Chapter

Comparing Effectiveness and costs of Home v. Hospital Care
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INTRODUCTION

The purpose of this chapter is, first, to summarize existing evidence on the effectiveness of home care for technology-dependent children and the components that may affect it. Second, the chapter presents evidence regarding the costs of home v. hospital inpatient care. More discussion of alternative settings of care can be found in appendix D.

EFFECTIVENESS

Evidence of the Effectiveness of Home Care

There is a broad assumption in the home care literature that, compared to institutional care, home care is both more desirable and more effective in promoting the mental, emotional, and physical health of children. This assumption seems a reasonable one for many, perhaps most, technology-dependent children. There is little reason to believe that when a family wants its child at home, and adequate medical services and support are available, the home is not an effective setting of care.

Unfortunately, concrete evidence on how much more effective home care is, or the circumstances under which it is as effective, is lacking. There is also virtually no evidence in the literature on the relative effects, either medical or psychological, of care across various alternative settings for the technology-dependent population, including alternatives such as board and care homes.

A few studies have attempted to document the beneficial effects generally ascribed to pediatric home health care, or to special services associated with this care. The largest and most rigorously designed of these studies was performed as part of an evaluation of the Pediatric Home Care (PHC) unit at the Albert Einstein College of Medicine-Bronx Municipal Hospital in Bronx, New York (150). In that evaluation, chronically ill children were randomly assigned either to the PHC unit or to standard outpatient clinic-based care (with no special services). Standard inpatient care was not compared. PHC services included delivery of health services, patient and family training, service coordination, and patient advocacy. Services were delivered by an interdisciplinary team whose core was the pediatrician, pediatric nurse practitioner, and family, but which also included physician specialists, a psychiatrist, a social worker, and a physical therapist.

Children enrolled in the PHC program had better psychological adjustment, families reported significantly higher satisfaction with care, and mothers showed reduced psychiatric symptoms compared to the control group (150). There was no difference between the experimental and control groups in the impact on the child’s functional status, or in the impact of the child’s illness on the family. The researchers in this study hypothesized that the social and psychological support offered by the program balanced the family’s burden of caring for the child at home, resulting in no change in net impact on family activities, structure, or burden.

An evaluation of the impact of the home care coordination and support programs for ventilator-dependent children in three States (Louisiana, Illinois, and Maryland) is currently being conducted by researchers at the University of Chicago (3). Results from this evaluation are expected in late 1987.
Numerous parents and clinicians have asserted for some time that home care is superior to hospital care for medically stable, technology-dependent children. Children cared for in the home are believed to make faster medical and developmental progress, and have better psychosocial development, than children in the hospital (69,95,141,156). There are no published objective investigations of this hypothesis. It is a difficult one to test, since one cannot compare a child’s progress at home with his or her progress in the hospital during the same time period.

The rate of chronic rehospitalization of children placed in family homes can be considered a measure of effectiveness of home care. It is to be expected that technology-dependent children will have occasional brief hospitalizations for acute episodes of infections and illnesses and for evaluation, but the ability of a program to reduce or eliminate avoidable rehospitalizations and emergency room visits could be a useful measure of its effectiveness.

Factors Influencing the Quality and Effectiveness of Home Care

Two sets of factors influence the effectiveness of home care: those internal to the home environment, including parental abilities and attitudes; and those external to the home, such as the availability of trained professional nurses and the quality of equipment available.

Internal Factors

A crucial condition for effective home care is that the family wants the child at home, and that it is willing and able to help care for the child (1) or to accept and support a professional, full-time caregiver into the household. Parents have expressed strong desires to have their child at home, and they commonly take over much of the child’s nursing needs (60,156). They may become so proficient in providing the necessary nursing that they train some of the professionals who assist in their child’s care (156).

However, there are families for whom full-time long-term home care may not be the best alternative for either the child or the family. The families of chronically ill children can sometimes encounter severe and ongoing psychological and emotional stress (54,173,180). Some families may be simply unable or unwilling, for physical, psychological, or financial reasons, to cope with intensive home care for the child. Other families might want to have the child at home, but might need a long adjustment period, or might need to feel confident that respite or long-term care outside the home is available if the stress becomes too great. In a few cases, a parent might be willing to care for the child but be unable to do so safely. These factors lead to less effective home care and the need for alternative settings of care.

External Factors

The availability of services in various settings is also crucial to the quality and effectiveness of home care relative to institutional care. Home care may not be more effective than hospital or other institutional care if the appropriate range of services are not provided. If a child can receive therapy or other vital services in the hospital but not at home due to lack of insurance coverage, home care is likely to be relatively ineffective. Conversely, if a child receives more intense, individualized therapy and education at home, home care is likely to be more effective than hospital care.

Professional nursing skills are a particularly important factor in the effectiveness of care, but skilled nurses are not always available for home care. In an acute-care hospital, nursing services for a technology-dependent child are most likely to be provided by a registered nurse (RN), and often by an RN with extensive training in pediatrics or intensive care. In home settings, on the other hand, professional nursing is much more variable. Some home care agencies specialize in “high-technology” home care or pediatric home care. Others, however, may not have nurses (whatever their certification level) trained to provide the specialized care needed by technology-dependent children. Most licensed practical nurses (LPNs) and many RNs, for example, are not trained to operate ventilators and provide respiratory care.

Third-party payers may place restrictions on the services that a nurse with a particular set of credentials can provide, although there is consid-
erable controversy over the relationship between credentials and quality of care. In New Mexico’s Medicaid program, for example, RNs may provide any respiratory- or nutritional-support home care; LPNs can provide most such care, but not ventilator-related care or parenteral nutrition; and paraprofessional attendants may not provide any such complex care (34). In Louisiana, on the other hand, families needing assistance at home rely heavily on trained paraprofessionals even for ventilator-related care (97). These different conventions are associated with differences in service availability, but they also reflect different implicit evaluations of the relationship between credentials and quality. The differences in the quality of home care provided by family members, paraprofessionals, LPNs, RNs, and specialty nurses has not been addressed explicitly in the literature. Undoubtedly, the level of skill-specific training is an important variable, regardless of the general certification of the provider.

Certain quality issues arise at home that rarely arise in the hospital because of established routines or protocols in the latter, but not the former, setting. For example, home chemotherapy introduces substantial concerns regarding the use and disposal of very toxic chemicals (87). Widespread use of and dependence on home ventilators introduces concerns regarding the quality of maintenance of equipment and issues of how the widely dispersed users are informed about potential mechanical defects (118).

Concerns about monitoring the quality of home health care have been raised before (160). These concerns are particularly relevant in the context of widespread emphasis on early hospital discharge. In a number of States, Medicaid pays hospitals a preset rate per discharge regardless of the actual length of hospital stay of a child (101). Once home care for technology-dependent children is widely accepted in an area, and funding becomes available, hospitals may be very reluctant to keep these children, whose length of stay is generally quite long. If the third-party payer’s interests also lie in encouraging home care, parents could be forced to take a child home, possibly with insufficient services, before they are adequately prepared. Or, parents could be forced into home care when they are unable and unwilling to provide the service at all. Anecdotal reports suggest that, in some cases where home care is a funded option, hospitals or payers are indeed putting pressure on families to take these children when the families are not ready to do so (104,120). These circumstances could have serious negative implications for the quality of home care.

**COST**

Cost considerations have played a substantial role in the evolution of home care for technology-dependent children. When the Federal Government first waived certain Medicaid rules to permit hospital-bound, technology-dependent children to receive Medicaid payment for equivalent home services, it did so on two grounds: that the home was equal or preferable to the hospital as a setting for a child’s care and development, and that home care would be a fraction of the cost of hospital care to Medicaid. These criteria, and particularly the second, have endured. From 1981, when the first exception was granted, to 1986, Medicaid (and other third-part payers) has continued to require a showing of program cost savings before paying for home care for many technology-dependent children. Of course, program cost savings and social cost savings are not necessarily the same.

This section first describes the components of home care costs—i.e., the factors that influence the costs of home care for different technology-dependent children. It then presents the issues and problems involved in comparing the costs of care across alternative settings. Finally, it presents existing evidence from the literature and from home care programs regarding comparative average total costs of technology-dependent children across settings.
Components of Home Care Costs

Startup Costs

Startup costs are one-time costs that are usually incurred before the child is placed in the home. They include the costs of home improvements, major equipment, and caregiver training.

Home improvements are often a necessary prerequisite to home care, particularly for ventilator-dependent children. Home modification needs can include:

- wiring and other electrical work;
- construction (storage and preparation space, wheelchair ramps, equipment accommodation);
- special needs (e.g., a generator for emergency power in rural areas); and
- general upgrading that requires the family to move (e.g., moving from an unsanitary apartment or one inaccessible to a wheelchair to other housing where appropriate modifications can be made).

The costs of necessary home modifications can vary substantially; in the first 3 years of Louisiana’s home care program for ventilator-dependent children, home modification charges ranged from $0 to $13,500 (97).

Equipment can be a major component of startup costs, particularly for children on ventilators or oxygen. (If the child is not expected to be technology-dependent at home for long, or if an insurer will only pay for rented equipment, much of the child’s equipment will be rented rather than purchased.) Special equipment for a ventilator-dependent child might include two ventilators (a primary and a backup ventilator), an emergency battery, an oxygen tank, a suction machine, a nebulizer (to deliver aerosol medication), a manual resuscitator, and an infusion pump (to control the administration of nutrients). The child may also need other supportive equipment such as a wheelchair, a commode, a special bed, and various other adaptive furniture and devices. A child dependent on intravenous feeding, by comparison, might have startup equipment costs that are a negligible proportion of total home costs.

Training in the necessary medical procedures, which may take days or weeks, is a vital first step for families. Even if they will have professional nursing help, they must learn to perform the necessary procedures as a guard against emergencies (e.g., resuscitation) or in situations where the regular nurse might be incapacitated or absent. Table 11 shows a list of skills the family of a child on respiratory support or infusion therapy (intravenous drugs or parenteral or enteral nutrition) might need to learn.

Training time and costs differ by training institution, by level of care the child requires, and by the family members’ ability to assimilate information and perform the necessary tasks. Institutions training families in respiratory care may do this in several days of intensive training (13). Or, they may gradually encourage family members to provide care while the child is in the hospital, perhaps requiring that the family provide total care for 48 hours before discharge (57,65). Training in intravenous techniques can also be time-consuming; one program reported a 3-week training period for home patients (181).

Ongoing Supplies and Services

Supplies are often purchased monthly through the hospital or home care agency. Table 12 details the supplies needed for intravenous therapy and tube feeding. The highest ongoing supply costs are probably incurred by children requiring total parenteral nutrition, because their nutrient formulas—consisting of “pre-digested” fat, carbohydrate, and protein solutions—are individualized, require special handling and storing, and have expensive components. In a 1982 survey, average charges for nutrition supplies and solutions were reported as $3,059 per month for hospital-supplied solutions and $4,615 per month for nonhospital-supplied (possibly pre-mixed) solutions (122). The range of charges, however, was very wide; the highest charges were nearly double the average in both categories.

Ventilator-dependent children also have high ongoing supply costs. As is shown by the child
Table 11.—Checklist of Respiratory and Infusion Skills for Home Care Patients and Families

Respiratory skills:
1. The disease process:
   - lung disease and its treatment
   - short- and long-term prognosis and goals
2. Pulmonary hygiene measures:
   - avoidance of infection (hand-washing and sterile technique)
   - adequate systemic hydration
   - chest physiotherapy procedure
   - sterile suctioning procedures
   - tracheostomy care procedure
   - tracheostomy tube cuff care procedure
   - signs of airway infection and cor pulmonae that should be reported to the doctor
3. Use and maintenance of the equipment:
   - daily maintenance of the ventilator
   - oxygen use, abuse, and hazards
   - cleaning and changing of ventilator circuits
   - resuscitation bag use and cleaning
   - suction machine use and cleaning
4. Nutrition counseling:
   - maintenance of ideal body weight
   - special dietary restrictions as needed
5. Physical therapy:
   - ambulation, where possible
   - general strengthening exercises
   - relaxation exercises

6. Educational and diversional activities:
   - encouraging child self-care
   - sedentary activities
7. Access to services:
   - nurses
   - physicians
   - respiratory equipment suppliers
   - therapists
   - emergency power
   - other services

Infusion skills
1. Understanding of components of home infusion therapy:
2. Sterile procedures:
   - caring for medications and solutions
   - preparing medications and solutions for infusion
3. Infusion techniques:
   - measuring components, using syringes, bottles, and bags
   - setting up the infusion
   - starting the infusion
   - discontinuing the infusion
   - operating the infusion pump
4. Recognizing complications:
   - of the catheter
   - of the infusion
   - of the medications

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Table 12.—Supplies Needed for Four Home Infusion Therapies

<table>
<thead>
<tr>
<th>Supplies</th>
<th>Parenteral nutrition</th>
<th>Enteral nutrition</th>
<th>Intravenous antibiotics</th>
<th>Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intravenous catheter</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Intravenous tubing</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Medications</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Nutrient solutions (e.g., lipids)</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Intravenous solutions (dextrose or saline)</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Infusion pumps</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Heparin lock and dilute solution</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Needles and syringes</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Dressings (gauze and tape or transparent)</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Nasogastric, gastrostomy, jejunostomy tubes</td>
<td></td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enteral bag and tubing</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

SOURCES List of respiratory skills adapted from J Feldman and P G Tuteur "Mechanical Ventilation From Hospital Intensive Care to Home Heart & Lung 11 (2)162 165 March April 1982 Infusion skills adapted from Blue Cross and Blue Shield Association Infusion Therapies in Home Health Care (Chicago, IL BC/BSA, January 1986)
whose reimbursable expenses are detailed in table 13, monthly costs for major supplies may total over $1,600 (116). Medications, special nutrient solutions, and equipment maintenance can add substantially to this cost.2

Nursing needs are highly varied and, for many children, are the most expensive component of home costs. Outlays for nursing care are inversely related to the amount of unpaid care that the family is willing and able to provide. As has been noted (148), most of the reduction in charges reported for ventilator-dependent patients at home results from shifting the burden of nursing costs from the payer to the family. Similarly, a significant part of the reduction in home charges observed by numerous intravenous therapy programs (96,130,132,151) is due to the fact that the patients in these programs receive little or no professional nursing at home.

1Inadequate or poorly coordinated equipment maintenance can present a major problem to a home care program and a significant expense to families or third-party payers (104). Programs are still accumulating experience in working with manufacturers and suppliers to minimize problems.

Table 13.—Sample Home Respiratory Care Costs That Were Reimbursed by a Third-Party Payer, 1985

<table>
<thead>
<tr>
<th>one-time Purchase of equipment</th>
<th>Unit cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suction equipment</td>
<td>$ 714.29</td>
</tr>
<tr>
<td>Manual resuscitator</td>
<td>157.31</td>
</tr>
<tr>
<td>Emergency 12V battery</td>
<td>70.00</td>
</tr>
<tr>
<td>Heating nebulizer</td>
<td>324.00</td>
</tr>
<tr>
<td>Total one-time cost</td>
<td>$ 1,265.60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Monthly services and supplies</th>
<th>Monthly cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home assistance:</td>
<td>$ 7,320.00</td>
</tr>
<tr>
<td>Nursing</td>
<td></td>
</tr>
<tr>
<td>Rentals:</td>
<td></td>
</tr>
<tr>
<td>Backup ventilator</td>
<td>200.00</td>
</tr>
<tr>
<td>Ventilator</td>
<td>450.00</td>
</tr>
<tr>
<td>Suction device</td>
<td>50.00</td>
</tr>
<tr>
<td>Apnea monitor</td>
<td>200.00</td>
</tr>
<tr>
<td>Oxygen system</td>
<td>130.00</td>
</tr>
<tr>
<td>Supplies:</td>
<td></td>
</tr>
<tr>
<td>Ventilator tubing</td>
<td>100.00</td>
</tr>
<tr>
<td>Oxygen masks</td>
<td>55.20</td>
</tr>
<tr>
<td>Liquid oxygen</td>
<td>816.00</td>
</tr>
<tr>
<td>Nebulizer</td>
<td>123.60</td>
</tr>
<tr>
<td>Sterile water</td>
<td>79.50</td>
</tr>
<tr>
<td>Tracheotomy tubes</td>
<td>143.70</td>
</tr>
<tr>
<td>Suction catheter w/ gloves</td>
<td>315.00</td>
</tr>
<tr>
<td>Cardiac leads</td>
<td>10.00</td>
</tr>
<tr>
<td>Total monthly costs</td>
<td>$9,993.00</td>
</tr>
</tbody>
</table>


Actual nursing care expenditures for a technology-dependent child depend on three factors: the complexity of care required, the amount of paid nursing care required (e.g., 3 hours per day v. 24 hours per day), and the certification level of the nurse. In general, 24-hour ventilator-dependent children with tracheotomies need the most constant and complex nursing care. Other children, such as those receiving intravenous nutrition or therapies, may need complex or intensive care for several specified hours per day; or they may need less complex care but need it constantly in order to avoid a life-threatening event (e.g., children requiring trachea suctioning).

Professional home nursing costs can be substantial and vary considerably with the certification level of the nurse. In New Mexico, for example, Medicaid pays $17 per hour for RNs and $13 per hour for LPNs, slightly more than the charges of the lowest priced home nursing agency in that State (34). If all care were provided by professional nurses, the monthly Medicaid payments for a child requiring an 8-hour professional nurse would range from $3,120 to $4,080; payments for a 24-hour nurse would range from $9,360 to $12,240. If Medicaid paid agency charges, as some insurers do, payments could be as high as $18,000 per month for a 24-hour RN.

Other factors can also affect nursing costs. For example, the need for an escort to accompany a nurse to work in a high-crime area would raise costs. Or, nurses might demand higher pay when working in such areas.

Specialized therapy is needed by most technology-dependent children in order to progress. Speech therapy, physical therapy, and occupational therapy are commonly provided to these children in one or more weekly visits. Basic respiratory therapy, however, often becomes a required skill of the primary caregiver, both because it is often required so frequently and because many third-party payers do not pay for home respiratory therapy visits.

Outpatient services to technology-dependent children in home care can include regular visits to one or more specialty physicians (e.g., a pediatric pulmonologist), frequent laboratory work-ups, and visits to a local pediatrician or family
physician who oversees the child’s “well child care.” A local physician who is familiar with the child’s health status and medical needs is particularly important for families who live a great distance from the specialty clinic or tertiary care hospital. Even with these outpatient visits, children in home care may have frequent hospitalizations for in-depth assessment, initiating new treatments, respite care, or complications or sudden emergencies relating to their conditions. These rehospitalization are often overlooked when comparing home and institutional care costs.

Although outpatient visits and laboratory tests are often relatively minor compared with other home care costs, they are ongoing and by no means negligible. For example, the individuals included in a 1982 survey of home parenteral nutrition programs averaged $23 to $32 per month in physician and clinic costs (for patients served by hospital- and nonhospital-programs, respectively), with extremes ranging from $6 to $83 (122). Laboratory work for stable patients in this survey averaged $69 and $82 per month for hospital- and nonhospital-supplied patients, respectively, and ranged from $4 to $350 per month (122).

Transportation to outpatient services and to school is required by technology-dependent children in home care and can be a substantial cost for some children. Children receiving intravenous antibiotic therapy or chemotherapy may require physician visits as often as twice a week (130). For stable ventilator-dependent children, visits may be less frequent—weekly, or monthly—but transportation costs may be very high because the transportation vehicle must be spacious enough to accommodate respiratory equipment and a wheelchair. Children served by the Louisiana home program for ventilator-dependent children travel up to 385 miles round-trip for physician and clinic visits (97). Of 23 children whose transportation needs were detailed by this program as of June 1985, 7 used the family car; 3 used special vans purchased for that purpose; 3 used public transportation; 1 child used an institutional van; and 8 children used ambulances.

Respite care is care that gives the family some relief from ongoing nursing care. It may be in the form of an occasional professional nurse or other person who provides care in the home. Or, it may be in the form of a nearby hospital or other facility that cares for the child while the family is on vacation or pursuing other activities. Respite care raises the immediate costs of home care, but it may lower total costs if the assurance of occasional respite enables the family to provide most ongoing care.

Case management-coordination and oversight of the package of services provided to an individual—is a vital service to most technology-dependent children because of the multiplicity of startup and ongoing services needed. Case management may be performed by a health care professional, such as the child’s pediatrician (112) or a specially trained pediatric nurse (129). Or, third-party payers may provide case managers (as part of an individual benefits management program) to ensure, first, that the appropriate mix of services are available to enable the child to receive appropriate care at home; second, that those services continue to be provided as arranged; and third, that the child’s progress is monitored, so that appropriate changes in service are made.

Case management can sometimes minimize the costs of care for children already being cared for at home. The Florida “Rural Efforts to Assist Children at Home” (REACH) program, a Medicaid demonstration project, succeeded in reducing rehospitalizations and emergency room visits of chronically ill children in that program as compared to equivalent children not served by the program (129). The program, targeted at high-cost children (not necessarily technology-dependent children) eligible for both Medicaid and Services to Children with Special Health Care Needs, used community-based pediatric nurses as case managers, coordinators, and consultants to help families make the most appropriate use of medical services (129).

The most important aspect of case management is that it can serve both the interests of the family and of the third-party payer. At present, it is closely linked with the expectation of cost savings, and the process of ensuring those savings. If a private insurer expects to eventually pay out the maximum lifetime benefit, however, the incentive

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1Three of the children using ambulances did so for emergency or interhospital transfer purposes only, while they resided in institutions or nursing homes. One other child required an ambulance twice for tracheotomy tube changes. Of the remaining 4 children using ambulances for transportation, 3 eventually died. No other forms of transportation are recorded for any of these 8 children.
to provide case management may be weakened. There is also a danger that case management will be superficial. Managers whose activities are limited by the payer's interests, or by a large caseload, may be hampered by not being intimately acquainted with the child's needs, or by ignorance of important resources that could be made available.

**Issues in Comparing the Costs of Hospital and Home Care**

1. **Cost to whom?**—The relative costs of hospital and home care depend on whether one is considering costs to Medicaid, costs to private insurers, costs to the family, or total resource costs. Home care might often involve fewer total resource costs than hospital care, but it might not cost the third-party payer less. For example, in some States, Medicaid pays hospitals a set rate per patient or per admission, regardless of the actual length of stay for that patient or the services provided. In these States, paying for adequate home care for technology-dependent children could cost the State and the Federal Government more than financing those children's care in a hospital at the fixed rate. (Of course, the uncompensated costs to the hospital caring for children in this situation are very high.)

   Home costs may be lower to third-party payers than institutional costs because of certain uncompensated costs incurred by the family when the child lives at home. The two most notable examples of such uncompensated costs are the costs of basic room and board, and the unpaid time of parents or other volunteer caregivers.

   For some children, paid home services may be replacing not institutional care but care previously provided by the family at great expense. These services reduce the costs to the family while increasing the net cost to the third-party payer.

2. **Comparing equivalent costs.**—Different sources of information on costs of technology-dependent children use different concepts of cost. For example, one may report hospital charges, while another reports third-party payments to the hospital. Hospital charges themselves may not be equal to the actual costs associated with providing a service. For example, one analysis of intensive care unit (ICU) services found that the charges in one hospital for room and board in the ICU were only slightly more than one-half of calculated actual costs to the hospital (77a). Even comparing average hospital charges (say, per month) with average home care charges for a technology-dependent child can be misleading if the two include different services. For example, hospital charges often include acute-care services such as surgery, while home charges do not. Inconsistency in comparing the appropriate equivalent costs (i.e., maintenance and recuperative treatment costs) in each setting is a major problem in the literature.

3. **Biased sources of data.**—Most third-party payers offering intensive home care services require that it be cheaper for them to pay for care in this setting. Consequently, most data on technology-dependent children served at home will, by definition, show that home care is cheaper. There may be some children who are not discharged home because it will not be cheaper to the payer, but since these children are not served at home their presumably higher home costs are not recorded.

4. **Different costs for different children.**—In the hospital, costs depend largely on medical need and on the physician's judgment and style of medical practice. At home, however, the costs of care vary not only with the type and severity of disability, but also with the family and home environment. Factors such as the ability of family members to provide most nursing care, and the extent of home care renovations needed, have great impact on costs of home care.

5. **Cost in which setting?**—Given sufficient equipment and services, many technology-dependent children could, if necessary, receive care in any of a number of settings that are intermediate between the acute-care hospital and home (see app. D). In some urban areas, several of these intermediate options may actually be available; in other areas, none may be. Thus, while for one child it may be appropriate to consider the relative costs and effectiveness of care in a long-term rehabilitation hospital as well as home and acute-care hospital costs, for another child the rehabilitation hospital may be unavailable, even if it theoretically offers the lowest cost care.
The primary reason for variations in average cost across institutional settings is that different settings offer a different mix of services and different levels of service intensity. For example, one setting may cost more because it offers full-time respiratory therapists on staff. However, cost is not a direct measure of effectiveness or services. Costs and effectiveness are related (e.g., adding home services to enhance effectiveness may increase costs), but, given no other information, one cannot deduce the relative effectiveness of different settings from their relative costs.

Evidence

There are two types of evidence on the costs of home care for technology-dependent children compared to care in other settings. First, there is evidence on the costs of care for children requiring ventilators and other device-based respiratory supports. Since the evidence is sparse, some information of the costs of care for ventilator-dependent adults is also included here. Second, there is literature regarding the cost of home care for people receiving home intravenous nutrition or drug therapy. In this case, there is little evidence specific for children, and the programs generally do not send home individuals whose families cannot provide the necessary nursing services. Published comparisons of home care costs with the costs of nonhospital institutional care (e.g., nursing homes) are nonexistent for technology-dependent children in either group.

There is some evidence regarding costs of care for children with less intensive needs, such as those on dialysis or apnea monitors. It is not discussed here because the relative costs of care for these children is less of an issue than the costs of care for children requiring respiratory and nutritional supports.

Evidence on Relative Costs of Care for Ventilator-Dependent Children

The evidence on the relative costs of caring for ventilator-dependent children in alternative settings is incomplete. Cost estimates are typically based on charges or payments and are available for small numbers of children enrolled in a particular program or discharged from a particular institution. All comparisons of home and hospital costs for these children show that their care is almost inevitably less expensive at home. These comparisons demonstrate that there are a considerable number of children for whom home care appears to be less expensive, often dramatically so. However, up to now no payer has reimbursed for an exceptional level of home care unless it is less expensive than hospitalization, so the ventilator-dependent children now on home care are by definition less expensive to care for in this setting.

Table 14 summarizes comparative hospital and home charges for ventilator-dependent people from the literature. Because of the few reports available, adults as well as children have been included. The figures in this table suffer from many of the problems discussed above. The services included in hospital costs are generally much more extensive than those included in home costs, and the fact that the figures are averages disguises high variations in the amount of paid nursing the patients required. Despite these methodological problems, however, table 14 still provides compelling evidence that for some technology-dependent children the home care charges are substantially less than those for intensive or intermediate hospital care.

The primary reason for this difference is simple: when a child is cared for at home, the costs of housing and much of the nursing are borne by the family rather than by the hospital or health care payer. If a child required 24-hour paid nursing at $20 per hour (slightly higher than Medicaid pays in New Mexico), monthly home nursing costs alone would total $14,400—nearly as much as monthly hospital costs in several of the studies in table 14. Thus, the extent to which total home care charges are less than total hospital charges depends largely on the extent to which the family is able and willing to provide nursing care and appropriate facilities for the technology-dependent child. The difference in charges also depends on whether less expensive nursing can be substituted for more expensive care, and on the medical effectiveness of home care. Home care becomes relatively cheaper if it speeds the time until a child achieves minimal dependence (or delays total dependence), and if it minimizes the
Table 14.—Summary of Comparative Average Monthly Charges Presented in the Literature of Ventilator-Dependent Individuals in Hospital and Home Settings

<table>
<thead>
<tr>
<th>Source</th>
<th>Average hospital charge</th>
<th>Average home charge</th>
<th>Number of patients</th>
<th>Adults (A) / children (C)</th>
<th>Home costs include some professional shift nursing</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Banaszak, et al., 1981</td>
<td>$15,469</td>
<td>$3,535</td>
<td>2</td>
<td>A</td>
<td>No</td>
<td>All hospital charges (not just maintenance charges) are included in hospital figure.</td>
</tr>
<tr>
<td>Burr, et al., 1983</td>
<td>19,613</td>
<td>2,388</td>
<td>6</td>
<td>C</td>
<td>Not given</td>
<td>Hospital charges include charges before patient was medically stable. Home charges include first month home.</td>
</tr>
<tr>
<td>Cabin, 1985</td>
<td>29,113</td>
<td>5,201</td>
<td>1</td>
<td>C</td>
<td>Not given</td>
<td>Based on survey of State respiratory therapist representatives' estimation of average charges.</td>
</tr>
<tr>
<td>Care for Life, 1985</td>
<td>25,063</td>
<td>1,853</td>
<td>—</td>
<td>A,C</td>
<td>Not given</td>
<td>Received nasal oxygen only (not ventilation).</td>
</tr>
<tr>
<td>Dorm, 1982</td>
<td>19,071</td>
<td>389</td>
<td>12</td>
<td>C</td>
<td>No</td>
<td>Hospital charges from intermediate care unit.</td>
</tr>
<tr>
<td>Feldman, et al., 1982</td>
<td>17,500</td>
<td>5,704</td>
<td>2</td>
<td>A</td>
<td>Yes (1 patient)</td>
<td>Charges are averages during one year, not necessarily before initial discharge home. Two patients were not hospitalized that year.</td>
</tr>
<tr>
<td>Goldberg, 1983</td>
<td>27,435</td>
<td>7,310</td>
<td>2</td>
<td>C</td>
<td>Yes</td>
<td>Hospital charges include surgery, acute care. Home &quot;charges&quot; include estimated cost of some services provided at no charge.</td>
</tr>
<tr>
<td>Goldberg, et al., 1984</td>
<td>24,590</td>
<td>7,425</td>
<td>2</td>
<td>C</td>
<td>Yes</td>
<td>Charges presented here are averages of ranges given in literature report.</td>
</tr>
<tr>
<td>Kahn, 1984</td>
<td>22,000</td>
<td>5,400</td>
<td>26</td>
<td>C</td>
<td>No (if included, home charges are $8,000)</td>
<td>Hospital charges are estimated and include physician charges. Home charges do not include physician charges or initial costs. If startup charges are included, home charges rise to $1,894.</td>
</tr>
<tr>
<td>Lee, 1983</td>
<td>40,590</td>
<td>5,490</td>
<td>8</td>
<td>C</td>
<td>Not given</td>
<td>Hospital is a rehabilitation hospital. Home care cost does not include drugs.</td>
</tr>
<tr>
<td>Perry and Lierman, 1985</td>
<td>51,517</td>
<td>7,361</td>
<td>2</td>
<td>C</td>
<td>Yes (1 patient)</td>
<td></td>
</tr>
<tr>
<td>Sherman, et al., 1982</td>
<td>40,332</td>
<td>1,943</td>
<td>9</td>
<td>C</td>
<td>Not given</td>
<td></td>
</tr>
<tr>
<td>Sivak, et al., 1983</td>
<td>15,600</td>
<td>1,760</td>
<td>10</td>
<td>A</td>
<td>Yes (4 patients)</td>
<td></td>
</tr>
<tr>
<td>Splaingard, et al., 1983</td>
<td>15,000</td>
<td>775-16,900</td>
<td>47</td>
<td>C</td>
<td>Yes (patient represented by high home charge figure)</td>
<td></td>
</tr>
</tbody>
</table>

SOURCES See references 13, 26, 28, 32, 55, 68, 69, 92, 103, 128, 146, 147, and 149
frequency of rehospitalization for infections or other problems.

An analysis of more detailed charge and payment data from children who have been served by high-service home care programs is illuminating. Maryland has computed the monthly hospital and home payments for 25 children served by the State’s home care program for children requiring respiratory support (93). For these children, the mean third-party payment for the last month of hospitalization (a proxy for typical hospital costs of a child when medically stable) was $24,715 (range: $210 to $41,057). These children were hospitalized an average of 421 days before discharge. The average monthly home care payments for these children, excluding the first month home, was $9,267 (range: $300 to $25,000). First-month payments averaged $9,798, or an average of $531 per child for one-time expenses (93).

In Louisiana, average third-party payments for the last month of hospitalization were comparable to those in Maryland ($25,995 for 19 children), but average monthly home care costs to the Louisiana program were considerably lower (97). Home payments (computed for 21 children) averaged only $3,012 per month, excluding startup costs. Children in this study were all at least partly ventilator dependent. Louisiana Medicaid, the source of support for many of these children, does not pay for home shift nursing, which may explain why the home care payments are so low.

Data from Illinois demonstrate the potential differences between private payers and Medicaid in cost-savings of home care to third-party payers. For children whose care was compensated only by Medicaid, payments for the last month of hospitalization averaged $16,984, while monthly home care payments averaged $6,358 (104). For children who had at least some private coverage, the payment for the last month of hospitalization averaged $26,616, while equivalent home care payments were $6,922. Thus, while the monthly home care payments for children in these two groups are roughly equivalent, the cost savings of home care experienced by private payers (or that would have been experienced had they covered home care) was substantially greater than that experienced by Medicaid alone. (Illinois’ Medicaid program pays for a maximum of 45 hospital days per year, which limits program hospital expenditures.)

Evidence on Relative Costs of Home v. Hospital Administration of Intravenous Therapies

Intravenous therapies—prolonged parenteral nutrition and drugs—have followed the pattern of renal dialysis and hemophilia treatment, in which treatments once received exclusively in the hospital have been adapted to the home. (Intravenous drug therapy may also be administered in outpatient settings.) Drug therapy usually takes a few weeks, compared with the months or years common with parenteral nutrition, but in other ways the two therapies have many similarities.

There is little information in the literature regarding relative costs of care in different settings for individuals receiving chemotherapy, but all programs reporting their experiences with home antibiotic therapy have reported substantially lower charges for home treatment compared to hospital inpatient treatment (table 15). In all cases in these programs, patients or their families administered the infusion at home. Patient selection was a vital component of these programs, because inadequately administered infusions can result in ineffective treatment and rehospitalization. In one study, 40 percent of the patients receiving prolonged antibiotic therapy were rejected by the home care program for reasons including inability to administer the antibiotic, poor family support, and poor motivation. Thus, patients who would have required substantial professional nursing to receive home treatment (had it been available)—and thus might have had more expensive home care—could not participate in the program. The major differences in charges for home and hospital treatment in the programs reported in the literature are the need for patient training, planning, and clinic or nurse visits for home patients; and the hospital room charge for hospitalized patients.

Most individuals on parenteral nutrition, too, go home only after they or their families have mastered the techniques and can provide all home care. One case has been reported in which a 58-
Table 15.—Comparative Charges for Home v. Hospital Administration of Intravenous Antibiotics as Reported in the Literature

<table>
<thead>
<tr>
<th>Study</th>
<th>Home charges</th>
<th>Hospital charges</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antoniskis, et al., 1978</td>
<td>$69 per day</td>
<td>$243 per day</td>
<td>Separate home and hospital groups studied.</td>
</tr>
<tr>
<td>Eron, 1984</td>
<td>$10 per day in charges incurred only by home patients (training clinic visits)</td>
<td>$170 per day in charges incurred only by hospital patients (room charge in community hospital)</td>
<td>Other charges (for services provided to both home and hospital patients) are assumed equal.</td>
</tr>
<tr>
<td>Harris, et al., 1986</td>
<td>$207 per day</td>
<td>$428 per day</td>
<td>Charges are for patients treated initially in the hospital, then at home. Hospital charges may include surgery.</td>
</tr>
<tr>
<td>Rehm and Weinstein, 1983</td>
<td>$1,652 per illness</td>
<td>$7,380 per illness</td>
<td>Hospital charges are estimates (patients all got home care). Charges are averages over 4 years of the program.</td>
</tr>
<tr>
<td>Stiver, et al., 1978</td>
<td>$40 per day</td>
<td>$137 per day</td>
<td>Hospital charges are estimates (patients all got home care).</td>
</tr>
</tbody>
</table>

NOTE All home infusions in these studies were administered by patients or their families.
SOURCES See references 6, 50, 78, 132 and 151

A year-old patient was discharged home on parenteral nutrition under the supervision of full-time home nurses (105). When this patient first went home, requiring 12 hours per day of parenteral nutrition administered by a nurse, her home care charges were comparable to charges for hospital care. Her need for parenteral nutrition and the associated nursing care diminished over time, however, lowering the home care charges (105).

The previously-mentioned 1982 survey of home nutrition programs found home care charges for parenteral nutrition that were roughly $3,400 per month for hospital-supplied patients and $4,900 per month for nonhospital-supplied patients (122). Individual programs have reported program costs of serving patients of approximately $1,800 per month (in 1976-78) and approximately $2,700 per month (in 1982-83) for the first year, when costs are highest (48,181). Even after adjusting for inflation, these costs are probably substantially less than the costs of a patient receiving parenteral nutrition in an acute-care hospital. A third study has reported per-patient monthly home care charges of $1,445, compared with hospital charges that would have been approximately $6,170 (23).

Thus, for both intravenous drugs and nutrition, the literature suggests that home treatment provided under an organized program is substantially less expensive to the payer than care in an acute-care hospital, provided that patients are carefully selected and can perform all necessary procedures themselves or with the help of family members. The literature also suggests, however, that home care charges for adult patients who require substantial professional nursing may approach hospital care charges. None of this literature specifically addresses the relative costs of offering these therapies to children in different settings.

CONCLUSIONS

There is no concrete evidence regarding the relative effectiveness of home and hospital care, Home care is generally considered more effective in promoting the psychological and emotional health of children; hospital care is generally considered more effective at providing medical and nursing care when necessary to promote physical health. With the adaptation of sophisticated technologies and care systems to the home, however, there is no reason to believe that home settings cannot be equally effective at promoting physical health. The desire of the family to have...
the child home, however, and the availability and quality of these sophisticated technologies and care systems, are critical determinants of effectiveness.

Cost savings to third-party payers have become an important factor in their willingness to finance intensive home care. Such cost savings are likely to exist for most children whose families are willing to bear some of the costs of home care, particularly nursing costs, by providing those services at no cost to the payer. However, because the technology-dependent child population is so diverse, and the nonmedical characteristics of the children and their families are so important a factor in nonhospital health care costs, there are no medical or clinical criteria that can be used to classify children according to their expected cost saving. Payers can ensure a high probability of overall cost savings only on a case-by-case basis, where each child is evaluated and the likely total costs of care for that child in alternative settings estimated. Still, some general factors that tend to increase or decrease relative costs (and, sometimes, relative effectiveness) can be identified.

1. **Nursing Costs**: Home care becomes more favorable to third-party payers as family nursing can be substituted for professional nursing, as less expensive professional or paraprofessional help can be safely substituted for more expensive help, and as intensive nursing needs decline. Paid 24-hour nursing may make home care as expensive as hospital care.

2. **Expected Duration of Dependence**: The high startup costs associated with home care can be more easily justified if a child is expected to be technology-dependent for a very long time and ongoing home care costs are relatively low.

3. **Family and Other Environmental Factors**: Some children cannot or should not return to a family home. If foster care cannot be found, there are often few options other than acute-level hospital care for such children, although other appropriate options (e.g., rehabilitation hospitals, pediatric skilled nursing facilities, or group homes) may be less expensive when available.

4. **Availability of Services**: Inadequate availability of respite care or caregivers trained in the appropriate skills can make hospital care the only viable option even where home care might be less expensive if those services existed. Or, choices in home services may be so constrained that families and third-party payers may be forced to pay high prices for the services.

5. **Substitution of Care**: Home care will be likely to reduce third-party payments only if it can substitute for institutional care, rather than augmenting the care of children already being cared for at home by their families. In many cases, however, augmented care—particularly respite care and case management—may be effective in increasing the quality of care and of life for these children, and may reduce rehospitalizations.