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Pediatric patients with home mechanical ventilation: The health services landscape

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Abstract

Objective: Children with invasive home mechanical ventilation (HMV) are a growing population with complex health service needs. Single institution studies provide insight into successful program structures and outcomes. Our study objectives were to assess health service structures, providers, and programs caring for this population throughout the U.S., and to understand barriers to high-quality care.

Design: Using purposeful sampling with capture-recapture and snowball sampling methods, we identified key informants for care of the U.S. pediatric HMV population. Informants received web-based surveys with two reminders. Survey domains included respondent characteristics, HMV team composition, and barriers to care.

Results: Survey response was 71% with 101 completed. Respondents caring for patients in 45 states included physicians (61%), nurses (20%), therapists (12%), case managers (4%), and social workers (2%). Half (53%) of physicians were fellowship trained, most commonly pulmonology (22%) and critical care medicine (13%). The majority (65%) of providers described a dedicated HMV service. The majority (61%) of respondents from a HMV service provided both inpatient and outpatient care. Nearly all respondents (96%) described an inadequate supply of home nurses and 88% reported inadequate respite facilities.

Conclusions: Children with HMV assistance receive care from a diverse group of providers with varied team structure. Heterogeneity may reflect patient diversity and provider interest,

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CONFLICT OF INTEREST

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increasing efficacy but challenging standardization nationwide. Despite team structure variability, similar home care difficulties were universally experienced. Data suggest that the home nursing shortage is a national impediment to quality and efficient discharge with limited community-based support for this vulnerable population.

Keywords

critical care; epidemiology; health services research; social dimensions of pulmonary medicine

1 | INTRODUCTION

The population of children assisted by invasive home mechanical ventilation (HMV) in the United States is increasing.^{1–3} Most children receive home-based care.^{4,5} A variety of underlying conditions lead to HMV dependency, including chronic lung disease of prematurity, congenital airway malformations, hypoventilation syndrome, neuromuscular diseases, and spinal cord injuries.⁶ When hospitalized, children with HMV assistance present with multiple comorbidities which require complex tertiary care.^{7,8} They have long hospitalizations, frequent readmissions, multiple providers involved in their care, high inpatient resource utilization, and challenging care coordination demands.^{5,7,9,10} Examples of outpatient needs include private duty nursing, durable medical equipment, primary care and subspecialty appointment coordination, and therapy and special education services. This health service complexity requires carefully coordinated, interdisciplinary discharge from inpatient to outpatient environments.¹¹ Discharge needs may also include transitional or long-term care, further adding layers to the care settings requiring coordination. Confusion around roles and disorganized health information management may impede effective care.¹² As an increasing number of children with HMV assistance receive healthcare in various settings with multiple providers, there is an urgent need to identify best practices to promote successful integration into the community. Prior reports on HMV programs represent single-institutions,^{1,4,13–18} providing important insights into underlying conditions and clinical outcomes. However, there is a shortage of information available on national practice patterns, composition of inpatient and outpatient patient care teams, and barriers to efficient hospital-to-home transition. Furthermore, no comprehensive database of providers and programs caring for children with HMV assistance exists. It is not known to what extent these programs exist within Complex Care programs, are embedded within neonatal and pediatric intensive care units, general pulmonary programs, or how many providers practice independently outside of programs.

In April 2016, the American Thoracic Society (ATS) released Clinical Practice Guidelines for Pediatric Chronic Home Invasive Ventilation.¹⁹ Recommendations include use of standardized discharge readiness criteria, a Medical Home model of healthcare delivery co-managed by a generalist and a respiratory subspecialist, and ongoing caregiver education. The authors concede, however, that there is a lack of evidence for all recommendations, highlighting a need to establish clinical evidence and inform best practices in pediatric HMV care. It is also not known to what extent current practices adhere to ATS guidelines a priori.

This exploratory study aims to begin to address these evidence gaps by describing the diversity of a sample of national providers who care for children with HMV assistance. We have aimed to capture a broad, purposeful sample of respondents throughout the United States. The objectives of this paper are to: (1) describe the backgrounds of individuals who care for children with HMV assistance; (2) understand care team compositions; and (3) assess provider perceptions of barriers and facilitators to providing care.

2 | METHODS

2.1 | Identification of key informants

We used a purposeful sampling method with capture-recapture and snowball sampling to identify key informants. Initially we contacted members of the Complex Care Listserv via email to solicit interest in participating in a research effort regarding children with HMV assistance; respondents provided their name and email for future research initiatives. The Complex Care listserv is a discussion forum for health professionals to discuss research, education, clinical care, and advocacy for children with medical complexity. The listserv is not publically available, and all members are approved by one of the coauthors who serves as a moderator (RA). We compared respondents from this initial screening to the Children's Hospital Association membership list to identify hospitals not yet represented and, for those, emailed potential key informant responders (pediatric critical care medicine physicians, pediatric pulmonologists, members of a complex care team). Investigators also directed additional unique survey links to other team members identified by the first and second round respondents. Overall, we received 148 unique email addresses forming our "key informant" list.

2.2 | Survey development

The authors developed a preliminary survey using branching logic and adaptive questioning to decrease overall respondent burden. Validation efforts included individual in-depth cognitive interviews with four independent practitioners with differing backgrounds and practice locations as well as further vetting with multidisciplinary members of the Complex Care team at Boston Children's Hospital. Cognitive interviews informed the survey content, flow, and technical functionality of the survey. The final survey included questions in the following categories: respondent demographics (eg, "What is your primary profession?"), environment of care information (eg, "In which healthcare settings does your HMV program deliver care?"), barriers to improvement in HMV care (eg, "How much improvement is needed in your practice for the following areas of care for children with HMV assistance?"), and availability of healthcare services (eg, "For children with HMV assistance in your practice, please select a response [strongly disagree, disagree, neither agree or disagree, agree, strongly agree] to each of the following statements: "There is an adequate supply of home nurses to meet the needs of children with HMV assistance.""). The survey was designed and administered using Research Electronic Data Capture.²⁰ Institutional Review Board approval was obtained from the University of Chicago and Data Use Agreements established between collaborating institutions.

2.3 | Survey data collection

We emailed closed survey invitations to 156 key informants. Respondents confirmed an electronic informed consent at the outset. They were able to review and change answers, and exit and re-enter the survey with a unique code. Non-responders received two reminder emails. A subset of non-responders well known to the investigators were contacted with an additional personal email. After initial data analysis, it was found that nine states were not yet represented. The Complex Care listserv was queried for potential respondents from those states; 16 additional research invitations were sent in response to this query. All survey responses were completed within 5 months.

2.4 | Analyses

Results are presented adhering to the CHERRIES checklist.²¹ Statistical analyses were completed using Stata/SE 14 (Stata Corp, College Station, TX). Descriptive statistics were used to describe participant and program characteristics. Differences of proportions were compared using chi-squared tests and Fisher's exact tests for small cells (<5). Statistical significance was defined as a two-tailed *P*-value less than 0.05.

3 | RESULTS

3.1 | Sample

The overall response rate was 71%. We sent emails to 172 unique addresses. Of the 122 respondents who opened the survey link, 6 did not complete consent, 5 did not confirm they cared for children with HMV assistance, and 8 respondents did not directly care for the population of interest. Of the remaining 103 responses, 13 were partially complete. Eleven of the partially complete surveys were determined to be complete enough to include in the analysis. A total of 101 surveys were analyzed.

3.2 | Respondent demographics (Table 1)

Respondents identified caring for patients from 29 "home" states, and routinely caring for patients from an additional 16. A majority of respondents were physicians (61%) or nurses (20%). Other respondents included respiratory therapists (12%), case managers (4%), and social workers (2%). Of 57 physicians who described their specialization, 18 practiced primary care, 29 practiced specialty care, and 10 practiced both. Of 13 nurses who described their specialization, 2 worked in primary care, 10 worked in specialty care, and 1 practiced both. Most physicians (97%, *N* = 58) completed pediatric residencies, and 5% (*N* = 3) of physicians completed combined Pediatrics and Internal Medicine residencies. Approximately half (53%) of physicians completed fellowship training, including Pulmonology (*N* = 13), Critical Care Medicine (*N* = 8), and General Academic Pediatrics (*N* = 4). Other respondents reported completing residency in Physical Medicine & Rehabilitation, and fellowships in Adolescent Medicine, Allergy/Immunology, Developmental and Behavioral Pediatrics, Hematology/Oncology, Hospital Medicine, Neonatology, Neurodevelopmental Disabilities, and Palliative Care. Only one-fifth of respondents were new in the field and reported five or fewer years of experience caring for children with HMV assistance. Thirty-three percent of respondents had 6–10 years and 49%

of respondents had at least 10 years of experience. The respondents' primary regions of practice were 35% Midwest, 23% Northeast, 14% Southeast, 11% Southwest, and 18% West.

3.3 | Environment of care – formal programs (Table 2)

Sixty-five percent of respondents reported that children with HMV assistance at their institution are cared for by a dedicated clinical program. Of these individuals, 52% ($n = 32$) reported their HMV program was part of larger program for children with medical complexity. Forty-eight percent ($n = 29$) reported that their HMV program functioned independently from other clinical programs. Most respondents (76%, $n = 47$) described their HMV programs as solely affiliated with academic institutions, compared to non-academic institutions (13%) or both (11%). Over half of respondents described that their formal programs saw 50 or more children with HMV assistance over the past year. Additionally, within the last 12 months, 47% of respondents' programs cared for 15 or more children with new HMV assistance.

Seventy-eight percent ($n = 50$) of the HMV programs described by our respondents deliver outpatient and 70% ($n = 45$) inpatient care. HMV programs were also described as active in other settings: the child's home (23%), long-term care facilities (23%), emergency departments (23%), and rehabilitation facilities (16%). A majority of formal programs collaborate with interdisciplinary providers: respiratory therapists, case managers advanced practice nurses, social workers, and registered nurses.

Of formal inpatient teams, 100% included a physician, 87% additionally a respiratory therapist, 71% also a social worker, and 53% also included a case manager. A third (31%) included a full team with a physician, respiratory therapist, social worker, case manager, and an APN or Physician Assistant. "Other" staff were most frequently collaborations with dietitians: 5 in the inpatient and 11 in the outpatient setting. HMV programs included physicians with the following expertise: 81% pulmonologists, 44% general pediatricians, 34% otolaryngologists, 27% critical care physicians, 11% neurologists, 9% developmental and behavioral pediatricians, 6% neonatologists, and 6% physical medicine & rehabilitation physicians.

3.4 | Environment of care – providers practicing outside of formal programs (Table 2)

Thirty-five percent of respondents deliver care to children with HMV assistance outside of a formal program. Twenty-four (77%) of these clinicians are affiliated with academic institutions, compared to non-academic institutions (10%) or both (13%). Over the past year, 62% reported seeing 20 or more children with HMV assistance and 31% cared for 10 or more children who required new HMV assistance. Seventy-nine percent of these clinicians provide outpatient and 56% inpatient care. Thirty-two percent report delivering home-based care, and 15% rehabilitation facilities and schools.

Most individual providers describe collaborating with interdisciplinary specialists for inpatient care: case managers (84%), social workers (79%), respiratory therapists (79%), palliative care providers (74%), durable medical equipment personnel (63%), advanced practice nurses (74%), registered nurses (58%), and home health providers (63%). Inpatient

specialty collaboration included Pulmonologists (84%), Otolaryngologists (89%), Pediatric Intensive Care (79%), General Pediatrics (42%), Neurology (47%), Neonatology (47%), and Hospital Medicine (47%). In outpatient settings, the majority of providers collaborate with DME personnel (78%), home health providers (78%), case managers (74%), respiratory therapists (67%), social workers (67%), advanced practice nurses (70%), and registered nurses (63%). Other physicians frequently involved outside of formal programs include specialists in: Pediatric Intensive Care (79%), General Pediatrics (42%), Neurology (47%), Neonatology (47%), and Hospital Medicine (47%).

3.5 | Discharge practices

A majority of respondents, whether independent practitioners or representing formal programs, report discharging children with HMV to other facilities before home. Interim locations included long-term care facilities (41%), rehabilitation facilities (33%), transitional facilities (20%), ventilator-dependent inpatient units (19%), and step-down units (14%).

3.6 | Barriers to improvement (Table 3)

The majority of respondents reported that substantial improvement is needed in respite care (65.2%), transition to adult care (60.9%), and home healthcare (58.9%). (Table 3) Forty-seven percent report that substantial improvement is needed for insurance/waiver coverage. Half of respondents said that little improvement is needed in readmissions (53.9%) and caregiver training and education (50.6%). Nearly all of respondents identified inadequate supply of home nurses (95.7%) and respite care facilities (88%). Forty-two percent of respondents described an inadequate supply of clinicians and 51.1% an inadequate supply of DME providers (Table 4).

4 | DISCUSSION

This exploratory survey representing providers for children with HMV from 45 states identified that care providers for children with HMV assistance have diverse training and work in heterogeneous settings with variable team composition. This variation reflects the organic evolution of programs to address local needs with existing resources and individual care interests and offers both opportunity and challenge. There may be lack of consistency in approach, yet we can learn from natural variations. Insufficient supply of home nurses and respite care facilities was consistently reported as a barrier, demonstrating the crisis in community-based services is a national issue. To the best of our knowledge, our study is the first to begin to describe the U.S. landscape of pediatric providers and common challenges in the care of children with HMV assistance.

Sixty-five percent of respondents described that children with HMV assistance at their institution were cared for by dedicated clinical programs and half of these were within a larger program for children with medical complexity. Given our methodology, sampling complex care provider networks, we may underestimate “independent” providers. Despite the lack of identifying themselves as codified programs, these providers, however, describe similar interdisciplinary collaborations (ie, APNs, RTs, case managers, and SWs) to those

within formal programs. Perhaps understanding the best practice components of HMV programs may help create more consistency where needed across institutions.

Providers describe similar barriers to delivering care to children with HMV assistance. Nearly all described inadequate supply of home nurses and respite care. While home nursing shortages are symptomatic of a larger national nursing shortage,²² the workforce appropriate for the quality care of children with HMV dependency faces the unique challenges of high skill requirements, inadequate incentives and high burnout in pediatric private duty nursing.²³ There is growing evidence that a lack of home nursing coverage negatively impacts caregiver health and wellness²⁴ and delays hospital discharge. Regional variation in nursing between and within states, in part due to discrepancies in insurance expectations and nursing availabilities, presents diverse challenges for providers and families within practice regions. Although the population of children with HMV is small, children with technology dependency are overrepresented in hospitals³ and healthcare expenditures.²⁵ Hence, home nursing shortages may have downstream impacts not only on the individual patient and his/her family, but overall on pediatric healthcare expenditures and the capacity for finite PICU beds to care for critically ill patients. Furthermore, it is not known to what extent home nursing and respite care shortages result in readmissions. In future investigations, we hope to explore the impact of these shortages from a national perspective.

Our study has several limitations. First, our method yielded only a sample of all HMV providers, and the sampling methodology was not representative or random. Intentional methodologic choice to survey individual practitioners, rather than programs, allowed us to capture the range of practice, but does preclude absolute enumeration of programs or patients. In particular, we likely under-sampled among the PICU and pediatric pulmonology workforce. Future investigations will expand our provider sample to describe the network and capture comprehensive care delivery, cross referencing responses within programs. Although we acknowledge these shortcomings, the primary objective was to describe provider and team heterogeneity throughout the country. Notably, our response rate of 71% was substantially higher than most surveys of healthcare providers by any modality.²⁶

The creation of this preliminary key informant list has created the foundation for future investigations. These providers, expert in care of children with HMV assistance, are a potential resource for optimizing the longitudinal care of this growing and vulnerable cohort of children. Rigorous evaluation of initial hospital-to-home transitions and adherence to ATS Clinical Practice Guidelines for Pediatric Chronic Home Invasive Ventilation, and determination of barriers, as well as solutions, across diverse practice settings will, ideally, contribute to more effective, efficient, and safe discharge practices. In the most recent guidelines, the ATS Pediatric Chronic Home Ventilation Workgroup proposed that collaborative generalist/subspecialist co-management is the most likely successful team structure. In this study, we identified that providers stem from various training backgrounds, perhaps blurring the traditional understanding of the generalist/subspecialist expertise they provide. More importantly, this study highlights concerns for patient safety, family quality of life, and resource utilization, as an outcome of home healthcare shortages. Interventions are needed to achieve the ATS recommendations for an awake, trained caregiver at all times. In light of learning that nearly every practitioner we surveyed described challenges in home

nursing availability, we hope to explore how programs address caregiver training and home care. In the current environment with an expanding population and increasing expenditures of children with medical complexity generally,²⁷ and children with home mechanical ventilation specifically,^{28,29} rigorous evaluation of current programs and practices is needed in order to improve care quality.

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TABLE 1

Respondent demographics^a

Profession	% (N)
Physician	60.6 (60)
Nurse	20.2 (20)
Respiratory therapist	12.1 (12)
Case manager	4.0 (4)
Social worker	2.0 (2)
Other	1.0 (1)
Region of practice	% (N)
Midwest	34.7 (33)
Northeast	23.2 (22)
Southeast	13.7 (13)
Southwest	10.5 (10)
West	17.9 (17)
Years of experience	% (N)
0-5	18.8 (19)
6-10	32.7 (33)
11-15	11.9 (12)
16-20	14.9 (15)
21-30	13.9 (14)
31-40	7.9 (8)

^aDue to rounding, percentages do not add up to 100%.

TABLE 2

Characteristics of teams providing HMV care

Practice settings	Formal program % (N)		Individual practitioner % (N)		P-value
	N = 64		N = 34		
Outpatient	78.1 (50)		79.4 (27)		0.88
Inpatient	70.3 (45)		55.9 (19)		0.15
Long-term care facility	23.4 (15)		20.6 (7)		0.75
Rehabilitation facility	15.6 (10)		14.7 (5)		0.90
Emergency Department	23.4 (15)		11.8 (4)		0.19
Child's home	23.4 (15)		32.4 (11)		0.34
Child's school	6.3 (4)		14.7 (5)		0.27
Inpatient collaborations	N = 45		N = 19		
APN	64.4 (29)		73.7 (14)		0.47
Case manager	68.9 (31)		84.2 (16)		0.35
DME personnel	22.2 (10)		63.2 (12)		0.002
Home health provider	17.8 (8)		63.2 (12)		<0.001
Occupational therapist	40 (18)		31.6 (6)		0.53
Palliative care	35.6 (16)		73.7 (14)		0.005
Physical therapist	42.2 (19)		36.9 (7)		0.69
Physician	100 (45)		100 (19)		
Physician assistant	8.9 (4)		36.8 (7)		0.01
Registered nurse	71.1 (32)		57.9 (11)		0.30
Respiratory therapist	86.7 (39)		79 (15)		0.47

Practice settings	Formal program % (N)		Individual practitioner % (N)		P-value
	N = 64		N = 34		
Speech therapist	46.7 (21)		42.1 (8)		0.74
Social worker	75.6 (34)		79 (15)		1.00
Other	26.7 (12)		0		0.13
Outpatient collaborations N = 50					
APN	66 (33)		70.4 (19)		0.87
Case manager	40 (20)		74.1 (20)		0.004
DME personnel	30 (15)		77.8 (21)		<0.001
Home health provider	22 (11)		77.8 (21)		<0.001
Occupational therapist	16 (8)		37 (10)		0.04
Palliative care	16 (8)		51.9 (14)		0.001
Physical therapist	14 (7)		37 (10)		0.02
Physician	98 (49)		100 (27)		1.00
Physician assistant	4 (2)		22.2 (6)		0.019
Registered nurse	76 (38)		63 (17)		0.23
Respiratory therapist	80 (40)		66.7 (18)		0.20
Speech therapist	18 (9)		48.2 (13)		0.005
Social worker	74 (37)		66.7 (18)		0.50
Other	36 (18)		0		<0.001

TABLE 3

Perceptions of improvement needed in areas of HMV Care % (N)

	Substantial	Moderate	Little	None
Respite care	65.2 (58)	24.7 (22)	6.7 (6)	3.4 (3)
Home healthcare	58.9 (53)	31.1 (28)	7.8 (7)	2.2 (2)
Transition to adult care	60.9 (53)	31 (27)	4.6 (4)	3.5 (3)
Insurance/waiver coverage	46.6 (41)	23.9 (21)	23.9 (21)	5.7 (5)
Hospital discharge	16.9 (15)	44.9 (40)	34.8 (31)	3.4 (3)
Urgent care	12.5 (11)	36.4 (32)	40.9 (36)	10.2 (9)
Care coordination	14.3 (13)	42.9 (39)	40.7 (37)	2.2 (2)
Primary care	13.3 (12)	36.7 (33)	40 (36)	10 (9)
Readmissions	7.9 (7)	29.2 (26)	53.9 (48)	9 (8)
Caregiver training and education	11 (10)	30.8 (28)	50.6 (46)	7.7 (7)
Durable medical equipment	10 (9)	52.2 (47)	31.1 (28)	6.7 (6)

Bolded values reflect the degree of improvement category most selected by respondents for each area of care.

TABLE 4

Is there an adequate supply of services for children with HMV assistance? % (N)

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
Home nurses	78.3 (72)	17.4 (16)	1.1 (1)	3.3 (3)	0
Respite facilities	65.2 (60)	22.8 (21)	6.5 (6)	5.4 (5)	0
DME providers	21.7 (20)	29.4 (27)	16.3 (15)	27.2 (25)	5.4 (5)
Clinicians	9.8 (9)	32.6 (30)	17.4 (16)	32.6 (30)	7.6 (7)