Family home checked for safety	60		
Local physician contacted for care	66	Financial coverage through:	
Following services available:		Private funding	42
Home health care vendors	78	Public funding	54
Equipment vendors	87	Other sources	12
Other special needs	39	Family case manager	37
Access to telephone	97	Health professional case manager	52
Percent of all elements in plan	63 (1.6)	Mean number of months since discharge	23 (1.9)

Postdischarge care

Rehospitalizations		Professionals providing service in the home	
Mean number for those with one or more stays	4.4 (.37)	Nurses	86%
Mean length-of-stay (days) for those with one or more stays	18.0 (3.5)	Physical therapists	41
		Teachers	38
		Occupational therapists	37
Specialty of principal physician		Respiratory therapists	34
Pediatrician	56%	Speech therapists	16
Neonatologist	18	Social workers	14
Pulmonologist	18	Recreational therapists	4
Other	8	Dietitians	3
Number of physicians seen		Child counselors	2
None	6%	Other professionals	20
One	21	Mean number of professionals	3.1 (.15)
Two	28		
Three or more	44		
Nursing hours per day		Case manager assigned at discharge	
1-8 hours	3%	None	44%
9-16 hours	29	Nurse	33
17-21 hours	5	Physician	19
22-24 hours	28	Other	4
Mean hours per day	13 (1.0)		
Mean number of visits			
Home	5.1 (1.1)		
Office	18.7(1.9)		

Note: The numbers in parentheses for the mean estimates are the standard errors of those estimates.

^a As outlined by the American Academy of Pediatrics.

Those who did averaged 18.7 visits to the physician’s office and around five home visits during the year. The vast majority of families reported having some type of nursing services in the home. Other professionals providing some services to the child at home (which varied considerably in intensity) included physical therapists, teachers, occupational therapists, and respiratory therapists. The children received around thirteen hours of professional nursing coverage each day on *average*. However, there was great variability by family in the extent of such coverage.

A large percentage of the families reported that no case manager was assigned to help them manage their child’s care at home, once the child was discharged. One-third of the families, however, were assigned a nurse case manager. Around 20 percent of the families thought of a physician as the principal case manager.

Impact Of Home Care On The Children

Exhibit 3 displays data on the impact of home or homelike care on the children in terms of educational status, functional and developmental status, and physical and psychological functioning. Almost seven out of ten children in the study were enrolled in an educational program in the year preceding the interview. Children not in school were often too young for school; alternatively, the state had no 0-3 educational mandate under P.L. 94-142 to provide services to such children. In only 2 percent of the cases did physicians advise against enrollment in a school program.

Caregivers evaluated the child’s developmental status on a scale from one to five, with the higher number representing greater improvement at home compared to the hospital. On average, caregivers thought the

Exhibit 3
Impact Of Home Care On Ventilator-Assisted Child

Percentage in school	68%
General development status at home compared to hospital ^a	
Physical activity	4.7(0.6)
Emotional development	4.7(.06)
Learning ability	4.6(.07)
Functional status score ^b	
Overall scale	2.6 (.03)
Personal Adjustment and Role Skills scale (PARS II) ^c	
Overall scale	3.5 (.05)

Note: The numbers in parentheses for the mean estimates are the standard errors of those estimates.

^a Mean score, all children. Maximum value is 5, meaning much improved at home.

^b All children. Maximum value is 3, meaning maximum physical functioning.

^c Children age five and older. Maximum value is 4, meaning maximum psychological functioning.

developmental status of the children was much improved in the home setting. The questionnaire also incorporated two standardized instruments, designed to capture the child's present functional status and personal adjustment, previously used in studies of chronically ill children (the Functional Status II instrument and the Personal Adjustment and Role Skills scale, or PARS II).⁸ On the measures used in this evaluation, family caregivers thought that the child's functional and developmental status and quality of life were more positive overall at home than when the child was hospitalized.

Impact Of Home Care On Families

Several open-ended questions in the interview asked families to identify issues and concerns regarding their experiences with home care. Any consistent patterns emerging in these responses have great substantive importance since the families spontaneously volunteered responses. Exhibit 4 presents the themes around which families' responses clustered for two of the questions.

Responses to the question, "Now that (CHILD) is home, what seem to be your greatest problems or concerns?," centered on the general health status of the child, personal and family issues, and technical issues. The response mentioned most often concerned the child's health-maintaining the child's health while in the home. and the long-term implications of the condition for the child's overall development. Additional concerns included the technical side of home health care delivery: financial aspects

Exhibit 4 Impact Of Home Care On Family

Main problems and concerns now that child is home

Themes related to general health status	42%	Themes related to personal/family issues	30%
Child's continued health	41	Being unable to leave house	18
Long-range development issues	21	Locus of responsibility for child	8
Themes related to technical issues	34	Professional boundaries and authority	8
Finances	26	Loss of privacy	6
Nursing	16	Feeling alienated	6
Equipment	7	Other themes	44
Home construction	3	Finances mentioned as serious problem	38

Greatest benefits/advantages to having child home

General positive experience	95%	Improvement in child's medical condition	19%
Family seen as "more normal"	70	Improved sibling situation	15
Improvement in child's emotional condition	33	Personal growth/satisfaction for caregiver	10
Reduced travel to hospital	31	Indicates child survived	
Feeling of greater control	27	Other benefits	6

of home care, the competence and availability of home nursing, and the maintenance of the equipment necessary to support the child in the home. On a more personal level, families expressed concerns about feeling tied down to the house because of the care demands; the burden of responsibility for the child's care; the constraints on their privacy; and the tension between the authority of home nurses and parents. Yet despite the concerns or problems home care presented for them, families felt extremely positive about having their child at home (Exhibit 4).

Regarding the seriousness of the financial burden on the family, almost four out of ten families indicated that out-of-pocket expenditures in caring for their child were a serious financial problem. This is, however, probably a low estimate of the true financial burden families experienced. Many families indicated that although the expenses did not cause serious financial problems, they had to forgo luxuries, had to postpone building up savings, had debts that were accumulating, and were lucky to "just get by." The overriding importance of finances in contributing to the stress families felt in caring for the children at home was confirmed in multivariate analyses conducted in connection with the CHAS evaluation.⁹

Cost Of Home Care

The data used to analyze the cost-effectiveness of home care were obtained for a subset of thirty-six children for whom accurate home and hospital cost data could be obtained. The direct and indirect costs of the illness, and the distribution of costs by type of service, were identified for each child. While a comparison of resource use for hospital and home care could employ cost or charge data (cost plus markup), cost-representing actual resource utilization—is the most appropriate basis. The data presented in Exhibit 5, therefore, highlight the costs of hospital and home care. These comparisons are based on "own case (reflexive) controls." The estimates for each child were calculated and, based on

Exhibit 5

Cost Comparison Of Hospital And Home Care Per Day For Ventilator Assisted Child

	Unadjusted hospital costs less home costs	Adjusted hospital costs less home costs
Site A	\$548 ^a	\$378 ^a
Site B	488 ^a	450 ^a
Site C	150	-12
Total	\$418 ^a	\$294 ^a

^a Significantly different than zero at $p < .01$.

physician judgments, were adjusted to account for any potential bias introduced by the expected change in the intensity of resource utilization over time, given the child's condition and the expected course of the disease.¹⁰

Overall home care was less expensive than hospital care; this relationship was maintained even after the calculations were adjusted to account for the expected change in resource use and the natural course of the child's illness (Exhibit 5). Most of the savings was attributed to substituting parental for professional nursing and eliminating frequent laboratory procedures once the child was home.

The extent of this cost savings did vary across the three program sites, due largely to differences in the case-mix of children; the costs associated with hospital care; the regional labor costs; and the availability of professional home nurses in each area. There were no significant differences in the costs of home and hospital care in Site C, in which a large number of families had full time nursing coverage provided in the home. After adjusting for each child's resource utilization and maturation over time, the estimated cost savings for all thirty-six children was \$294 per day.

Multivariate analyses of the differences between hospital and home care costs confirmed the importance of professional home nursing services as a determinant of costs; the greater the extent of professional nursing in the home, lower the cost savings.¹¹ For children with conditions other than BPD, the substitution of parental for professional nursing may, in fact, be the only source of cost savings in the home. However, the nonpecuniary costs to families of caring for their ventilator-assisted child at home should not be overlooked. Additional analyses for these thirty-six children did illustrate that families who had fewer than thirty-two hours per week of nursing coverage at home were more likely to indicate they were unprepared for how unremitting the situation was; felt abandoned in their home; and experienced substantial social isolation in caring for their child. On the other hand, families with more than thirty-two hours of nursing coverage per week were more likely to indicate that they were unprepared for the lack of privacy associated with having professional nurses in their home. Considerable thought is needed on balancing the pecuniary and nonpecuniary costs to these families of having a twenty-four-hour nursing staff in their home.

Policy Implications

The findings reported here are intended to provide input to national, state, and institutional efforts to design programs and policies to serve technology-assisted children and their families and the health profes-

sionals who care for them. OTA and the Health Care Financing Administration (HCFA) have examined the social, psychological, and financial burdens of caring for children with “special needs.”¹² The preliminary results of the CHAS evaluation were an important source of empirical data in these deliberations. The Senate Finance Committee is reviewing alternatives for providing and financing care for chronically ill children.¹³ The issue of catastrophic coverage of services for such children has received increased attention as a result of extending such coverage to the elderly through Medicare.

A number of policy recommendations seem appropriate, based on these analyses. First, children and families with comparable needs in different states may have access to very different types of services and benefits. More attention needs to be given at the federal level to ensuring that the benefits provided to such children by federally subsidized public financing mechanisms (such as Medicaid and Crippled Children’s Services) are more uniform across states.

Second, policies to reduce the financial burden on families should take into account the out-of-pocket costs that are not covered under existing policies, as well as the exceedingly high medical bills associated with caring for such a medically complex child. The criteria for determining whether these combined expenses are catastrophic for a particular family should focus on the proportion they represent of the family’s income—not a single dollar amount.

Third, creativity is needed to provide cost-effective alternatives for these children and their families. Policymakers should consider funding nontraditional sources of support to families, such as respite or home-maker services, as cost-effective alternatives to reduce both the psychological and financial burden on families caring for these medically complex children in intensive-care-like settings in their home for years. In the long run, these may be useful strategies to reduce the rates of rehospitalization for the child, as well as the physical and psychological stress on the principal caregivers themselves.

Finally, not every family is able to handle the responsibility of caring for their technology-assisted child at home. Alternative institutional or foster care placements with home care service arrangements should be developed for such children to reduce the financial and human costs of their long-term institutionalization in acute care hospitals.

This research was sponsored by the Division of Maternal and Child Health, Department of Health and Human Service, under grant no. MCJ PHS 173363-03-3, and was conducted at the Center for Health Administration Studies, the University of Chicago, Chicago, Illinois.

NOTES

1. U.S. Congress, Office of Technology Assessment, *Technology Dependent Children: Hospital v. Home Care—A Technical Memorandum*, OTA-TM-H-38 (Washington, DC.: U.S. Government Printing Office, 1987).
2. U.S. Department of Health and Human Services and the Children's Hospital of Philadelphia, *Report of the Surgeon General's Workshop on Children with Handicaps and Their Families—Case Example: The Ventilator Dependent Child*, DHHS Pub. no. PHS 83-50194 (Washington, D.C.: DHHS, 1982).
3. L.A. Aday, M.J. Aitken, and D.H. Wegener, *Pediatric Home Care: Results of a National Evaluation of Programs for Ventilator Assisted Children* (Chicago: Pluribus Press, 1988).
4. OTA, *Technology Dependent Children*.
5. B.H. Burr et al., "Home Care for Children on Respirators," *The New England Journal of Medicine* 309 (24 November 1983): 1319–1323; and E.A. Lawrence, "Home Care for Ventilator-Dependent Children: Providing a Chance to Live a Normal Life," *Dimensions of Critical Care Nursing* (January-February 1984): 45–52.
6. Burr et al., "Home Care for Children on Respirators;" M.M. Andrews and D.W. Nielson, "Technology Dependent Children in the Home," *Pediatric Nursing* 14 (1988): 111–114, 151; E.A. Feinberg, "Family Stress in Pediatric Home Care," *Curing* (May 1985): 38–41; M.S. Schreiner, M.E. Donar, and R.G. Ketrick, "Pediatric Home Mechanical Ventilation," *Pediatric Clinics of North America* 34 (1987): 47–60; and E.A. Thorp, "Mothers Coping with Home Care of Severe Chronic Respiratory Disabled Children Requiring Medical Technology Assistance," *Dissertation Abstracts International* 48, no. 4 (1987), 901A.
7. Ad Hoc Task Forces on Home Care of Chronically Ill Infants and Children, "Guidelines for Home Care of Infants, Children, and Adolescents with Chronic Disease," *Pediatrics* 74 (September 1984): 434–436.
8. R.E.K. Stein and D.J. Jessop, *Evaluation of a Home Care Unit as an Ambulatory ICU*, Final Report, Report to the Department of Health and Human Services, Division of Maternal and Child Health, Grant no. MCR360402 (Washington, D.C.: DHHS, 1984).
9. Aday et al., *Pediatric Home Care*.
10. For a more detailed discussion of the methodology in these cost analyses, see Aday et al., *Pediatric Home Care*, chapter 9.
11. *Ibid.*
12. OTA, *Technology Dependent Children*; and U.S. Department of Health and Human Services, *Report of the Task Force on Technology-Dependent Children: Fostering Home and Community-Based Care for Technology-Dependent Children*, vols 1 and 2, HCFA Pub. no. 88-021271 (Washington, D.C.: U.S. GPO, 1988).
13. American Public Health Association, "Chronically Ill Children Garner Senate Attention," *The Nation's Health* (5 February 1988).