Chapter 8

Efficiency of families managing home health care*

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Over the last decade, cost-containment pressures, health care reform debates, movement to case-managed health care, and reductions in health care benefits have required most families to be responsible for selecting specific health care services that keep costs to a minimum. As Eddy [17–20] discussed in a series of articles on making decisions in health care, the consensus among health care policymakers is that family values are to be respected, but application of cost benefit analyses are essential because of limited resources. Therefore, only approaches proven beneficial can be prescribed, even though a family might desire other methods. Costs and health care benefits have become critical concerns to families due to the continuing escalation of health care costs and potential bankruptcy from such costs.

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1. Background

In families managing complex technical care at home, cost minimization becomes an integral and highly-valued attribute, because even with extensive health benefits, the annual expense of treatment far exceeds families' expendable incomes. For example, annual costs to individuals requiring complex technological care for survival range from $90,000 to $150,000 [56, 67]. In addition to the medical expenses, family home care interferes with the employment and earning power of the family member who must care for the patient. Just as competitive markets force businesses that do not pursue cost minimizations into bankruptcy, people in the United States who use all their health benefits are declared medically disabled and must apply for government assistance.

Psycho-emotional expenditures also are high in families that manage complex technical care at home. Daily psychological challenges include fear of an unexpected catastrophic event, the burden of knowing the patient is dependent solely on the caregiver, and abrupt swings in mood [56]. Caregivers have been advised by attorneys to divorce their chronically ill spouse of many years to protect property from being sold to cover medical bills [54]. However, families who efficiently manage their resources while still following their values can serve as examples for other families to learn how to maintain quality home care that also is efficient. This process is similar to benchmarking, whereby businesses or hospitals are evaluated by comparing the "benchmark" organization that has similar patient care demands (e.g., acuity), budgets, and staffing constraints but exhibits optimal outcomes [44]. Data Envelopment Analysis (DEA), an econometric procedure that facilitates benchmarking, is based on the precept there are more ways than one to combine inputs (resources) to achieve optimum outcomes [5].

1.1. Evaluating efficiency of family home care

The conceptual foundation for use of DEA with families is derived from Donabedian's series [11–14] of writings on providing quality care. Donabedian, an expert known for evaluation of care provided to patients, argues that effectiveness, efficiency, and optimality are essential for quality care. Effectiveness is deemed to be the acceptable standard of care. Efficiency is the ability to provide the greatest services at the lowest cost. Optimality is defined as the most advantageous balancing of costs and benefits. Families managing home care must provide acceptable care (effectiveness) at the lowest cost (efficiency) that results in the most advantageous benefits according to that family's set of values or beliefs (optimality). For this study, values are considered inherent in the choices that families make related to costs and benefits. Considering Donabedian's concepts, a family's values are related to both the efficiency and effectiveness of outcomes of home care.

1.1.1. Efficiency and effectiveness

A letter to the editor of *The New England Journal of Medicine* in January, 1986, described the use and misuse of the term cost-effectiveness in medicine [15]. The authors of the letter challenge the common practice of equating cost-effectiveness to cost savings and pointed out there are no accepted dollar trade-offs for extended years of life or health outcomes gained and that efficiency must be considered. Cost-effectiveness needs a broader scope of application to cost-benefit analysis. Hammond [29] placed costs into three categories: direct, indirect, and intangible. Direct costs refer to equipment, supplies, and services used in caring for the patient. In economic terms, the indirect costs are known as opportunity losses or the lost ability to earn income. A major indirect cost is the loss of income or unemployment due to caregiving responsibilities. Other indirect costs such as doctors' office calls or home remodeling needed to accommodate ventilator equipment are seldom covered by insurance [51]. Costs of home care to the family for equipment support services, for training and education to provide ventilatory care, and for expenses such as electrical bills, supplies, and special transportation not covered by third party payers also drain family resources [34, 37]. Intangible costs are referred to as caregiving costs in this study and reflect the values and consequences of acting on such values by the caregiver. In home care, many intangible caregiving costs are positive (caregivers' sense of accomplishment or caregiving esteem) and many are negative (the burden felt by the caregiver or burnout). Evidence from elder home care indicates that when the burden becomes too great, the caregiver's decision making about resources become less effective, and a tendency to provide poor care occurs [34].

1.1.2. Application of DEA to family evaluation

Data Envelopment Analysis (DEA) permits the input of nonmonetary variables that reflect the values of the family, as well as the input of economic indicators. Using DEA analysis, one family may be found to be less efficient than another because the balancing of costs and benefits (optimality or considering values) leads to a lower standard of care (lack of effectiveness) or the use of expensive services (inefficiency) and increased costs [16, 21]. Combining the variables that reflect costs and values in different steps of DEA will distinguish the inefficiencies that are related to values or economics. When variables that reflect family values as well as costs are compared using DEA, the families at risk for depleting their resources or caregiver burnout [38] are identified.

The coefficient of efficiency represents each unit's (in this study, each family's) use of inputs (resources) compared to outputs (outcomes). Each family is compared to all other families on each measure, resulting in a multidimensional function in which families with similar resources and outcomes are analyzed as reference sets. Families with minimal use of resources and optimal outcomes have the largest coefficient of efficiency within their reference set. Costs of resources needed to

assist families in obtaining larger coefficients of efficiency can be calculated [48]. Comparison to the reference set, rather than to an average, a norm, or an artificially-determined "ideal" family [24], overcomes the limitations of other programs used for cost/efficiency analyses [49, 50]. Thus, DEA provides specific information to health professionals for counseling families to conserve their resources and to explore value-related decisions that may put the family caregiver at risk for over-burden or the patient at risk for poor quality of care. Counseling families about efficient uses of resources may reduce the likelihood of the family caregiver losing time from work, experiencing burnout (burden), poor health, or quickly depleting health insurance policy capitation limits.

Chilingerian and Sherman [7] judged efficiency and effectiveness (quality care outcomes) in medical decision making using the DEA method. These authors note the importance of limiting the analysis to cases that share central clinical features. Morey et al. [40] emphasize the need to use outcome indicators that have been validated, as in this analysis. The families studied and the variables used herein meet these criteria.

1.2. Families as health care decision-making units

Families' living rooms are being described as miniature intensive care or clinic units, with families managing not only patient care but also medical equipment and supply inventories [2, 8, 36, 65]. Families oversee professional consultations from physical or occupational therapists, nurses, and social workers, as well as pay for services from paraprofessional attendants. In addition, families spend energy in organizing unpaid assistance from extended family, community organizations, and neighbors and in working with insurance caseworkers and financial counselors [22]. The overwhelming majority of these families prefer providing care at home to minimize medical expenses and to involve the patient in everyday activities [26, 27, 60].

The families compared in this study provided home care for an adult dependent on mechanical ventilation for survival. Mechanical ventilation is the continuous or periodic use of a machine that forces air and oxygen into the lungs to assist with breathing. Patients at home on ventilators range from infants born prematurely to paraplegic adults who are able to continue employment by using portable ventilators attached to their wheelchairs [33]. Caregiving costs in home ventilator populations are heavily influenced by the direct expense of therapy and the indirect costs related to the training needed to provide care. In 1991, the average cost per patient for home ventilator care was $21,192 compared to $270,828 for hospital care. In 1992, Blue Cross/Blue Shield indicated the average savings of home versus hospital care were $800 per day for ventilator-dependent patients [43]. Family members and ventilated patients agree that home care costs are significantly less than nursing home or rehabilitation units [3, 10].

1.3. Triangulation of family data

Financial, employment, medical expenses, and family coping data were collected from caregivers and adult patients during home visits conducted from 1988–1989 [57]. Financial data included costs of medication, equipment, and health services used over the preceding three months, as well as use of insurance benefits. Employment data included absences from work, unnecessary use of sick days, and difficulty in seeking better positions due to caregiving responsibilities. Family coping data included patient and caregivers ratings on a family function questionnaire. The family function questionnaire reflects the family's ability to meet a person's basic needs. Data from these questionnaires were selected as inputs and outputs for DEA evaluation of direct, indirect, and caregiving cost efficiency.

The DEA results in this analysis were first compared to evaluations of the families by a nurse clinician who routinely assessed needs, provided patient education, and helped in determining when home care was no longer effectual and the patient required institutionalization, typically into a nursing home. Next, other data collected about each family from interviews and home evaluations of the environmental and family adaptation by a research nurse were compared to the efficiency scores (coefficient of efficiency). The families' efficiency ratings on the DEA were then compared to long-term clinical evaluations of the nurse clinician to determine if use of DEA at the onset might have identified families who were successfully managing resources over time. Comparison of these data with efficiency scores was used to assess DEA results across families with different values and across time to determine if, indeed, families who were inefficient (based on economics, values, or patients' deteriorating condition) were using more resources three years later than peer families.

2. Methods

The methods section includes a description of the subjects or families in this sample, the stepped procedures used in the analysis, and the DEA model selected. Also described are the input and output variables used in each step of the DEA for analysis.

2.1. Subjects

Although 20 patients and their family caregivers participated in the original study, only the 17 families who provided economic data were used in this analysis. Ten caregivers were employed and five were retired. Three of the retired caregivers resigned from their employment to meet their caregiving responsibilities. One patient was employed, going to work in his wheelchair daily, and another patient ran a successful business out of his home. Mean annual family income was reported as $9,800 with a range from $5,000 to $30,000 or more. The patients and caregivers ranged in age from 18 to 74 years. Over half of the patients ($n = 9$) had been using home

mechanical ventilation for less than one year; the remainder from two to nine years. Eight patients were completely ventilator-dependent for 24 hours per day, seven used ventilator assistance 10 hours per night, and the remainder used ventilation at intervals during the day as needed in addition to the eight hours at night. The medical diagnosis of the patients was respiratory insufficiency predominantly due to neuromuscular illness or trauma. Twelve patients needed assistance with three or more activities of daily living (feeding, bathing, or toiletry). In this sample, no patient improved enough to discontinue the ventilator. However, one young patient was able to move to an apartment and live with attendants who were available 24 hours per day. Caregivers (all relatives of the patient) provided an average of 7.3 hours per day of direct care, with little assistance from extended family or professionals. The average hours per day do not adequately represent each individual family, however. For example, two family caregivers provided 24-hour care with no assistance, three provided 24-hour care with help from extended family, while the others provided less than 24-hour care but these hours were during the night. Each individual family's amounts of like inputs were considered in the analysis.

2.2. DEA analysis of family caregiving: A stepped procedure

The authors devised a stepped procedure so that the analysis of efficiency in direct, indirect, and caregiving costs could be linked (see table 1). The linking was deemed essential because direct costs (medical expenses/income) impact each family's indirect costs (employment hindrance, training complexity/family function), and

Table 1

Inputs and outputs for stepped DEA.

Step in DEA	Inputs	Outputs
Step 1: Direct costs	Medical expenses	Family income
Step 2: Indirect costs	Training complexity, employment hindrance Efficiency score from direct costs (step 1)	Patient and caregiver APGAR (Family function) scores
Step 3: Caregiving costs	Hours/day care Months/caregiving Medication (score) Efficiency score from indirect costs (step 2)	Caregiver burden score Caregiving esteem score

both direct and indirect costs influence caregiving costs (amount of time spent in caregiving and subsequent psychoemotional reactions of burden or esteem). This stepping was judged to allow for the natural nesting or hierarchy of variables that are

relevant to overall family home caregiving efficiency in this population, where medical expenses are exorbitant. The cumulative stepped procedure allowed comparisons of families such that financial resources (direct costs) were reflected in subsequent analyses of indirect and caregiving costs. This linking procedure was undertaken so that all important variables, including economics, values, and family function (whereby the family transforms their labor into caregiving for the patient), were considered.

In the stepped procedure, the efficiency score resulting from direct costs was entered for each family as an input in the indirect costs analysis. The efficiency score resulting from the indirect DEA analysis was then entered for each family as an input into the caregiving costs analysis. Therefore, differences for a family in efficiency scores across each step might be explained by varying monetary situations, caregiving practices, or caregivers' reactions. Differences in efficiency scores could also identify values or trade-offs in family decision-making between direct, indirect, and caregiving resources.

2.3. DEA model selection

The additive model was selected for this cumulative stepped approach because the variables used in both inputs and outputs can be influenced by health professionals [6, 50].

2.4. Theoretical underpinnings of the stepped procedure

This linking procedure is not unlike the two- and three-stage regression models used in econometrics and other research [4, 23, 31, 35, 46, 47, 61]. The steps were ordered with the variables that theoretically are considered most powerful and related to efficiency entered first (home care costs and income). Literature in the area of finances, family, and caregiving verify the assumption that direct costs and economic resources have the greatest bearing on the efficiency of a family management of high technology home care [56, 64]. The indirect costs, being closely aligned with the direct costs, are entered next because out-of-pocket expenses impact family function and overall available monetary resources [39, 66]. The caregiving costs are the last step, because caregiving labor in this population is posited to override inefficiencies in direct or indirect costs [9]. The advantage of the stepped analyses is that a close examination of variables (economic and value-oriented) known to influence the outcome (efficiency) can be undertaken [42]. In other home care populations where the medical costs are not as great but where caregiving demands are excessive (e.g., home care of frail elderly), these steps might be reversed. Alerting health care professionals to audit families with potential inability to continue home care is a crucial advantage of using DEA.

A limitation of this study is that the medical condition of the patient is not entered into the analysis. Patient condition (patient cannot be left unattended, or patient needs

help with bathing, dressing, or eating) and the extent to which the extended family helps with caregiving are influenced by medical condition. These categorical and discretionary data are used to further describe families and to explain the relative position of the family on the efficiency frontier [25].

2.5. Inputs and outputs selected for analysis

Inputs and outputs were selected for analyzing direct, indirect, and caregiving costs from data collected by interview and questionnaires from both patients and caregivers. Formulations of inputs and outputs are presented in table 1. The questionnaires, described below, have extensive psychometric validity and reliability evidenced from other medical and nursing research studies. Item internal consistency (Cronbach's alpha) was greater than 0.74 across all questionnaires used in this sample.

2.5.1. Direct costs: Input and output

Direct costs analysis used one input and one output. Data for direct costs input and output were collected using a demographic questionnaire. Input for direct costs was total out-of-pocket medical expenses that the family had to pay for doctor, hospital, nursing home, home nurse, or attendant services, as well as equipment, medications, and other special health-related bills. Interview data was used if the demographic questionnaire was not complete.

Output for direct costs was the total family income. Data on other sources of income (stocks, bonds, rental property) were collected, but these categorical data could not be used in the IDEAS® software. Information was gathered on the types and amounts of insurance, disability, or Medicaid used by the family. Dollar resources (stocks, savings) were used in describing the families.

2.5.2. Indirect costs: Input and output

Indirect costs analysis used three inputs and two outputs. The data for two inputs of indirect costs (employment hindrance, complexity of training) were obtained from two questionnaires. Employment hindrance included items about ways caregiving can affect employment (caused you to miss days, decrease hours, turn down a better job, stop looking for a job, or seek another job that lets you continue caregiving). The total sum score of these questions represents the magnitude of employment hindrance. The training complexity input was obtained from the total sum score on the Learning Needs Checklist [59]. In this checklist, the caregivers rated their training needs for learning to manage home ventilation. The checklist also included questions about training needed for diversional activities or hobbies, communicating with the patient, arranging for respite care, handling financial problems, ordering supplies, submitting insurance forms, and understanding the illness. The total sum score on the checklist represents the magnitude of difficulty of content needed to train the caregiver for home ventilator care. A review of the literature established that teaching does have

therapeutic value and is, therefore, an important expense [37,41]. The third input for indirect costs was the direct costs efficiency score for the family from step 1 of the analysis.

The indirect costs data outputs were obtained from the patient and caregiver ratings of their family's global functioning on the Family APGAR questionnaire [52]. The Family APGAR was introduced in 1978 as a clinically usable screening instrument for family function [53]. On the Family APGAR, each person separately rates the family function, defined as adaptation, partnership, growth, affection, and ability to provide economic support [30]. In clinical trials, this instrument has established accuracy for predicting families with high psychological distress and families at risk for malfunction [62]. Both the patients' and the caregivers' APGAR rating scores were used in this analysis, as they consistently have been found to differ statistically in couples managing high technology care [58]. Because each person perceives or values family differently, they contribute differently to the family functions. The patient may do less self-care, thus creating more direct costs, if they perceive the family function as poor, while the caregiver may do less and perceive family function positively. It is well established that each family members' perception of family function is a different phenomenon that influences economics, adaptation, and affection distinctively [45].

2.5.3. Caregiving costs input and output

Caregiving cost analysis used four inputs and two outputs. Data for the caregiving costs input were obtained from the demographic questionnaire. Three of the inputs were hours per day of care, length of caregiving in months, and number of medications given daily to the patient (as an indicator of complexity of care). The fourth input was the indirect costs efficiency rating for the family from step 2 of DEA.

The data for outputs of caregiving costs came from one questionnaire, the Caregiver Reaction Inventory (CRI). The CRI measured factors that influence negative reaction (burden including financial strain) to caring for family members in the home as well as positive factors (esteem gained from caregiving) [28]. Two measures (burden and esteem) provided an estimate of the perceived value (whether negative or positive) caregivers place on the care they provide. The data are widely accepted to represent outcomes of family caregiving, which in turn impact the quality of care for the patient [28,55]. Studies of caregivers of homebound elderly, total parenteral nutrition patients, and victims of Alzheimer's and cancer have indicated the CRI is predictive of caregiver outcomes both negative (inability to give care) and positive (quality of life) [54].

3. Results

The results section presents the findings from the DEA steps used in the analyses. Figure 1 is a two-dimensional representation of those families forming the efficiency frontier at each step. Figure 1 lists the families on the frontier by identification number

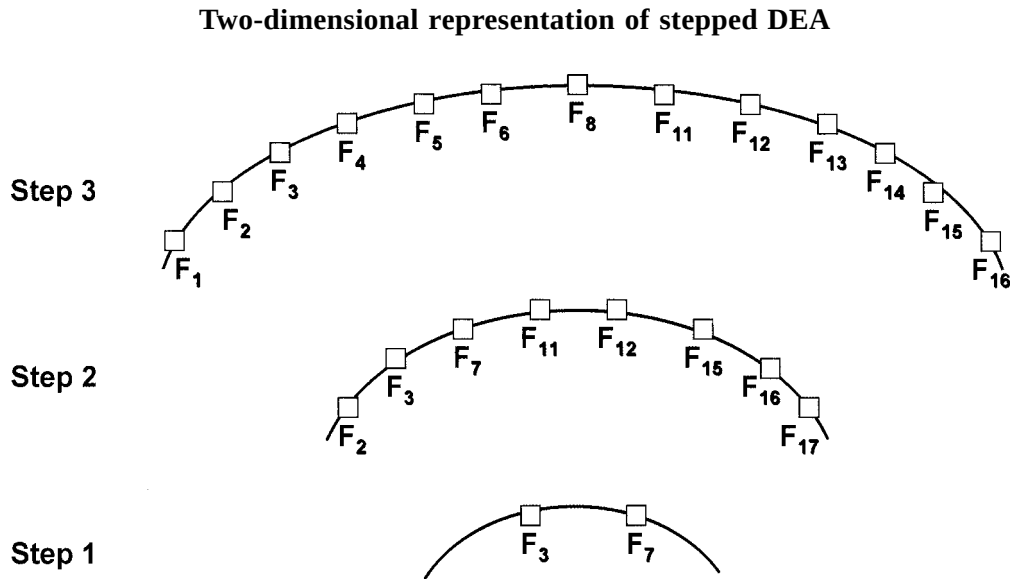

Figure 1. Families (F) that formed the efficiency frontier at each step of DEA.

(for anonymity). Table 2 lists the distance (Σ) value results from the efficiency frontier that each family has in each step of the DEA. A sigma (Σ) score of zero indicates the best practice frontier at that step (figure 1). Pertinent clinical data and the evaluation ratings by the nurse are described to supplement the data interpretation.

3.1. Cumulative stepped DEA results

When direct costs input (medical expenses) and output (income) data were analyzed in the first DEA step, two of 17 families formed the efficiency frontier. These two families had the highest incomes and reported having pensions and interest from stocks and bonds. Of the 15 families not on the frontier, 11 had output slacks in income and also input excesses in medical expenses (see table 3). The least efficient family reported high out-of-pocket expenses, lived in a rental home, and had an annual income of between $5,000 and $6,000.

In the second DEA step, indirect costs were analyzed. A total of eight families, including the two efficient families from the direct costs analysis step, were placed on the efficiency frontier. Inputs for indirect costs included caregiver employment hindrance, training complexity, and each family's direct costs efficiency score from the first DEA step. All the families not on the frontier in step 2 had output slacks in either or both patient and caregiver family function (see table 4). Most notable was that all nine inefficient families had input excesses in training complexity, while only three inefficient families had input excesses in employment hindrance. These findings

Table 2

Distance values* from the efficiency frontier for each step of the three-stepped DEA analysis.

Family number and if on frontier	Step 1 direct costs Σ	Step 2 indirect costs Σ	Step 3 caregiving costs Σ
1	19	12	0
2	4	0	0
3 – on frontier	0	0	0
4	10	101	0
5	35	64	0
6	15	53	0
7 – on frontier	0	0	43
8	12	79	0
9	14	89	43
10	10	20	40
11	19	0	0
12	19	0	0
13	23	74	0
14	24	162	0
15	6	0	0
16	23	0	0
17	23	0	80

* Symbols for distance values are as follows:
Σ = Sigma score for each step rounded to nearest whole number.
NB: A zero sigma (Σ) value indicates that the family is functioning on the efficiency frontier.

indicate that each family had a different array of excesses or slacks that led to their inefficiency, so that optimality or the balancing of costs and benefits were determined in each family according to their values. The least efficient family had excesses across all three of the indirect inputs and was the same family identified as least efficient in step 1 of the analysis.

In the third DEA step, caregiving costs were analyzed, and a total of 13 families formed the efficiency frontier (see table 5). These 13 families included six of the families found efficient in step 2 and seven families who had been inefficient at both steps 1 and 2 (see figure 1). Two families who had been efficient in step 2 were no longer on the frontier. Two families never achieved the efficiency frontier on any of the three steps. The four families not on the efficiency frontier in step 3 had input excesses in number of daily medications, hours per day of care, and months of caregiving provided.

Table 3

Step 1.

Family number and if on frontier	Inputs (excess)*			Outputs (slack)**
	Physician expenses*	Medication expenses*	Home health service expenses*	Family income**
1	1.99	1.99	0.00	15.00
2	3.99	0.00	0.00	0.00
3 – on frontier	0.00	0.00	0.00	0.00
4	3.99	1.99	3.99	0.00
5	3.99	3.99	0.00	27.00
6	0.99	0.00	3.99	10.00
7 – on frontier	0.00	0.00	0.00	0.00
8	3.99	3.99	3.99	0.00
9	0.00	3.99	0.00	10.00
10	0.00	0.00	0.00	10.00
11	3.99	0.00	0.00	15.00
12	1.99	1.99	0.00	15.00
13	0.00	0.00	0.00	22.69
14	0.00	0.99	0.00	22.69
15	3.99	1.99	0.00	0.00
16	0.00	0.00	0.00	22.69
17	0.00	0.00	0.00	22.69

* = Input variables are the amount of money spent on physician, medications, and home health professionals' assistance in previous six months, entered as: 1 ≤ $100; 2 = $101–$299; 3 = $300– $499; 4 = ≥ $500.

** = Output variable is family income; mean value (in thousands) of range reported by family over past two years.

0.00 = No excess or slack.

3.2. DEA results compared to clinical data

The nurse ratings indicated that all families had adapted to the technology in their homes and could manage the mechanical ventilation with safety, so inefficiencies were not due to poor technical ventilator care being provided. The seven families that were not efficient in either steps 1 or 2 achieved efficiency frontier status in step 3 by contributing personal hours and months of care, which apparently overcame inefficiencies due to direct and indirect costs. In one family that became efficient at step 3, the caregiver's health had improved since the patient went on the ventilator at night (the caregiver reported getting more rest). The two families that had been efficient on step 2, but were no longer efficient at step 3, used 24-hour paid assistance in addition to their own caregiving. One of the patients from these families has since

Table 4

Step 2.

Family number and if on frontier	Inputs (excess)		Outputs (slack)	
	Training complexity[a]	Employment hindrance[b]	Caregiver APGAR[c]	Patient APGAR[d]
1	8.00	4.00	0.00	00.0
2 – on frontier	0.00	0.00	0.00	0.00
3 – on frontier	0.00	0.00	0.00	0.00
4	91.83	0.00	0.00	9.50
5	41.99	1.00	1.00	4.00
6	35.75	0.00	9.00	2.00
7 – on frontier	0.00	0.00	0.00	0.00
8	76.82	0.00	0.00	2.37
9	73.00	1.00	7.00	0.00
10	8.00	0.00	8.00	0.00
11 – on frontier	0.00	0.00	0.00	0.00
12 – on frontier	0.00	0.00	0.00	0.00
13	55.00	0.00	1.00	1.00
14	38.00	0.00	2.00	4.00
15 – on frontier	0.00	0.00	0.00	0.00
16 – on frontier	0.00	0.00	0.00	0.00
17 – on frontier	0.00	0.00	0.00	0.00

[a] Training complexity ranged from 42 to 225; *M* = q134.65, *SD* = 63.98.
[b] Employment hindrance ranged from 1 to 7; *M* = 3.24, *SD* = 1.86.
[c] Caregiver APGAR ranged from 14 to 25; *M* = 21.28, *SD* = 3.36.
[d] Patient APGAR ranged from 13 to 25; *M* = 21.50, *SD* = 3.27.

died. The two families who were not efficient on any step have since placed their relatives in nursing homes. These findings indicate that time spent in caregiving and indirect costs variables (employment hindrance and training complexity) impact caregiving efficiency, whereas medications have a more limited effect.

It is interesting that only two output slacks occurred at step 3. One inefficient family had slacks in esteem of caregiving, and one had slacks in burden. A slack in caregiving esteem might indicate that the caregiver feels confident but also over-obligated to provide care. A slack in burden indicated the caregiver perceives burden to be beyond that expected. Input excesses appear to contribute more frequently to inefficiency rather than output slacks. Since the value-oriented variables were used as outcomes, families appear to be balancing costs (inputs). One family was efficient on both direct and indirect costs (steps 1 and 2) but was inefficient in caregiving costs. Even though this family had good financial resources and managed indirect costs

Table 5

Step 3.

Family number and if on frontier	Input (excess)			Output (slack)	
	Hours per day of caregiving[a]	Medication complexity[b]	Months of caregiving[c]	Burden of caregiving[d]	Esteem from caregiving[e]
1 – on frontier	0.00	0.00	0.00	0.00	0.00
2 – on frontier	0.00	0.00	0.00	0.00	0.00
3 – on frontier	0.00	0.00	0.00	0.00	0.00
4 – on frontier	0.00	0.00	0.00	0.00	0.00
5 – on frontier	0.00	0.00	0.00	0.00	0.00
6 – on frontier	0.00	0.00	0.00	0.00	0.00
7	7.00	5.00	29.00	0.00	2.00
8 – on frontier	0.00	0.00	0.00	0.00	0.00
9	0.77	5.12	21.60	0.00	0.00
10	0.09	5.00	15.90	0.09	0.00
11 – on frontier	0.00	0.00	0.00	0.00	0.00
12 – on frontier	0.00	0.00	0.00	0.00	0.00
13 – on frontier	0.00	0.00	0.00	0.00	0.00
14 – on frontier	0.00	0.00	0.00	0.00	0.00
15 – on frontier	0.00	0.00	0.00	0.00	0.00
16 – on frontier	0.00	0.00	0.00	0.00	0.00
17	2.11	0.00	77.77	0.00	0.00

[a] Hours per day of caregiving ranged from 1 to 24; $M = 8.71$, $SD = 7.90$.
[b] Medication complexity ranged from 1 to 9; $M = 4.54$, $SD = 2.35$.
[c] Months of caregiving ranged from 2 to 312; $M = 43.6$, $SD = 70.88$.
[d] Burden of caregiving ranged from 0.6 to 1.11; $M = 0.81$, $SD = 0.14$.
[e] Esteem from caregiving ranged from 13 to 20; $M = 17.24$, $SD = 1.80$.

(complexity of training and employment hindrance), the months and hours of caregiving contributed to inefficiency. One family who became efficient only at step 3 had caregiving responsibilities shared by spouse and children of the patient. That spouse became very ill and was no longer able to provide care. The patient's condition worsened and he died. Two of the five families identified as maladaptive by the nurse now have the patient in a nursing home and were never on the efficiency frontier in any step of DEA.

4. Discussion

Analysis of the 17 families providing at-home ventilator care suggested three areas of resource allocation: direct monetary expenses, indirect training and employ-

ment costs, and the psycho-emotional expenditure required to provide long-term physical care to a loved one. To incorporate each of the critical elements in this analysis, a cumulative stepped DEA process was followed.

Overall DEA analysis of direct costs indicated two families were on the efficiency frontier. Including the direct cost efficiency ratio or metric with indirect costs resulted in the frontier expanding to eight efficient families. The addition of caregiving costs resulted in a different grouping of 13 families on the frontier. One family efficient at step 1 because their income was greater than $30,000 was not found efficient in step 3. Conversely, several families inefficient on direct costs because of lower incomes achieved efficiency at step 3 through their personal caregiving in months and hours of labor. In one of the step 3 inefficient families, caregiving inputs were overwhelming to the caregiver and resulted in caregiver burden and burnout three years later. Thus, it appears that families who are inefficient at steps 1 and 2, but achieve efficiency in step 3, may be harmful to the caregiver. The stepped DEA procedure allowed variables to be nested across steps so that pertinent factors (economic and values) impacting efficient home caregiving could be studied.

4.1. Cumulative stepped procedure repeated in a different home care population

Further evidence for the utility of the stepped DEA procedure to alert clinicians to audit family status comes from a longitudinal study with DEA analysis, using detailed records of direct home care costs of 44 families managing another expensive health care technology (intravenous nutrition infusions with average national costs of $150,000 annually). As in the ventilator-stepped DEA procedure, direct, indirect, and caregiving costs were analyzed. In step 1, income was compared to costs of home care, medical equipment, physician, and any hospital costs. Only two families achieved efficiency rating. Major input excess was on costs of nondurable supplies and excess home nursing care. In step 2, there were 12 of 44 families on the best practice frontier, with job hindrance being the major input excess. At step 3, 23 families were efficient, with inefficient families having output slacks in caregiving burden. Evaluation of the DEA methodology for predicting the human and time resources expended in the year following the DEA efficiency rating for these nutrition infusion families was undertaken in a dissertation by Fernengel [24]. Longitudinal data indicated a significantly higher frequency of emergency room or urgent care visits by caregivers of families in the inefficient versus the efficient group [24]. Furthermore, even though patients' physical condition and occurrences of infection did not differ, those in the efficient family group had significantly higher life satisfaction, perceived health, quality of spiritual life scores, and fewer episodes of situational depression compared to the inefficient group [24]. Results also indicated that the DEA assessment of efficient or inefficient was congruent with the clinical profile of the nutrition infusion patients' and caregivers' interview data, with the exception of one case, a family with a severely depressed patient [24]. This case-by-case verification

of the family status as efficient or inefficient led to the conclusions that each family's unique values and ways of achieving efficiency (using their internal and external resources) was represented accurately using DEA and that efficient families can serve as "benchmarks" or examples to less efficient families on how to conserve their economic and human resources.

It is interesting that caregiving costs in both the intravenous and ventilator analyses resulted in some families moving off the frontier and others moving on to it. Many moved off due to excess in daily hours and months of caregiving. It seems logical that length of caregiving over months in ratio to caregivers burden and esteem influenced the efficiency designation. Yet, the Pearson Product Moment correlations of these variables were not significant for the association between burden scores and length in months of caregiving. Thus, parametric correlations would not have alerted health professionals to monitor these families, but the DEA results did. Further evidence of the utility of the DEA analysis is that in both populations, clinical data coincided with inefficiency ratings from DEA.

4.2. DEA monitoring useful in preventing family shift to inefficient status

Over time, DEA could be used to alert the nurse clinician to determine if the family or patient is at risk. If families become efficient by using caregiving inputs but do not have help, and the patient condition requires increasing care, those caregivers are at risk for strain and burn out [66]. The family must be assisted to carefully consider the extent of the medical expenses, recognize the point at which medical insurance will run out, and evaluate the degree of employment hindrance against the relative loss of resources to caregiving hours required [63]. For example, the family who was efficient in all three steps had numerous ideas on how to manage 24-hour per day ventilator care without overspending their insurance and their own additional costs. Sharing these ideas with another family on a peer-to-peer basis would provide support and realistic suggestions for efficiency.

In other studies where family function is used as a single indicator, and indirect costs, employment hindrance, and training complexity are not considered, the true picture of family function may not be given [1]. DEA permits a more realistic analysis of the family, including incorporation of variables representing their values along with other variables that impact function.

Overall, it appears that families do manage their health care resources in many ways, mainly by using their personal caregiving efforts (hours of labor). This study tested the novel use of DEA with families and compared the DEA analyses to available clinical information. DEA can provide information that is specific to each family and assist families in the challenges of efficiently managing their resources to care for their ventilator-dependent loved one in the home, where health care services are provided as an everyday fact of life [32].

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