Home Mechanical Ventilation: Transitions, Healthcare utilization and costs

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TRANSITION – WHAT DOES IT MEAN?

Patient transitions relevant to individuals requiring ongoing ventilatory assistance: A Delphi study

Can Respir J Vol 21 No 5 September/October 2014

TABLE 5
Transition from institutional care to care within the community (home/assisted living)

Criteria that should define transition	%
Availability of ongoing access to continuing interprofessional care	100
Willingness and ability of supportive network comprising family/friends/caregivers to provide required care	100
Adequate modification of environment/physical space to accommodate patient and equipment	100
Informed choice on behalf of the patient to live in the community	100
Physiological stability of patient to live in the community	100
Availability of appropriate support for informal caregivers including respite	100
Client/caregivers ability to demonstrate required knowledge/skills to live in community safely	100

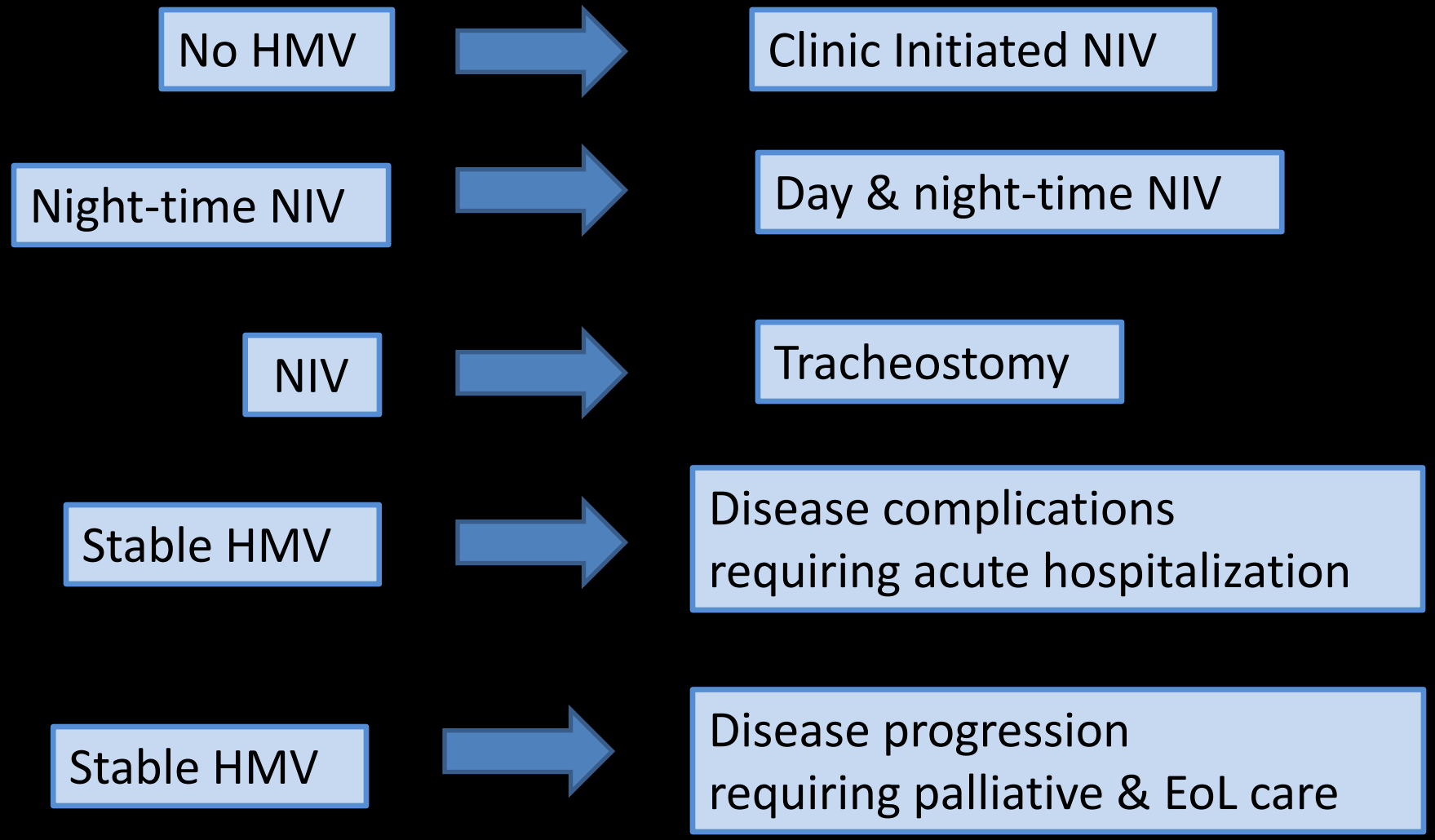
Patient transitions relevant to individuals requiring ongoing ventilatory assistance: A Delphi study

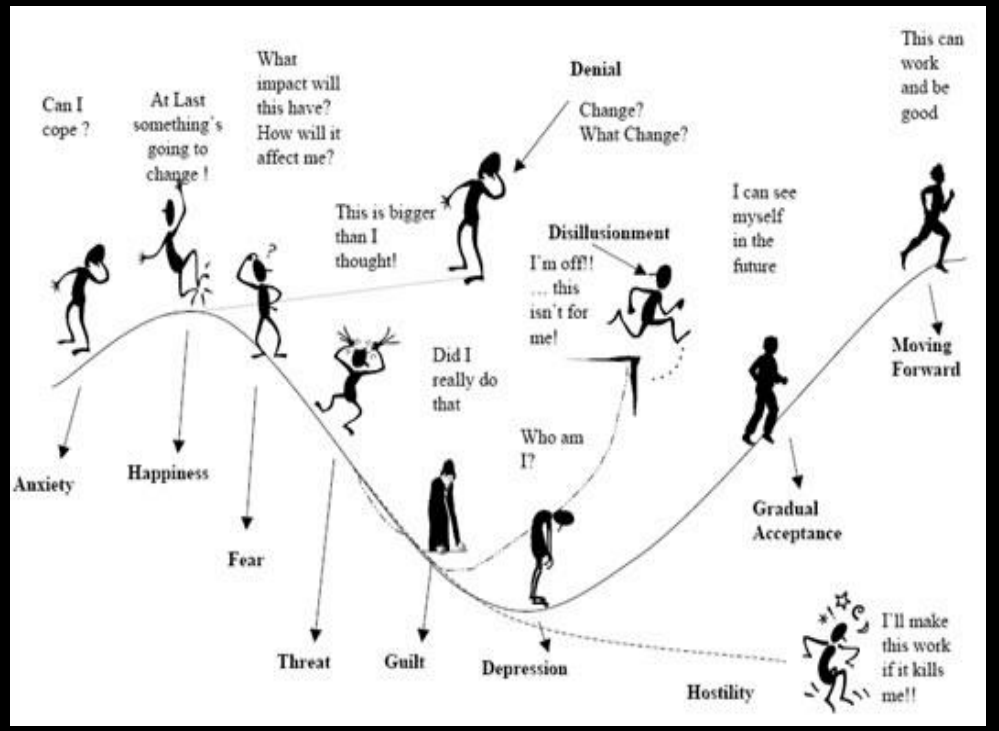
Can Respir J Vol 21 No 5 September/October 2014

TABLE 7
Transition from pediatric to adult long-term mechanical ventilation services

Criteria that should define transition (n=34)*	%
Transfer of care from pediatric team/specialists to adult team/specialists	100
A plan that commenced in adolescence that views transition as a continuum	100
Chronological age	97
A transition plan being in place	97
Appropriate environment/equipment for developmental stage	94
Appropriate environment for physical size	94
Availability of trained/skilled health care workers	88
The likelihood of an acceptable quality of life	82
Adequate resources in the adult sector	79
Family readiness	79
Patient readiness	74

Other Transitions





WHY TRANSITION?

Quality of Life

Clinical Outcomes Associated with Home Mechanical Ventilation: A Systematic Review

Canadian Respiratory Journal
Volume 2016, Article ID 6547180, 10 pages

Disease state	SF-36	n	Physical capacity						Mental capacity			
			PF	RP	BP	GH	PCS	Vi	SF	RE	MH	MCS
RTD	Windisch et al. [7]	29	NC	NC	NC	NC	NC	+	+	+	+	NC
	Hein et al. [13]	8	NC	NC	NC	NC	NR	+	NC	NC	+	NR
	Nauffal et al. [12]	35	NC	+	NC	NC	NR	NC	+	+	NC	NR
	Tsolaki et al. [6]	17	NR	NR	NR	NR	+	NR	NR	NR	NR	+
NMD	Windisch et al. [7]	17	NC	NC	NC	NC	NC	NC	+	NC	NC	NC
	Hein et al. [13]	8	NC	NC	NC	NC	NR	NC	NC	NC	+	NR
	Nauffal et al. [12]	27	—	NC	NC	NC	NR	NC	NC	NC	NC	NR
	Bourke et al. [3]*	41	NC	NC	NC	+	NC	+	NC	NC	+	+
	Bourke et al. [3]†	20	NC	NC	NC	+	NC	+	+	+	+	+
	Tsolaki et al. [6]	11	NR	NR	NR	NR	NC	NR	NR	NR	NR	NC
OHS	Windisch et al. [7]	9	+	+	NC	+	+	+	NC	+	+	+
	Tsolaki et al. [6]	28	NR	NR	NR	NR	+	NR	NR	NR	NR	+

NC = no change; NR = not reported

HRQL was generally described as good for HMV users.

Quality of Life

Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease (Review)

Cochrane Database of Systematic Reviews 2017, Issue 10. Art. No.: CD004427.

Radunovic A, Annane D, Rafiq MK, Brassington R, Mustfa N

Moderate-quality evidence from a single RCT of NIV in 41 participants suggests that it significantly prolongs survival, and low-quality evidence indicates that it improves or maintains quality of life in people with ALS. Survival and quality of life were significantly improved in the subgroup of people with better bulbar function, but not in those with severe bulbar impairment. Adverse effects related

Quality of life in home-ventilated children and their families

Eur J Pediatr (2017) 176:1307–1317

Conclusions: Perceived QOL by children with HMV and their families is lower than that of healthy children. Parents are happy to care for their children at home, even though it negatively affects family life.

Home Non-Invasive Ventilation Fails to Improve Quality of Life in the Elderly: Results from a Multicenter Cohort Study

PLOS ONE | DOI:10.1371/journal.pone.0141156 October 21, 2015

264 elderly patients

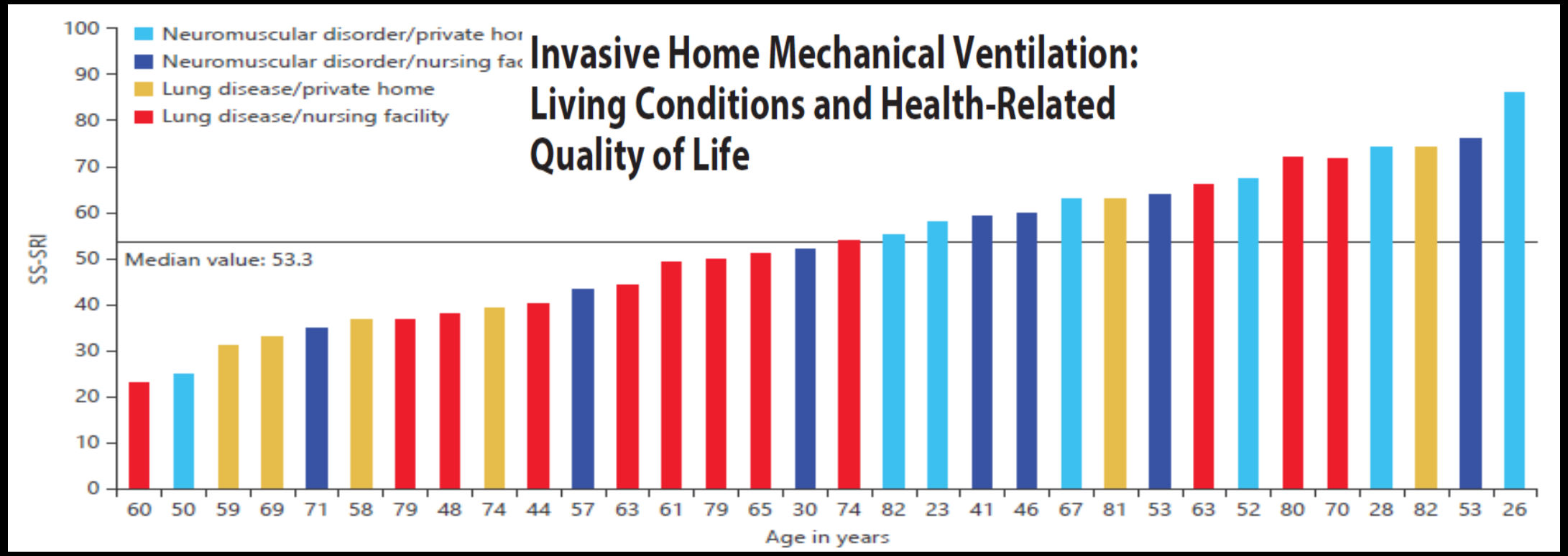
Conclusion

NIV was efficient in the elderly while evaluation at 6 months showed a good adherence but failed to improve HRQL.

Quality of Life

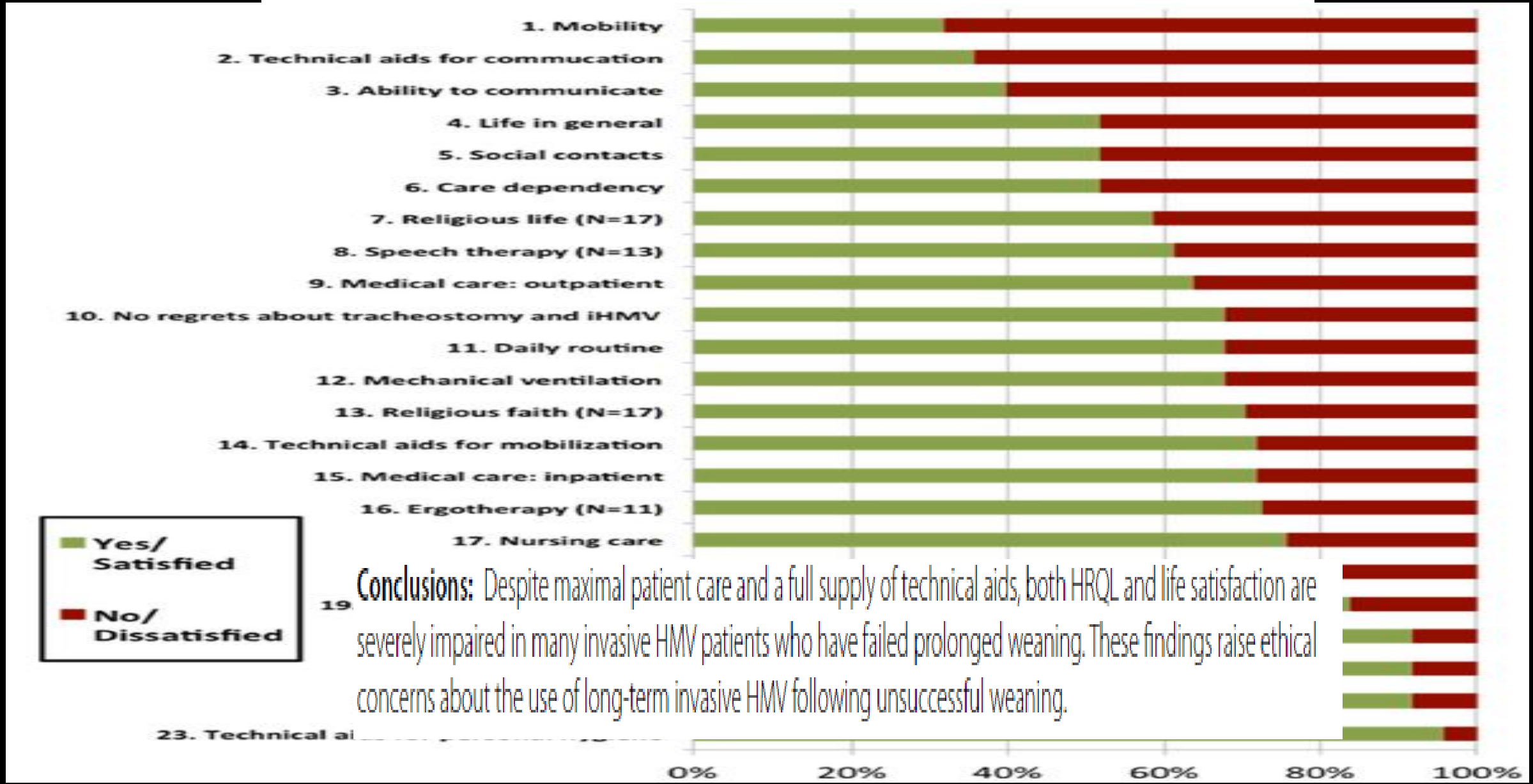
Invasive Home Mechanical Ventilation: Living Conditions and Health-Related Quality of Life

Respiration 2015;89:312–321



Quality of life and life satisfaction are severely impaired in patients with long-term invasive ventilation following ICU treatment and unsuccessful weaning

Huttmann *et al. Ann. Intensive Care (2018) 8:38*



Conclusions: Despite maximal patient care and a full supply of technical aids, both HRQL and life satisfaction are severely impaired in many invasive HMV patients who have failed prolonged weaning. These findings raise ethical concerns about the use of long-term invasive HMV following unsuccessful weaning.

Quality of Life

Transitions to Home Mechanical Ventilation
The Experiences of Canadian Ventilator-assisted Adults and Their Family Caregivers

Ann Am Thorac Soc Vol 15, No 3, pp 357–364, Mar 2018

It gave me independence [and] *it made my life a lot easier. And it meant I don't have to be in hospital, which is really good.* (VAI 14)

Improved health status
Advanced autonomy & quality of life as well as facilitating return to home

I couldn't believe when they put me on the respirator, that I would go to bed at ten, ten-thirty at night, and wake up at six-thirty in the morning and how rested I would actually feel since I was in the hospital. I kind of realized that the darn machine was actually saving my life. (Ventilator-assisted individual [VAI] 13)

"Now I have a lot more energy and as I like to say I have a life. Where before all I wanted to do was sleep." (VAI 3)

My brain was in a fog. I couldn't wake up in the morning. My wife couldn't wake me up. I was losing my memory. (VAI 12)

Transitions to Home Mechanical Ventilation

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Ann Am Thorac Soc Vol 15, No 3, pp 357–364, Mar 2018

Facilitators

- Knowledge
  - Experiential 'hands-on' training
- Self-efficacy
  - Timely telephone support
- Social support
  - Continuity of support from diverse range of people
- Home environment
  - Mutually agreeable discharge date to enable preparation
  - Familiarity of equipment set up and routines

Barriers

- Relationships with providers
  - Maintaining right to transition to home while ventilated
  - Discordance with physician opinions of ability to manage at home
  - Prolonged hospitalization & delays in ventilation training
- Access to information
  - Fight for acquisition of practical information
  - Service fragmentation due to termination of regular contact/access to ventilator experts at hospital discharge

Transitions to Home Mechanical Ventilation

The Experiences of Canadian Ventilator-assisted Adults and Their Family Caregivers

Ann Am Thorac Soc Vol 15, No 3, pp 357–364, Mar 2018

Barriers

– Skilled personal support workers

- incomplete understanding of home care funding policy, roles of service agencies, & skills of PSWs
- Unavailability of PSWs experienced in HMV

The negatives were from other people. You know the nurses telling me I wouldn't be able to do it, "You, you cannot do this, you can't". You know that was a difficult thing. And it took a while to persuade them. (Caregiver 4)

One of the big slogans is "home is best" but they really don't make it easy. Now, I have a couple of [PSWs] for 4 hours a day but they're not actually going to touch the vent. (VAI 18)

We had completely copied exactly how it's all set up at the hospital. So, we have the ventilator on the right of his bed with the humidifier set up next to it. We have the suction machine right underneath there. We have the cough assist machine on the left side of the bed. I need it exactly the same, because if anything is even slightly different it's going to confuse me. (Caregiver 4)

Healthcare Utilization

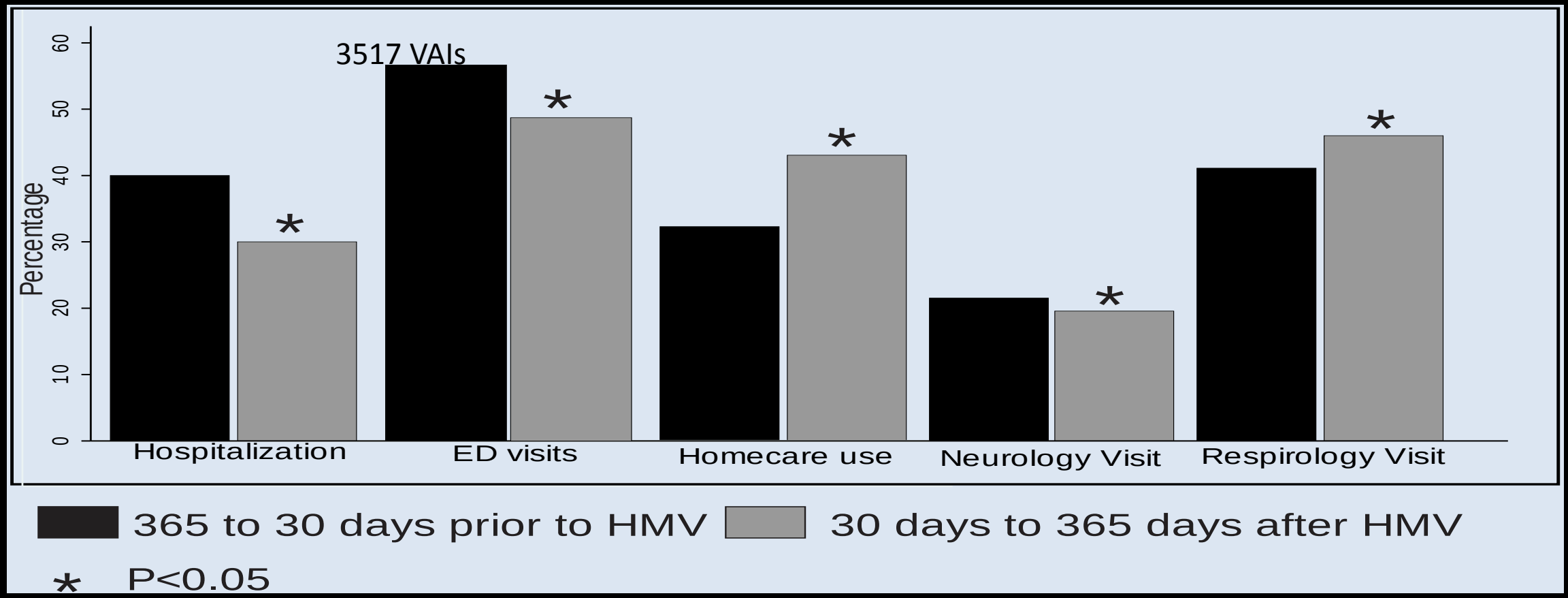
Clinical Outcomes Associated with Home Mechanical Ventilation: A Systematic Review

Canadian Respiratory Journal
Volume 2016, Article ID 6547180, 10 pages

Study	Disease state	n	Before* #admissions/y	After† #admissions/y
Windisch et al. [7]	NMD, RTD, COPD, OHS	85	NR	0.1
Nauffal et al. [12]	NMD	27	1.1 (1.2)	0.3 (1.2)
	RTD	35	1.2 (1.8)	0.8 (1.2)
Farrero et al. [9]	NMD, RTD, OHS	43	2.2 (2.4)	0.5 (0.6)
Bach et al. [14]	NMD, RTD	654	1.5 (2.5)‡	<0.6§
Vitacca et al. [23]	NMD	375	NR	0.5 (0.4)‖
	RTD	128	NR	0.8 (0.5)‖
			d in hospital/pt/y	d in hospital/pt/y
Tsolaki et al. [6]	NMD	11	NR	2.4 (NR)
	RTD	17	NR	0
	OHS	28	NR	3.8 (5.7)
Janssens et al. [11, 15]	NMD, RTD	77	22 (2)	17 (4)
	OHS	32	26 (4)	17 (5)
Gonzalez et al. [10]	RTD	16	10.9 (13.3)	0

Healthcare Utilization

30%VAIs hospitalized year following HMV compared to 40% year prior (P<0.001)
49% visited ED year following HMV compared to 57% year prior (P<0.001)
44% used home care services compared to 33% prior (P < 0.001)
47% respirology outpatient visits compared to 42% year prior (P < 0.001)



Povitz et al. Respir Care. 2018 Apr;63(4):380-387

Healthcare Utilization

Patterns of healthcare utilization for respiratory complications of adults with neuromuscular disease: a population study

N = 497	n (%)[a]	Overall prior[b]	Overall after[c]	P	n (%)[d]	1 year prior	1 year after	P
Respiratory ED visits	196 (39)	1.7 (1.9)	1.7 (1.8)	0.95	136 (27)	1.4 (1.3)	1.4 (1.0)	0.72
Respiratory hospital admission	162 (33)	1.7 (1.4)	1.6 (1.4)	0.62	132 (27)	1.5 (1.2)	1.4 (1.0)	0.70
Respirology outpatient clinic	443 (89)	**8.9 (21.7)**	**22.7 (44.7)**	**<0.0001**	443 (89)	**7.4 (20.6)**	**10.5 (20.1)**	**0.02**
Hospital respirology consult	47 (9)	7.9 (12.9)	12.3 (28.2)	0.07	47 (9)	7.3 (11.0)	8.7 (13.7)	0.39
Pulmonary function tests	465 (94)	**3.1 (3.0)**	**4.1 (7)**	**0.02**	448 (90)	2.3 (1.7)	2.8 (5.1)	0.10
Sleep studies	251 (51)	**1.6 (0.9)**	**1.3 (0.6)**	**<0.0001**	229 (46)	**1.4 (0.6)**	**1.1 (0.3)**	**<0.0001**
All cause ED visits	464 (93)	3.9 (4.5)	3.7 (4.9)	0.53	407 (82)	2.4 (2.5)	2.4 (2.5)	0.81
All cause hospital admission	406 (82)	2.2 (1.8)	2.2 (2.0)	0.77	347 (70)	1.7 (1.2)	1.7 (1.2)	0.52
ICU admission	224 (45)	2 (1.72)	2 (1.6)	0.80	175 (35)	1.9 (1.3)	1.6 (1.2)	0.07

Healthcare utilisation and costs of home mechanical ventilation

Nonoyama ML, *et al*. *Thorax* 2018;**0**:1–8. doi:10.1136/thoraxjnl-2017-211138

134 VAIs (86 Ontario, 53 BC)

Median (IQR) of total monthly summed cost*

Item	Entire cohort (n=134)	Non-invasive (n=89)	Invasive (n=45)
Total public	2410 (955–5361) 58%	1380 (572–3440) 53%	5246 (2730–7333) 54%
Home-based visits	622 (27–3723)	101 (15–1002)	3780 (2036–5106)
Ambulatory-based clinic visits	144 (73–249)	153 (85–252)	106 (69–189)
Hospitalisation ED hospice care	0 (0–1002)	0 (0–288)	37 (0–1092)
Medications	175 (65–392)	173 (36–344)	184 (123–487)
Supplies	173 (38–410)	68 (9–408)	244 (157–410)
Caregiver lost time	1609 (0–5527) 39%	1108 (0–3559) 42%	4262 (0–6586) 44%
Total private out-of-pocket	141 (67-438) 3%	136 (73-438) 5%	142 (67-403) 1%
HCP visits (in or out of home)	17 (0–92)	30 (0–79)	0 (0–98)
Travel	30 (13–81)	45 (18–85)	26 (10–55)
Medications	4 (0–18)	3 (0–15)	13 (0–28)
Supplies	30 (4–149)	24 (3–134)	51 (6–178)
Total third-party insurance	0 (0–21) 0%	0 (0–29) 0%	0 (0–7) 0%
Home-based visits	0	0	0
Medications	0	0	0
Supplies	0	0	0
Total healthcare costs	5275 (2291–10181)	3925 (1212–7390)	8733 (5868–15274)

Healthcare utilisation and costs of home mechanical ventilation

Nonoyama ML, *et al*. *Thorax* 2018;**0**:1–8. doi:10.1136/thoraxjnl-2017-211138

134 VAIs (86 Ontario, 53 BC)

Median (IQR) of total monthly summed cost*

Item	<10 hours (n=54)	10–19 hours (n=39)	≥20 hours (n=41)
Total public	1222 (423–3970) 76%	1542 (762–3228) 39%	5800 (4000–8021) 62%
Home-based visits	62 (12–692)	162 (25–2109)	3825 (2346–5634)
Ambulatory-based clinic visits	183 (86–284)	153 (99–200)	91 (13–173)
Hospitalisation ED hospice care	0 (0–648)	0 (0–288)	0 (0–1098)
Medications	159 (46–303)	158 (40–392)	240 (147–507)
Supplies	52 (1–249)	203 (50–473)	280 (165–574)
Caregiver lost time	236 (0–2547) 15%	2257 (126–6880) 58%	3380 (0–6262) 36%
Total private out-of-pocket	151 (73-365) 9%	125 (63-403) 3%	148 (78-502) 2%
HCP visits (in or out of home)	19 (0–58)	17 (0–97)	8 (0–159)
Travel	44 (15–97)	45 (18–82)	27 (10–45)
Medications	9 (1–18)	1 (0–16)	9 (0–25)
Supplies	20 (2–104)	27 (8–131)	69 (5–264)
Total third-party insurance	0 (0–33) 0%	0 (0–37) 0%	0 (0–6) 0%
Home-based visits	0	0 (0–5)	0
Medications	0	0	0
Supplies	0	0	0
Total healthcare costs	2997 (950–5304)	4980 (2291–10181)	8551 (6131–17090)

Healthcare utilization & costs

Variable	Exponentiated Estimate	95% CI	p-value
Intercept			<.0001
ALS diagnosis (ref=COPD)	1.88	1.42-2.49	0.03
FIM (ref=76-100th percentile) = best functioning			
0-25th percentile	6.98	5.18-9.42	<.0001
26-50th percentile	6.83	5.24-8.91	<.0001
51-75th percentile	2.93	2.36-3.65	<.0001
Male (ref=female)	1.12	0.96-1.31	0.47
Age	1.00	1.00-1.01	0.81
Tracheostomy (ref=non-invasive interfaces)	1.41	0.89-2.25	0.15
Ventilation duration	1.00	0.97-1.03	0.95

Healthcare utilisation and costs of home mechanical ventilation

Nonoyama ML, *et al*. *Thorax* 2018;**0**:1–8. doi:10.1136/thoraxjnl-2017-211138

The monthly median cost of $5275 for our cohort is equivalent to $63 300 each year; considering the most costly group, ALS, the median annual cost is estimated at $154 512. Previous Canadian reports estimate the per diem costs of individuals requiring ventilation and cared for in an intensive care unit would range from $2328 to $4435 ($849 720–$1 618 775 per year) with costs of $921–$1587 ($336 165–$579 255) (2015 $C) in a chronic respiratory, weaning, step-down or rehabilitation unit.[25] We found

Caregiver Burden

Clinical Outcomes Associated with Home Mechanical Ventilation: A Systematic Review

Canadian Respiratory Journal
Volume 2016, Article ID 6547180, 10 pages

Study	*n*	Would choose HMV again (*n*, %)
Evans et al. [19]	12	NR
Kaub-Wittemer et al. [25]*	52	46 (88)‡‡
van Kesteren et al. [27]	31‡	29 (94)
Moss et al. [29]*	36	30 (83)
Aggregate data (*n*, %†)	131	105 (88)
Marchese et al. [18]	77	42 (55)§§
Fernández-Álvarez et al. [21]	20§	NR
Tsara et al. [24]	50	NR
Sevick and Bradham [28]	277	NR
Aggregate data (*n*%†)	424	42 (55)

	Out-of-pocket and/or lost wages	Cost coverage
Kaub-Wittemer et al. [25]/NMD	3,624–29,942† 3,151–78,955‡	All were eligible for federally funded nursing care
Sevick and Bradham [28]/COPD, NMD/OHS	14,412§ 0–545,449	NR
Moss et al. [29]/ALS	15,829 0–367,925	91% privately insured Insurance covered >94% of expenses for 64% of patients
Bötel et al. [30]/SCI	NR	NR

Conclusions

- VAIs experience transitions of varying types
- Reasons to transition
  - HrQoL
  - ↓ emergent health utilization
    - ↓ burden on acute & long-term institutional care
  - ↓ cost to public healthcare
- Important transition facilitators
  - VAI health status, knowledge & self-efficacy, social support, advanced preparation of home environment
- Important transition barriers
  - conflict with HCPs, limited access to information, lack of skilled personal support workers
- Caregiver burden & loss of earnings are important & under-studied considerations

Thank you for your attention and Questions?

louise.rose@utoronto.ca

CURRENTLY RECRUITING!!!!

Please email me if you know caregivers that might be interested

louise.rose@utoronto.ca

DEVELOPMENT & PILOT EVALUATION OF AN ONLINE PEER SUPPORT PROGRAM FOR FAMILY CAREGIVERS OF VENTILATOR-ASSISTED INDIVIDUALS WITH NEUROMUSCULAR DISEASE LIVING IN THE COMMUNITY

FUNDING:
MUSCULAR DYSTROPHY CANADA
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