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ORIGINAL RESEARCH ARTICLE

Cost and Physician Effort Analysis of Invasive vs. Noninvasive Respiratory Management of Duchenne Muscular Dystrophy

ABSTRACT

Bach JR, Tran J, Durante S: Cost and physician effort analysis of invasive vs. noninvasive respiratory management of Duchenne muscular dystrophy. Am J Phys Med Rehabil 2015;94:474–482.

Background: Continuous tracheostomy mechanical ventilation users with Duchenne muscular dystrophy are institutionalized or have home nursing services (licensed practical nurse/registered nurse), whereas patients dependent on continuous noninvasive ventilatory support (CNVS) can avoid hospitalizations and publically paid services.

Design and Objective: This is a retrospective analysis comparing cost and physician effort for managing CNVS and continuous tracheostomy mechanical ventilation users with Duchenne muscular dystrophy.

Results: Compared with ongoing personal care, physician services and intercurrent hospitalization costs were negligible. Ten home continuous tracheostomy mechanical ventilation users had 16.4 hrs per day of licensed practical nurse/registered nurse care costing $269,370 per year; 14 were institutionalized at $237,350 per year; and 8 were decannulated to CNVS, with 5 subsequently returning home, costing only $9,800 per year for respiratory equipment. For 93 CNVS users, costs ranged from $9,800 per year for 37 without publically funded assistance, $44,968 per year for 3 with nurses' aides, $81,395 per year for 35 with unskilled personal assistance services, and $239,805 per year for 12 with licensed practical nurses/registered nurses. Twenty-eight became CNVS dependent without hospitalization or evaluation for home care.

Conclusions: Noninvasive management permits cost-effective living at home but is disincentivized by fixed hospital diagnosis-related groups compensation that encourages rapid tracheotomy as well as expensive institutionalization and nursing care.

Key Words: Neuromuscular Disease, Duchenne Muscular Dystrophy, Noninvasive Mechanical Ventilation, Mechanical Ventilation, Cost Analysis, Disposition

"Sometimes what can be counted doesn't really count and what can not be counted, does." — Albert Einstein

With progressive respiratory muscle weakening, patients with Duchenne muscular dystrophy (DMD) often develop symptomatic hypercapnia during sleep that extends into waking hours and can develop into carbon dioxide (CO_2) narcosis, especially when treated with supplemental oxygen. This can be prevented by using noninvasive ventilatory support (NVS) and mechanical insufflation-exsufflation (MIE) as needed instead of oxygen therapy and/or low spans of bilevel positive airway pressure.[1–4] On the other hand, DMD patients not introduced to NVS inevitably develop acute respiratory failure (ARF), especially when upper respiratory tract infections develop into pneumonias (URI-pneumonias). This occurs principally because cough flows become inadequate to clear airway secretions.[2,3] They are then intubated; eventually fail unsupported breathing; undergo tracheotomy; and, in the United States, are then discharged to long-term acute care (LTAC) and/or skilled nursing facility (SNF) ventilator units or return home with 16–24 hrs per day of skilled nursing care (licensed practical nurse/registered nurse [LPN/RN]) for the rest of their lives.

On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* (Lois Curtis) that institutionalization of persons with disabilities who might otherwise be managed in the community constitutes discrimination in violation of Title II of the Americans with Disabilities Act and that public entities must offer community-based services to persons with disabilities when feasible. The Olmstead decision justifies home management of patients using long-term mechanical ventilation.[5] Despite this, the population of institutionalized continuous tracheostomy mechanical ventilation (CTMV) users is increasing.[6]

An approach that can avoid hospitalization, ARF, tracheostomy, and institutionalization begins by introducing nocturnal noninvasive intermittent positive pressure ventilatory assistance/support (NVS), usually via nasal interface, for symptomatic hypoventilation.This usually occurs when the vital capacity (VC) is approximately 640 ml.[3] As the patients weaken further, VC decreases lower than approximately 400 ml, and they require some daytime NVS. They can usually be switched from using nasal to mouthpiece interfaces for it. With VCs lower than approximately 320 ml, patients tend to depend on NVS continuously (continuous NVS [CNVS]).[3] Others have found that similar values of VC parallel NVS dependence.[7]

For NVS users, manually assisted coughing, which involves abdominal thrusts applied after air stacking to deep lung insufflations,[8] and MIE can be critical for providing effective cough flows to avoid intercurrent pneumonias and to facilitate extubation of ventilator "unweanable" patients to CNVS without resorting to tracheotomy.[2,9] The MIE is essentially noninvasive airway suctioning. Its importance in preventing URI-pneumonias and ARF for DMD was described in 1983, more comprehensively in 2002, and subsequently.[10,11]

The relative value unit (RVU) is designed to capture physicians' effort and productivity for the purposes of compensation. RVUs were developed by the Centers for Medicare and Medicaid Services in 2006. An RVU total for a physician's intervention is composed of the "work RVU," which, in theory, takes into account physician effort, skill, and training to provide the intervention, the practice [overhead] expense [PE] RVU, and the physician malpractice [PM] cost component. The RVU total is then multiplied by a conversion factor [CF], and the product is multiplied by a geographical practice cost index [GPCI]. Because the Medicare budget is fixed, these CF and GPCI factors are adjusted for budget neutrality and have facility [i.e., hospital, nursing unit, home care]/nonfacility [private practice] indices incorporated into them to determine compensation by the following formula: nonfacility or facility payment amount = [(work RVU × work GPCI) + (PE RVU × PE GPCI) + (PM RVU × PM GPCI)] × CF adjusted for budget neutrality. The current system incentivizes invasive procedures over noninvasive interventions that preserve wellness.[12,13] This work compares long-term costs and physician effort for invasive *vs.* noninvasive management. (see Supplemental Digital Content, http://links.lww.com/PHM/A85).

METHODS

All DMD patients presenting to one center who became continuously ventilator dependent were retrospectively assessed for long-term disposition and cost of care. No patients were excluded. They were diagnosed by having a typical clinical course including wheelchair dependence before the age of 13 yrs, maximum creatine kinase levels of greater than 5000 IU, and diagnostic muscle biopsy and/or DNA evidence of Xp21 mutation/deletion. Demographics, diagnosis-specific pulmonary function, need for gastrostomy

TABLE 1 DRG and personal care costs

		DRG Relative Weight 2013	Medicaid Cost
AP-DRG description			
79	Respiratory tract infections and inflammations, adult, with comorbidities	1.3102	$7,992
881	Respiratory system diagnosis, mechanical ventilation ≥ 96 hrs	5.6296	$34,338
882	Respiratory system diagnosis, mechanical ventilation < 96 hrs	2.208	$13,469
LTAC-DRG description			
207	Respiratory system diagnosis, mechanical ventilation ≥ 96 hrs	2.0242	$48,000[a]

Service	Cost	Annual Cost	Notes and Assumptions	Source
SNF	$650 per day	$237,250 per year		Bach 2005[6]
Home LPN/RN	$45 per hour	$262,000 per year for 16 hrs per day $393,000 per yr for 24 hrs per day	$38 per hour for LPN and $52 per hour for RN with approximately 50% provided by RN, averaging overall to $45 per hour	Personal communication (2014) with Sam Grasso, vice president, Preferred Home Health Care, New Jersey; Ms Linda Dooley, administrator, Alaris Health at St Mary, Orange, NJ; Mrs Arlene Gray
RN aides	$16 per hour			Personal communications (2014) Mr Gary Novak; Mrs Arlene Gray, New Jersey; Ms Marilyn Saviola
PASs	$10 per hour	$30,000 per year for 8 hrs per day $90,000 per year for 24 hrs per day	20%–30% in addition for care management, administration, and provision of supplemental services (see text)	
Respiratory equipment rental[b]	$800 per month	$9600 per year	2 ventilators, mechanical in-exsufflator and oximeter	Personal communication (2014), Lou Saporito, BS, Millennium Respiratory Services, Whippany, NJ

[a]Personal communications with Gary Huck, director of Managed Care Operations & Reimbursement at University Hospital, Newark, NJ; Mr Gene Gantt, BS, RT, chief executive officer of EVENTA LLC, USA; and Linda Dooley, administrator, Alaris Health at St Mary, Orange, NJ.

[b]On-call and monthly routine visit respiratory therapy services are included in the monthly rental of respiratory equipment.

AP, all patient.

tube (GT), as well as family and other support services were recorded.[3] Diagnosis-specific pulmonary function evaluation included end-tidal CO_2 monitoring, oximetry, spirometry, and cough peak flow assessments. Ventilator use was considered continuous when used 24 hrs per day. All TMV users referred after 1999 were offered decannulation to NVS.

Physician RVUs for outpatient and minimum mandated facility visits were derived from the 2013 national physician RVUs of the Department of Health and Human Services.[14] Medicaid compensates each RVU approximately $20. Because there are no current procedural terminology codes for measuring end-tidal CO_2, pulse oxyhemoglobin saturation (Spo_2), (handheld) spirometry, as well as assisted and unassisted cough peak flows or for training in NVS and MIE, these were bundled into 30- to 60-min outpatient visits.[8]

Hospitalization and LTAC reimbursements were derived from diagnosis-related groups (DRGs) data (Table 1). When intubated patients were not successfully extubated, they underwent tracheotomy and were transferred to SNF ventilator units compensated per diem by Medicaid or they went home with multiple LPNs/RNs assigned to them.[8] The CNVS users were treated in their homes. Any intercurrent intubations were managed by extubation back to CNVS and MIE. They were discharged home directly from the critical care unit.[2] Medicaid waivers (in New Jersey) authorized a fixed sum of money specifically determined for each patient either for unskilled personal assistance services (PASs) for 20–168 hrs per week or for LPN/RN and/or nurses' aides (Table 1). Waivers varied from county to county and state to state, but hourly rates were similar. New York Medicaid provides for up to 24 hrs per day of PASs.

Patient data were gathered by state (New Jersey, New York, other); years of ventilator dependence (CTMV and/or CNVS); institution *vs.* home management with publically sponsored PASs, LPN/RN, LPN/RN aides, or no aid; parental/spouse support (0, 1, 2); and presence or absence of GT. These are all factors that might influence disposition and personal care decisions. Group comparisons were made by *t* test, with $P < 0.01$ considered significant.

First, massive quantities of data were gathered and compared for the longest invasively (case 1) and noninvasively (case 2) treated patients. Another patient treated long-term by PASs was also chosen for comparison with case 2, whose Medicaid waiver permitted only LPNs/RNs. Finally, the two best documented patients who were decannulated to noninvasive management (cases 4 and 5) were analyzed. Because it became obvious that personal care costs dwarfed all other medical costs, data of the remaining 132 patients were confined to it.

RESULTS

Of 275 patients presenting with DMD, 25 and 108 were treated by CTMV and CNVS, respectively, with 8 additional CTMV users decannulated to CNVS and then considered in the latter category. All had typical DMD clinically, and 37 were diagnosed by DNA analysis; 64, via dystrophin levels and muscle biopsy; and 32, by both. The mean (SD) age was 18.6 (2.3) yrs at tracheotomy, 18.8 (2.4) yrs (P = not significant) at introduction of NVS, and 22.3 (4.7) yrs ($P < 0.001$) at CNVS. The mean (SD) age at death or last follow-up was 27.3 (5.4) yrs for the 25 CTMV users and 30.4 (5.7) yrs for the 108 CNVS users. Thus, the mean follow-up was 8.7 yrs (range to 29) for the 25 CTMV users and 8.1 yrs (range to 29) for the 108 NVS users. The most recent mean (SD) VC was 174 (145) ml (range, 0–280) for the CNVS group and 155 (131) ml (range, 0–330) for the CTMV group.

The 25 CTMV users had never used NVS or MIE, yet 14 lost all ventilator-free breathing ability from the time of tracheotomy. All 16 of the 25 who had GTs had them placed along with tracheotomy. Three of the eight decannulated patients, however, had their GTs removed. Eighteen of the 108 CNVS users, including 5 who had been decannulated, had GTs. Both invasive and noninvasive groups had limb function limited to trace finger as well as minimal neck and facial movements, had insufficient VC for breathing autonomy, and had dysphagia but could speak. Twenty-two of 25 CTMV users and 81 of 93 CNVS users for whom this was known had two involved parents. Of the eight CNVS users with one parent, one had LPN/RN aides, two had PASs, and three had no publically sponsored physical assistance. Four CNVS users in New York lived only with continuous PASs.

Summaries of the detailed assessments of RVUs and expenses for a CTMV user (case 1), two CNVS users (cases 2 and 3), and two CTMV users decannulated to CNVS (cases 4 and 5) are in Table 2. The complete detailed assessments are available from the corresponding author. The 93 CNVS users for whom it was known had 53 hospitalizations for respiratory complications (0.07 hospitalizations per year), necessitating 38 intubations for 726 patient-years of CNVS. All 38 patients were successfully extubated back to CNVS and discharged home directly from the critical care unit. Intercurrent hospitalization rates for the CTMV users were unavailable. Reviewing Table 2, it is apparent that costs for physician RVUs, miscellaneous

TABLE 2 Medical *vs.* personal care costs, invasive *vs.* noninvasive management

	Case 1			Case 2			Case 3			Case 4			Case 5		
	Pre-CMV to Age 19			Pre-CMV to Age 22			Pre-CMV to Age 27			Pre-CMV to Age 24			Pre-CMV to Age 28		
	Conventional Management			Noninvasive Management			Noninvasive Management			Conventional Management			Conventional to Noninvasive Mgmt		
Item	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost
Manual WCs	2	—	$8,000	2	—	$8,000	3	—	$12,000	3	—	$12,000	3	—	$12,000
Motorized WCs	2	—	$24,000	2	—	$24,000	3	—	$36,000	3	—	$36,000	3	—	$36,000
Misc equipment	—	—	$1,870	—	—	$1,330	—	—	$1,410	—	—	$420	—	—	$2,100
Outpatient visits	—	—	—	6	26	—	2	10	—	—	—	—	—	—	—
ARF admission	—	—	—	—	—	—	—	—	—	1	121	$28,275	—	189	$28,275
Hospitalization	—	—	—	—	—	—	—	—	—	4	164	$26,322	4	130	$13,160
LTAC	—	—	—	—	—	—	—	—	—	—	—	—	49 days	23	$60,000
Vent rental	—	—	—	3 yrs	—	$28,800	1 yr	—	$9,600	—	—	—	2 yrs	—	$19,200
Cough assist	—	—	—	—	—	$4,750	—	—	$4,750	—	—	—	—	—	$4,750
Subtotal		0	$33,870		26	$66,880		10	$63,760		285	$103,017		342	$175,485
	CTMV Ages 19–48			CNVS Ages 23–48			CNVS Ages 27–43			CNVS Ages 24–39			CNVS Ages 28–31		
	Conventional Management			Noninvasive Management			Noninvasive Management			Noninvasive Management			Noninvasive Management		
Item	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost	Count	RVU	Cost
Outpatient visits	—	—	—	25	92	—	9	33	—	1	6	—	3	10	—
ARF admission	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
Waiver	—	—	—	21 yrs	—	$1,470,000	15 yrs	—	$432,000	14 yrs	—	$134,400	—	—	—
LPN/RN	10 yrs	—	$2,271,360	—	—	—	—	—	—	—	—	—	—	—	—
ARF admission	1	248	$28,275	—	—	—	—	—	—	—	—	—	—	—	—
Hospitalization	4	224	$113,099	4	361	$113,099	—	—	—	—	—	—	—	—	—
Manual WCs	3	—	$12,000	—	—	—	—	—	—	—	—	—	—	—	—
Motorized WCs	3	—	$36,000	—	—	—	—	—	—	—	—	—	—	—	—
Vent rental	10 yrs	—	$96,000	—	—	—	—	—	—	—	—	—	3 yrs	—	$28,800
SNF vent unit	19 yrs	546	$4,507,750		—	—	—	—	—	—	—	—		—	—
Subtotal		1018	$7,064,484		453	$1,583,099		33	$432,000		6	$134,400		10	$28,800
Grand Total		1018	$7.06 million		479	$1.65 million		43	$495,760		291	$237,417		352	$204,285

Case 1 is a New Jersey patient hospitalized for ARF at age 19 yrs, failed two extubations, and underwent tracheotomy and gastrostomy. He was then discharged home after 63 days with 16 hrs per day of LPN/RN care for 10 yrs then lived in an SNF ventilator unit all supported by Medicaid until his death after 29 yrs of CTMV at age 48 yrs. After tracheotomy, he had four hospitalizations of 7–14 days for pneumonias.

Case 2 is a New Jersey patient who had annual outpatient visits from ages 17 to 47 yrs, began nocturnal NVS at age 19 yrs with a VC of 700 ml, and began CNVS from age 23 yrs without being hospitalized. He used mouthpiece CNVS during daytime hours. He had four subsequent hospitalizations for URI-pneumonias and was intubated once but successfully extubated to CNVS. He had a Medicaid waiver for 21 yrs capped at $98,000 per year, of which $86,000 was for an LPN/RN 42 hrs per week at $45 per hour, but because of a nursing shortage, he used approximately $70,000 of the allotment (as low as 10 hrs of LPN/RN care per week). Had he been treated by tracheostomy, he would have been institutionalized because 16 hrs per day of home LPN/RN care could not have been ensured. He had a single working parent, and no home care plan would have authorized PASs to suction via tracheostomy tubes (Ms Arlene Gray, Newton, NJ, personal communication, 2014). He mastered glossopharyngeal breathing for ventilator-free breathing.

Case 3 is a New Jersey patient with 11 outpatient visits in 17 yrs who began sleep NVS at age 26 yrs with end-tidal CO_2 of 68 mm Hg and VC of 440 ml then became CNVS dependent 6 mos later. He uses daytime mouthpiece CNVS (Fig. 1). He has never been hospitalized for respiratory difficulties. A Medicaid waiver of $2400 per month provides 48 hrs per week of PASs paid $11.45 per hour including benefits. His PASs clean his GT, set up his respirator, and transition him between mouthpiece and nasal CNVS.

Case 4, a New Jersey patient born in 1977, had four URI-pneumonias, then, in April 2000, he was intubated for ARF and transferred to an SNF ventilator unit using CTMV with an inflated cuff, was averbal, and was forced to drop out of law school. Five weeks later, he was brought to the authors' clinic, was decannulated to CNVS, developed some ventilator-free breathing ability, and returned home and to law school. He graduated and has remained CNVS dependent for 14 yrs, cared for by two parents with no public assistance other than for respiratory equipment.

Case 5 is a Pennsylvania man hospitalized for URI-pneumonias at ages 15 and 26 yrs. After the latter, he returned home with oxygen therapy, developed CO_2 narcosis the following month, was intubated, failed two extubations, and underwent tracheotomy during a critical care stay of 32 days. After an LTAC stay for 49 days and an SNF ventilator unit stay for 7 mos, despite no ventilator-free breathing ability, he was transferred and decannulated with a VC of 440 ml (8%).[6] Two days later, his VC increased to 610 ml as MIE cleared his airways and normalized his Spo_2, and he weaned to nocturnal-only nasal NVS. On day 5 of the transfer, he was discharged to his parents' recreational vehicle and driven 400 miles home. He had no further inpatient or outpatient care, PASs, or LPN/RN. Five years later, at age 31 yrs, with severe cardiomyopathy, he died of sepsis from an indwelling peripheral intravenous catheter. The conversion to NVS permitted him 2 additional years free from continuous ventilator dependence before requiring CNVS the last 3 yrs of his life.

Costs for durable medical products and services: standard wheelchair, $4000; motorized wheelchair, $12,000; and miscellaneous equipment including shower chair, $80; commode, $260; braces, $300; and walkers, $240 (Carlos Collazo, president at CMC Adaptive Seating & Homecare, LLC, Whippany, NJ, personal communication, 2014).

CMV, while dependent on continuous mechanical ventilation; Misc, miscellaneous; Pre-CMV, before dependence on continuous mechanical ventilation; WC, wheelchair; Vent, ventilator.

equipment, and intercurrent hospitalizations were negligible by comparison to personal care/facility costs (Table 2), so only the latter were evaluated for the remaining 132 patients.

The 8 decannulated patients and the other 100 NVS users ultimately became CNVS dependent with no ventilator-free breathing ability, but none underwent tracheotomy electively or for extubation failure. Twenty-eight became CNVS dependent without being hospitalized and were not evaluated for home assistance. Because they did not have tracheostomies, they did not want to go there, and SNF units have no expertise in CNVS, CNVS users are not admitted to SNFs. The disposition, personal care needs, and expenses for the 93 CNVS users whose dispositions and personal care needs were known as well as for the CTMV users are in Table 3.

Eight of the last ten presenting CTMV users including one from an SNF ventilator unit were decannulated to CNVS and MIE despite having VCs ranging from 150 to 380 ml, having little or no ventilator-free breathing ability, and having used CTMV for 1.6 and 1.3 yrs in two cases. After decannulation, several individuals weaned to sleep-only NVS before becoming definitively CNVS dependent 1 yr or more later. After decannulation, the costs were for respiratory equipment only for the five who no longer had any home care despite CNVS dependence for 12, 10, 6.1, 4, and 1.5 yrs but were unchanged for the two for whom 16 and 24 hrs per day of LPN/RN services were not discontinued including for 12 yrs thus far for one CNVS user.

DISCUSSION

A key difference between CTMV and CNVS management was that ARF was inevitable for the former, and, when intubated and unweanable, they underwent tracheotomy.[2,3,11] On the other hand, all of the CNVS users, even when intubated, were extubated to CNVS and MIE and discharged using them. Although, conventionally speaking, most clinicians would assume that patients with tracheostomy tubes are more severely affected than those without them, this is clearly not the case for these patients.

Only invasive *vs.* noninvasive management influenced disposition and cost. Cost for invasively treated case 1, with the same severity, years of continuous ventilator dependence, and age at death as case 2, a CNVS user with an LPN/RN, was four times greater ($7 million *vs.* $1.6 million); it was nine times greater than that for case 3, a CNVS user with PASs for 15 yrs, prorated to an equivalent of 29 yrs of ventilator use ($865,200), and approximately 24 times greater than that for an equivalent CNVS user with public funding only for respiratory ($9,600 per year) and other equipment for approximately $300,000. The cost of treating 25 TMV users for 218 patient-years

TABLE 3 Disposition of 122 continuously ventilator-dependent patients with DMD

93 Patients Using CNVS

Disposition	Caregivers	*n*	CNVS Years	Hours Daily	Hourly Care Cost	Total Care Cost	Equipment (Resp) Cost	Care and Equip Cost
Institution	—	2	7	—	$27.08($650 per day)	$3,321,500	$3,321,500	
Home	LPN/RN	12	8.7 (7.1)	14.6 (1.8)	$45 + $1.25	$23,908,230	$1,002,240	$24,910,470
Home	LPN/RN aides	3	6.7 (3.1)	7.7 (3.3)	$16 + $1.25	$903,857	$192,960	$1,096,817
Home	PASs	35[a]	10.3 (3.8)	16.1 (7.7)	$12 + $1.25	$25,421,739	$3,460,800	$28,882,539
Home	None	37	5.4 (4.9)	—	$1.25[b]	—	$2,187,810	$2,187,810
Assisted[c]	PASs	4	6.8 (2.3)	24	$6.88	$1,638,120	$ 261,120	$1,899,240
		93	7.8 (3.6)			$55,193,246		$62,298,376

25 Patients Using CTMV

			CTMV Years		Hourly Cost			
Institution		14	9.2 (8.1)		$27.08 ($650 per day)	$30,557,800		
Home	LPN/RN	10	8.6 (7.9)	16.4 (1.2)	$45	$23,165,820		
Home	PASs	1	3	3	$10	$32,850		
Total		25	8.7 (6.8)			$53,756,470		

[a]Twenty with PAS 24 hours, of which 16 of the hours are compensated at about $12/hour and 8 are compensated at $2/hour as an "overnight differential" because the aides are benefitting from free room and board (see text); therefore $35 \times 16.1 = 563.5 - 20 \times 7 = 423.5$ effective hours paid at $12/hr.

[b]$1.25 per hour or $30 per 24 hrs a day for respiratory equipment rental.

[c]Began assisted-living residencies using sleep NVS at $165 per day and remained there despite CNVS dependence.

was approximately the same as that for 93 CNVS users for 726 patient-years (Table 3). Extent of ventilator dependence (continuous), number of relatives at home, and presence of GT had no bearing on whether respiratory management was invasive or noninvasive, nor did they influence disposition. However, because tracheotomy, by piercing the strap muscles in the neck, exacerbates dysphagia, decannulation permitted three gastrostomies to be closed. Many CNVS users but no CTMV users were cared for by single mothers without publically paid physical assistance. Because four CNVS-dependent patients in New York lived alone with only PASs, continuous ventilator dependence without family support did not necessitate institutionalization or ongoing nursing care.

Besides being a small fraction of the cost, PASs can be an effective and desirable alternative to LPNs/RNs for self-directed CNVS users. In 1977, DMD and other CNVS users from the Goldwater Memorial Hospital long-term ventilator unit, where Medicaid was paying $718.50 per day for each, successfully picketed the New York City Board of Estimate to return to private domiciles and to self-direct PASs. This resulted in two-thirds of cost savings.[15] As a result, New York Medicaid dollars were and continue to be funneled to county social service agencies that contract with managed long-term care and consumer-directed programs to provide durable medical equipment; respite; meal delivery services; accessibility adaptations; respiratory, physical, occupational, and speech therapies; transportation; medications; nutrition; podiatry; optometry; dental care; and PASs at a small fraction of the cost of institutionalization or daily nursing care.[16]

The PASs perform traditional nursing functions including ventilator management as directed by the client (Ms Marilyn Saviola, vice president for Advocacy and Woman's Health, Independence Care Systems, personal communication, 2014, and Mr Ira Holland, founder and client of Concepts of Independence Inc, New York City, and quality control advisor, Respironics International Inc, personal communication, 2004).[16] Despite this, since 1977, there has been no tort litigation for any medical issues and there has been great patient satisfaction with this program.[6,17,18] Indeed, at least 20% of the program's CNVS users married their PASs.[15] Whereas LPNs/RNs are proscribed from performing risky tasks such as driving a client's car, PASs are not.[16] Of the 33 New York CNVS users in this study, only 5 had no assistance, 24 had PASs, 2 were institutionalized (Goldwater unit), and 2 had LPNs/RNs despite having been decannulated to CNVS.

Like most states, New Jersey has no comparable program. Of 37 New Jersey CNVS users, 22 had no publically paid personal assistance, 6 had LPN/RN directed care, and only 9 had PASs, who were limited to 8 hrs per day. All New Jersey CTMV users have LPNs/RNs for airway suctioning. One New Jersey but no New York CNVS users underwent tracheotomy locally. He retained PASs and had them suction his tube thus far for 3 yrs without informing Medicaid so that PASs could be retained in favor of ongoing nursing care or institutionalization.

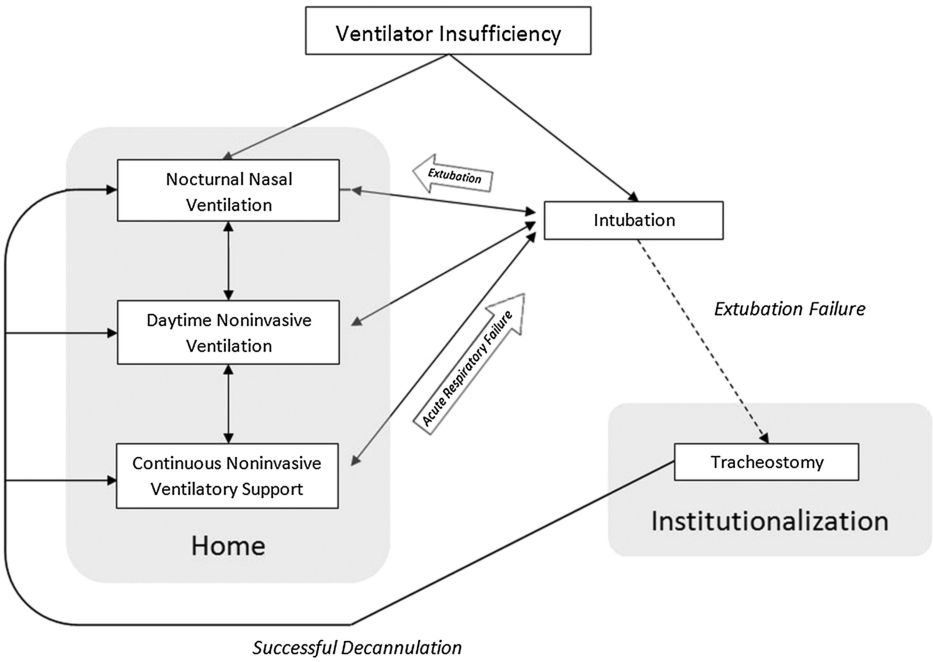

FIGURE 1 *Invasive vs. noninvasive management decision tree.*

Tracheotomies are rewarded by 11.75 RVUs and provide considerable income for hospitals, but they are often unnecessary. On the other hand, avoiding tracheotomy by instructing patients in air stacking,[19] manually[20] and mechanically assisted coughing,[3,9] glossopharyngeal breathing,[21] and NVS via various noninvasive interfaces[22] as well as evaluating cough flows,[20] maximum insufflation capacity,[19] end-tidal CO_2 and oximetry have no current procedural terminology codes. Likewise, there are no specific current procedural terminology codes for extubating or decannulating unweanable patients to NVS and MIE, which can take considerable physician and respiratory therapist time.[6] The extensive patient and family counseling and training, as well as letters of medical necessity and solicitations to payer surrogates to provide respiratory equipment, are also uncompensated. For the five representative patients in Table 2, invasive management incurred 2–30 times more RVUs per patient than noninvasive management. Thus, RVUs are considerable and cost astronomical by comparison to effort-intensive noninvasive management. In a 1998 study, it was found that the mean acute, mostly critical care hospital stay for DMD patients undergoing tracheotomy was 72 days.[15] Patient and family reluctance for tracheotomy often leads to multiple extubation failures, ventilator-associated pneumonias, and other complications that prolong critical care stays. Further, although CTMV user hospitalization rates were not available in this study, long-term hospitalization rates for CTMV users have been reported to be significantly higher ($P < 0.0001$) than for CNVS users.[15]

The CTMV users with VCs of 250 ml or more but no ventilator-free breathing ability usually wean to sleep-only NVS once decannulated, as did cases 4 and 5, and do so without LTAC stays.[8] Thus, by noninvasive management, hospitalization, LTAC, and SNF stays as well as complications of tracheostomies[22] and airway suctioning[23] can be completely avoided[3,15,22,24]; quality-of-life is preserved by living in the community[25] and having prolonged survival[1]; and noninvasive management is universally preferred by patients.[6,25] Various consensus groups now promote this approach.[26–28] As for case 2, mastery of glossopharyngeal breathing can free ventilator users from fear of ventilator failure and accidental disconnection.[21] Further, all this is possible in addition to enormous cost savings. On the other hand, more than 97% of unweanable SNF ventilator (CTMV) users remain institutionalized for life.[2] Does this not beg for a treatment paradigm shift and a proposal to the American Medical Association for new current procedural terminology codes?[29] A decision tree emphasizing this and satisfying the United States Supreme Court's 1999 Olmstead ruling can be seen in Figure 1.[30–32]

A limitation of this study is that cognitive function was not tested. It is likely, however, that because more patient cooperation is required to use NVS and MIE than TMV, severe mental retardation would hinder it. In addition, it is a limitation that the VCs of the TMV users were not known at the time of tracheotomy. This is the case because all of the patients had undergone tracheotomy before presenting to the authors.

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1. B
2. B
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