

Original Article

*E.-L.M. and J.M.J. provided equal contribution as first authors.

Cite this article: Marcus E-L, Jacobs JM, Stessman J (2023). Prolonged mechanical ventilation and caregiver strain: Home vs. long-term care facility. *Palliative and Supportive Care* **21**, 429–437. <https://doi.org/10.1017/S147895152200027X>

Received: 27 October 2021
Revised: 11 January 2022
Accepted: 20 February 2022


Key words:

Homecare; Home hospital; Informal caregiver; Patient–caregiver dyad; Prolonged mechanical ventilation

Author for correspondence:

Jeremy M. Jacobs,
Department of Geriatric Rehabilitation and the
Center for Palliative Care, Hadassah Medical
Center, Mt. Scopus. P.O. Box 24035, Jerusalem
91240, Israel.
E-mail: jacobsj@hadassah.org.il

Prolonged mechanical ventilation and caregiver strain: Home vs. long-term care facility

Esther-Lee Marcus, M.D.^{1,2,*} , Jeremy M. Jacobs, M.B.B.S.^{2,3,4,5,*} 
and Jochanan Stessman, M.D.^{2,3,4,5}

¹Chronic Ventilator-Dependent Division, Herzog Medical Center, Jerusalem, Israel; ²Faculty of Medicine, The Hebrew University of Jerusalem, Jerusalem, Israel; ³Jerusalem Home Hospital Unit, Institute of Geriatric Medicine, Clalit Health Services, Jerusalem, Israel; ⁴Department of Geriatrics and Geriatric Rehabilitation, Hadassah Medical Organization, Jerusalem, Israel and ⁵Institute for Aging Research, Hadassah Medical Organization, Jerusalem, Israel

Abstract

Objective. The number of patients treated with prolonged mechanical ventilation (PMV) is steadily rising. Traditionally treated within specialized long-term care facilities (LTCFs), healthcare providers are increasingly promoting homecare as a technologically safe, humane, and cheaper alternative. Little is known concerning their informal caregivers (ICGs), despite their crucial role in facilitating care. This study examines caregiver strain among the primary ICG of PMV patients treated at home vs. LTCF.

Method. This study was an observational cross-sectional study. The study enrolled 120/123 PMV patients ≥ 18 years within the study region (46 treated with homecare/74 treated at the LTCF) and 106 ICGs (34 ICGs/46 homecare patients and 72 ICGs/74 LTCF patients). Caregiver assessment included the 13-item Modified Caregiver Strain Index (Mod CSI) (0–26 maximum); patient assessment included symptom burden (the revised Edmonton Symptom Assessment System).

Results. The mean age of ICGs was 58.9 years old; 60.4% were females; 82.1% were married; 29.2% were patient's spouses; and 40.6% were patient's children. The total Mod CSI was 13.58 (SD 6.52) and similar between home vs. LTCF (14.30 SD 7.50 vs. 13.26 SD 6.03, $p = 0.50$), or communicative vs. non-communicative patients (13.50 SD 7.12 vs. 13.64 SD 6.04, $p = 0.93$). Hierarchical analysis identified three clusters of caregiver strain, with ICGs at home vs. LTCF reporting significantly lower mood strain, higher burden, and similar levels of lifestyle disturbance. In adjusted models, homecare was significantly associated with reduced mood strain and increased burden, while increased patient symptomatology was significantly associated with total strain, mood, and burden strain clusters.

Significance of results. Recognizing the different patterns of caregiver strain at home or LTCF is a prerequisite for addressing their palliative care needs and improving the wellbeing and resilience of informal caregivers, who often play a critical role in deciding whether to treat the PMV patient at home or LTCF.

Introduction

Prolonged mechanical ventilation (PMV) (defined as >6 h daily ventilation for >21 days) is an increasingly common and challenging area of long-term care (Zilberberg et al., 2012). While the number of older adult patients treated with PMV in long-term care facilities (LTCFs) continues to rise, increasing numbers of PMV patients and their families are now opting to remain at home. The growing interest and availability of complex homecare models, incorporating increasingly sophisticated medical technology, have opened up the possibility of long-term care for PMV patients at home. Indeed, models of home hospital in general and PMV home hospital specifically have been found to be both a humane and preferred alternative to hospitalization from the patient perspective and an attractive cheaper alternative to health-care providers (Rose et al., 2015; Simonds, 2016; Nonoyama et al., 2018; Jacobs et al., 2021a). In contrast to research concerning the impact of long-term care upon informal caregivers across a range of patient populations with common chronic diseases (Adelman et al., 2014), remarkably little is known concerning the profile and unique challenges which typify the PMV patient–informal caregiver dyad. Furthermore, despite increasing numbers of PMV patients treated at home, it is unknown if the burden upon their informal caregiver is different at home compared with patients treated in the LTCF. An accepted prerequisite for optimal patient long-term care, particularly at home, is the maintenance and safeguarding of caregiver health, competence, and resilience (Adelman et al., 2014). Indeed, the informal caregiver may play a pivotal role in the decision concerning whether the PMV patient will be cared for in the

© The Author(s), 2022. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

LTCF or at home. Therefore, identifying the specific needs of informal caregivers of PMV patients is important for healthcare professionals in order to highlight potential avenues for intervention, with the ultimate goal of improving the wellbeing, health, and overall care of patient and informal caregiver alike, incorporating multidisciplinary palliative and supportive care.

The current study forms part of a recent research program, aimed at gaining a deeper understanding of different aspects of care among a cohort of PMV patients, comparing and contrasting those being cared for either at home or in the LTCF. Recently reported findings have included the patients' clinical characteristics, complications, and mortality; patients' mood, distressing symptomatology, overall wellbeing, and attitudes concerning the decision to be ventilated; predictors of site of care, as well as a comparison of costs to the Health Maintenance Organization (HMO) (Jacobs *et al.*, 2021a, 2021b). The objective of the present study was to describe the profile of informal caregivers of PMV patients, to characterize the specific areas of caregiver strain, and compare informal caregiver strain among those caring for PMV patients at home vs. LTCF. We hypothesized that informal caregiver strain would be greatest for patients treated at home.

Methods

Study design

The current study is a cross-sectional observational study of 106 informal caregivers of 120 PMV patients (ventilation via tracheostomy ≥ 21 days) either treated at home or in the LTCF, enrolled between May 1st 2016 and April 31st 2018. Study methodology and findings have been recently described in detail (Jacobs *et al.*, 2021a, 2021b).

Setting

We approached all PMV patients and their primary informal caregivers living within the Jerusalem area, who were insured by the Clalit Health Services, the largest health maintenance organization in Israel, which provides a mandatory comprehensive health coverage to Israeli citizens. The vast majority of patients lived within the city, while five patients were cared for in a surrounding rural setting. The primary caregiver was identified either by the patient where possible, or by self-definition. PMV care in Jerusalem is provided either as in-patient at the Herzog Medical Center, a single specialized university-affiliated LTCF with capacity for 120 PMV adult patients at the time of the study, or at home by the Jerusalem Home Hospital (Jacobs *et al.*, 2007, 2021a). The decision concerning the site of care depends upon patient's and/or custodian's agreement, sufficient informal/formal home care, and medical condition. Both settings provide comprehensive multidisciplinary care, with 24/7 on-call medical and respiratory back up at home, and on-site medical, nursing, and respiratory care in the LTCF.

Participants

All adults treated with PMV (aged ≥ 18 and Clalit Health Service insured) in Jerusalem, and their informal caregivers were eligible for inclusion. Informal caregivers self-identified as the most involved in caregiving. We identified a total of 123 potential PMV participants (47 at home and 76 in the LTCF), among whom one home participant and two LTCF guardians declined. Among the resulting 120 PMV participants enrolled in the study, we enrolled 106

informal caregivers: 34 caregivers/46 home PMV subjects (28 caregivers/40 communicative PMV subjects and 6 caregivers/6 non-communicative PMV subjects) and 72 caregivers/74 LTCF PMV subjects (21 caregivers/22 communicative PMV subjects and 51 caregivers/52 non-communicative PMV subjects). In brief, PMV subjects at home vs. LTCF were younger (mean age 53.8 ± 21.3 vs. 73.4 ± 16.5 years, $p < 0.001$), more educated, less likely to be married, had fewer children, were ventilated for a longer duration (median 51.2 months, IQR 28–199, vs. 17.9 months, IQR 9–36.9, $p < 0.001$). The reason for PMV was more frequently degenerative neurological conditions (amyotrophic lateral sclerosis/neuromuscular diseases) and chronic lung diseases, compared with acute neurological and medical changes (following stroke, head trauma, status post-resuscitation, and sepsis) among LTCF subjects.

Data collection

The study assistant was a nurse who specialized in PMV care and who collected data by direct structured interview of patients and caregivers and reviewed patient records. Data, coded with a unique identifier, were stored in a secured research database. Informed consent was given by the PMV participants or their custodians, and caregivers. The local ethics committee approved the study proposal.

Measures

Patients

Standardized patient questionnaire included sociodemographic, medical, and functional data. For communicative PMV subjects, attitudes toward ventilation were assessed, and symptomatology was assessed using the revised Edmonton Symptom Assessment System (r-ESAS) (a 10-item set of patient reported outcomes assessing the current feeling of tiredness, lack of appetite, pain, drowsiness, nausea, shortness of breath, overall wellbeing, depression, anxiety, and other problems), each symptom graded by patient from 0 to 10 (most severe), with total score ranging from 0 to 100 (100 most severe) (Hui and Bruera, 2017). The r-ESAS has been validated in 20 languages including Hebrew.

Caregivers

Caregivers were interviewed for sociodemographic data, and caregiver strain was assessed using the 13-item Modified Caregiver Strain index (Mod CSI) (Thronton and Travis, 2003), validated Hebrew version (Bar *et al.*, 2012). Individual items assess: (1) sleep disturbance; (2) inconvenience; (3) physical strain; (4) confinement; (5) family adjustments; (6) changes to personal plans; (7) demands on time; (8) emotional adjustments; (9) feeling upset by patient behavior; (10) feeling upset that the person being cared for has changed; (11) work adjustments; (12) financial strain; (13) feel completely overwhelmed. Each item scored 0, 1, and 2 for "never", "sometimes", and "always", respectively, with maximum severity scored as 26 points.

Statistical methods

Caregiver's characteristics are presented as mean and SD or percentages, and compared between caregivers of home and LTCF patients using *t*-test, χ^2 , or Fisher exact, as appropriate. Individual strain items among caregivers of home and LTCF patients were compared using the *t*-test for the continuous score and a Wald test for the binary variable. We used Ward

hierarchical clustering for the 13 individual strain items to determine three separate clusters. Strain within each cluster was analyzed as both a continuous variable (calculated as the sum of all elements in that cluster, divided by the maximum score of that cluster) and a binary variable (defined as strain either sometimes or always in >1 element within the cluster). These were compared between home and LTCF patients using the *t*-test or the Wald test as appropriate. Multivariate linear regression models were performed to identify factors associated with caregiver strain. Caregiver and patient variables with $p \leq 0.3$ in the univariate analysis were included in the multivariate model, which accordingly adjusted for caregiver age, gender, relationship to patient, site of

care, and patient communicative status. An additional model examined only caregivers of communicative PMV patients for whom r-ESAS symptomatology was available ($n = 47$), adjusting for caregiver age, gender, caregiver relationship to patient, site of care, and patient r-ESAS score. Both models were repeated for either the total caregiver strain score, or the score in each cluster separately. Statistical analysis was performed using R 3.4.3.

Results

As shown in Table 1, the mean age of caregivers was 58.9 years old; 60.4% of caregivers were females; 82.1% were married;

Table 1. ICG of PMV patients: baseline characteristics at home and in the LTCF

		Overall ($N = 106$), n (%)	Home ($N = 34$), n (%)	LTCF ($N = 72$), n (%)	p -value
Gender	Female	64 (60.4)	22 (64.7)	42 (58.3)	0.68
	Male	42 (39.6)	12 (35.3)	30 (41.7)	
Age (years)	Mean (\pm SD)	58.9 (\pm 13.8)	59.5 (\pm 15.9)	58.7 (\pm 12.7)	0.79
Marital status	Married	87 (82.1)	28 (82.4)	59 (81.9)	0.62
	Single	9 (8.5)	2 (5.9)	7 (9.7)	
	Divorced	5 (4.7)	1 (2.9)	4 (5.6)	
	Widow	5 (4.7)	3 (8.8)	2 (2.8)	
Number of children	Mean (\pm SD)	3.88 (\pm 2.44)	4.12 (\pm 2.47)	3.76 (\pm 2.44)	0.50
Religion	Jewish	81 (76.4)	29 (85.3)	52 (72.2)	0.22
	Muslim/other	25 (23.6)	5 (14.7)	20 (27.8)	
Self-defined religious level	Secular	23 (22.1)	5 (14.7)	18 (25.7)	0.17
	Traditional	25 (24.0)	12 (35.3)	13 (18.6)	
	Orthodox	35 (33.7)	9 (26.5)	26 (37.1)	
	Ultra-orthodox	21 (20.2)	8 (23.5)	13 (18.6)	
Relation to patient	Partner	31 (29.2)	10 (29.4)	21 (29.2)	<0.001
	Child	43 (40.6)	8 (23.5)	35 (48.6)	
	Sibling	11 (10.4)	3 (8.8)	8 (11.1)	
	Parent	16 (15.1)	13 (38.2)	3 (4.2)	
	Other	5 (4.7)	0 (0.0)	5 (6.9)	
Caregiver is patient's legal guardian	Yes	62 (58.5)	15 (44.1)	47 (65.3)	0.08
	No	40 (37.7)	18 (52.9)	22 (30.6)	
Living arrangement (for LTCF patients, prior to admission)	With patient	55 (51.9)	29 (85.3)	26 (36.1)	<0.001
	Without patient	47 (44.3)	5 (14.7)	42 (58.3)	
Occupation	Employee	43 (43.0)	9 (27.3)	34 (50.7)	0.07
	Retired	29 (29.0)	10 (30.3)	18 (26.9)	
	Student	2 (2.0)	2 (6.1)	1 (1.5)	
	House wife	26 (26.0)	12 (36.4)	14 (20.9)	
Frequency of visits (LTCF patients only)	6-7/week			43 (61.4)	
	2-5/week			21 (30.0)	
	1/week			4 (5.7)	
	<1/week			2 (2.9)	

LTCF, long-term care facility.

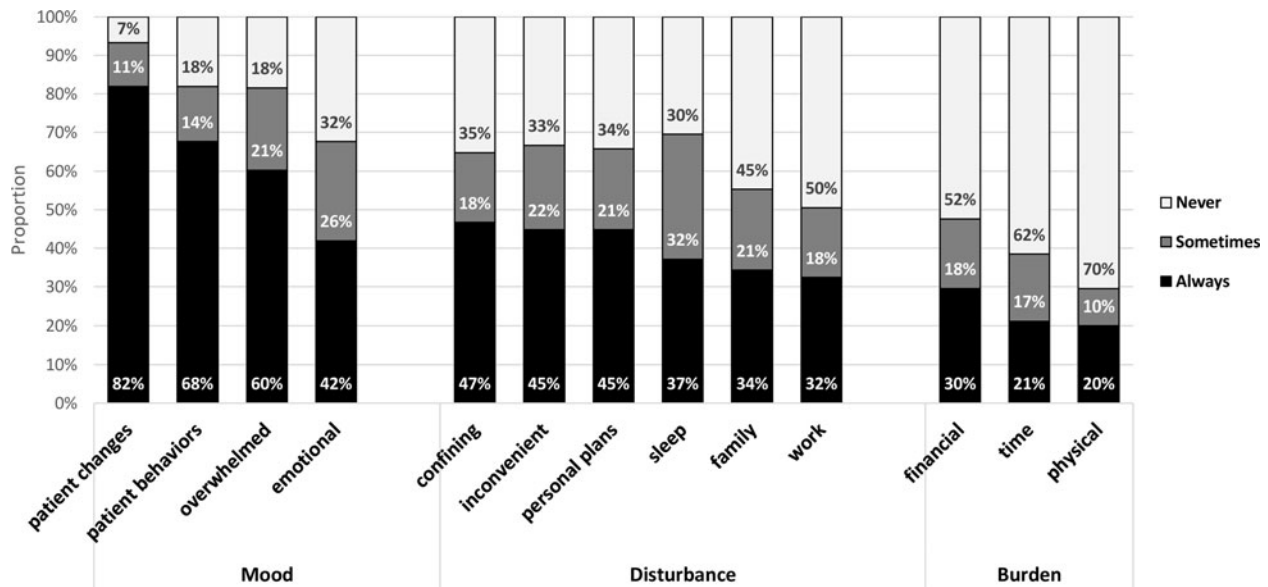


Fig. 1. ICGs of PMV patients: patterns of caregiver strain. Each of the 13 items of the Mod CSI are shown separately, according to the percentage of caregivers who reported strain always, sometimes, or never for each item.

29.2% were patient's spouses; and 40.6% were patient's children. Differences between the caregivers of PMV patients at home vs. LTC are shown in Table 1. The mean total caregiver strain (Mod CSI score) was 13.58 (SD 6.52), with similar levels between home and LTCF (14.30 SD 7.50 vs. 13.26 SD 6.03, $p = 0.50$). Similarly, no differences were observed between the 49 caregivers of communicative patients vs. the 57 caregivers of non-communicative patients (13.50 SD 7.12 vs. 13.64 SD 6.04, $p = 0.93$). As shown in Figure 1 and Table 2, among the 13 different individual items of the Mod CSI, the most frequent complaint was being upset (sometimes or always) that "the person I care for has changed" (93.3%), upsetting patient behavior (81.9%), feeling frequently overwhelmed (81.6%), sleep disturbance (69.5%), and emotional adjustment (67.6%). Caregivers of PMV patients at home vs. LTCF experienced significantly higher levels of physical strain (47.1% vs. 21.1%, $p < 0.01$), confinement (82.4% vs. 59.2%, $p < 0.01$), work adjustment (64.7% vs. 43.7%, $p = 0.04$), and financial strain (64.7% vs. 39.4%, $p = 0.01$), while caregivers of LTCF patients vs. caregivers of patients at home reported high levels of emotional adjustment (74.6% vs. 52.9%, $p = 0.03$), upset that the patient has changed (97.2% vs. 85.3%, $p = 0.06$), that the patient's behavior is upsetting (90.1% vs. 64.7%, $p < 0.01$), and feelings of being overwhelmed (88.4% vs. 67.6%, $p = 0.02$). For most items, findings were similar when strain items were examined either as a binary variable as presented above or as a continuous mean. Hierarchical clustering identified three clusters within the 13 items of the Mod CSI, which broadly identified domains of "burden" (physical/financial/time), "mood" (emotional adjustment/feeling overwhelmed/upsetting changes in patient/upsetting patient behaviors), and general "disturbance" (personal plans/sleep/work/family adjustment/feeling confined/inconvenient). The most frequent complaint among the informal caregivers was mood (91%), followed by disturbance (80%), and lowest for the burden cluster (32%). As shown in Figure 2, caregivers for home PMV patients displayed statistically significantly higher burden cluster (48% vs. 25%, $p = 0.016$), while the mood cluster was consistently higher among caregivers for LTCF PMV patients (97% vs. 79%, $p = 0.024$). Results were consistent for both binary

and continuous measures of strain. As shown in Table 3, after adjusting for caregiver age, gender, relationship to patient, site of care (home or LTCF), and patient's communicative status, the only variable that was statistically significantly associated with caregiver strain was the site of care, with caregiving at home associated with increased burden cluster (β 1.74; CI 0.8, 2.68; $p < 0.001$), and reduced mood cluster (β -1.7; CI -2.85, -0.54; $p = 0.004$). Among the 47 caregivers of communicative patients, after adjusting for caregiver age, gender, relationship to patient, site of care, and patient r-ESAS score, caregiving at home remained associated with reduced caregiver mood cluster (β -2.28; CI -3.95, -0.61; $p = 0.009$). The patient r-ESAS score was statistically significantly associated with the total Mod CSI (β 0.17; CI 0.03, 0.31; $p = 0.018$), burden cluster (β 0.04; CI 0.01, 0.08; $p = 0.02$), mood cluster (β 0.06; CI 0.01, 0.11; $p = 0.031$), and approached near statistical significance for disturbance cluster (β 0.07; CI -0.01, 0.15; $p = 0.07$).

Discussion

In this study of PMV patient-informal caregiver dyads, the mean age of caregivers was approximately 60 years of age, 60.4% were females, and they were more likely to be children of LTCF patients compared with spouses or parents of patients treated at home. Caregivers most frequently reported complaints concerning the negative impact upon emotional domains, followed by general disturbance, and least for overall burden. Despite the finding that the total caregiver strain score was similar irrespective of either site of care (home vs. LTCF), or patient's ability to communicate or not, nonetheless significantly different patterns of individual caregiver strain items, and clusters were observed between home compared with LTCF. Caregiving for a PMV patient at home was significantly associated with a lower level of mood strain, yet greater financial, time, and physical strain, and among communicative patients able to express their symptomatology, increased patient symptom burden was independently associated with an increase in all aspects of caregiver strain.

Table 2. Caregiver strain items among ICGs of PMV patients: home vs. LTCF

Caregiver strain items	All caregivers (N = 105)		Caregivers at home (N = 34)		Caregivers LTCF (N = 71)		p-value (binary)	p-value (mean)
	n (%) (sometimes/always)	Mean (SD)	n (%) (sometimes/always)	Mean (SD)	n (%) (sometimes/always)	Mean (SD)		
Mood cluster								
Upset that the person I care for has changed from former self	98 (93.3%)	1.75 (0.57)	29 (85.3%)	1.47 (0.75)	69 (97.2%)	1.88 (0.39)	0.06	<0.001
Patient's behavior is upsetting	86 (81.9%)	1.49 (0.79)	22 (64.7%)	1.05 (0.88)	64 (90.1%)	1.70 (0.64)	<0.01	<0.001
Feeling overwhelmed	84 (81.6%)	1.42 (0.79)	23 (67.6%)	1.29 (0.94)	61 (88.4%)	1.48 (0.69)	0.02	0.64
Emotional adjustments	71 (67.6%)	1.09 (0.86)	18 (52.9%)	0.76 (0.82)	53 (74.6%)	1.25 (0.84)	0.03	<0.01
Disturbance cluster								
Confining	70 (66.7%)	1.11 (0.88)	28 (82.4%)	1.50 (0.79)	42 (59.2%)	0.93 (0.87)	<0.01	<0.01
Inconvenient	68 (64.8%)	1.11 (0.90)	24 (70.6%)	1.12 (0.84)	44 (62.0%)	1.11 (0.93)	0.38	0.96
Changes in personal plans	69 (65.7%)	1.10 (0.89)	25 (73.5%)	1.32 (0.88)	44 (62.0%)	1.00 (0.87)	0.23	0.08
Sleep disturbed	73 (69.5%)	1.07 (0.82)	25 (73.5%)	1.12 (0.81)	48 (67.6%)	1.04 (0.83)	0.53	0.64
Family adjustments	58 (55.2%)	0.89 (0.89)	17 (50.0%)	0.88 (0.95)	41 (57.7%)	0.90 (0.86)	0.46	0.91
Work adjustments	53 (50.5%)	0.83 (0.89)	22 (64.7%)	1.03 (0.87)	31 (43.7%)	0.73 (0.89)	0.04	0.11
Burden cluster								
Financial strain	50 (47.6%)	0.77 (0.88)	22 (64.7%)	1.12 (0.91)	28 (39.4%)	0.61 (0.82)	0.01	<0.01
Demands on my time	40 (38.5%)	0.59 (0.82)	16 (48.5%)	0.79 (0.89)	24 (33.8%)	0.51 (0.77)	0.16	0.10
Physical strain	31 (29.5%)	0.49 (0.81)	16 (47.1%)	0.82 (0.94)	15 (21.1%)	0.34 (0.69)	<0.01	<0.01
Total score		13.58 (6.52)		14.26 (7.50)		13.30 (6.03)		0.50

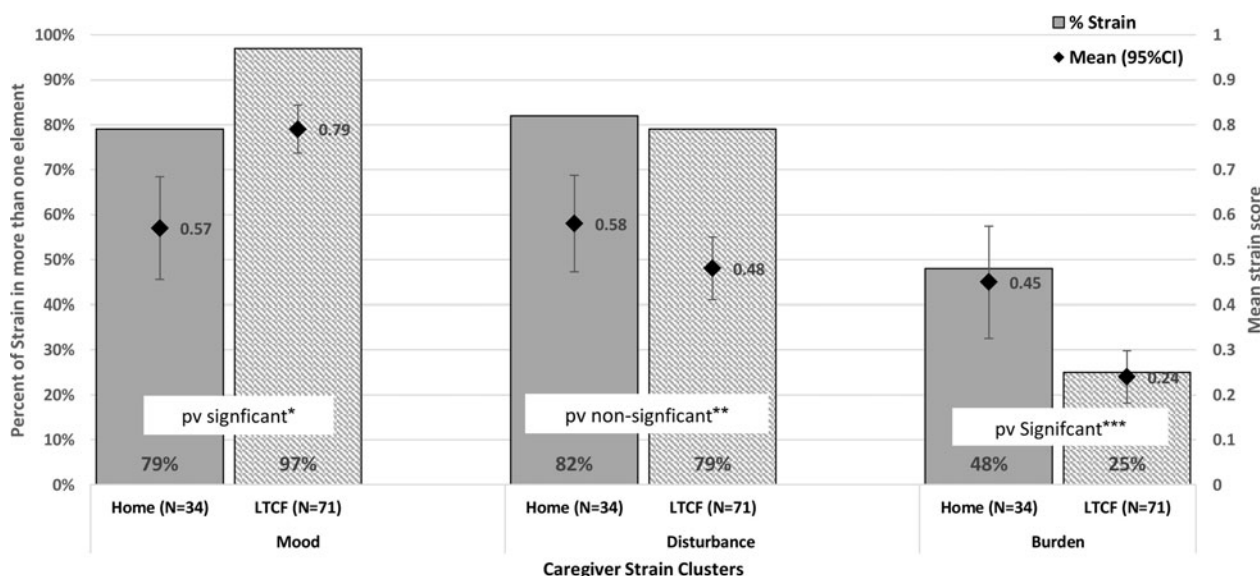


Fig. 2. ICG strain clusters: home vs. LTCF. We compared the differences in caregiver strain clusters at home vs. LTCF. Clusters were examined as both binary (% of caregivers with strain in >1 cluster element) and continuous (mean strain score) variables, and p-values (pv) were determined. *Binary pv = 0.024; continuous pv = <0.001. **Binary pv = 0.67; continuous pv = 0.12. ***Binary pv = 0.016; continuous pv = <0.001.

The small body of research among caregivers of PMV patients has frequently focused upon caregivers' attitudes toward ventilation and their role as surrogate decision-makers (Sviri et al., 2009; Cox et al., 2019; Lee et al., 2020). In one of the few existing studies

concerning caregiver burden associated with PMV in Canada, 21 informal caregivers of home PMV patients with progressive neuromuscular disease were assessed using the Caregiver Burden Inventory as well as semi-structured interview (Evans et al., 2012).

Table 3. Predictors of caregiver strain: multivariate models

1. Predictors of caregiver strain: all patients (including communicative/non-communicative status)												
Variable	Total Mod CSI			Burden cluster			Mood cluster			Disturbance cluster		
	β	CI	p-value	β	CI	p-value	β	CI	p-value	β	CI	p-value
Age	-0.03	(-0.13-0.07)	0.55	0	(-0.02-0.03)	0.72	-0.01	(-0.04-0.02)	0.60	-0.03	(-0.08-0.03)	0.34
Gender	-0.34	(-3-2.31)	0.80	0.16	(-0.57-0.89)	0.66	-0.28	(-1.18-0.62)	0.54	-0.18	(-1.68-1.32)	0.81
Home	0.67	(-2.76-4.1)	0.70	1.74	(0.8-2.68)	<0.001	-1.7	(-2.85--0.54)	<0.01	0.64	(-1.3-2.58)	0.51
Relative partner	-1.89	(-5.37-1.6)	0.29	0.11	(-0.85-1.07)	0.82	-0.71	(-1.88-0.45)	0.23	-1.29	(-3.26-0.68)	0.20
Relative child	-0.1	(-3.45-3.25)	0.95	0.59	(-0.34-1.51)	0.21	-0.75	(-1.87-0.38)	0.19	0.09	(-1.8-1.98)	0.92
Not communicative	-0.29	(-3.42-2.83)	0.85	0.48	(-0.38-1.34)	0.27	0.5	(-0.56-1.56)	0.35	-1.24	(-3-0.53)	0.17
2. Predictors of caregiver strain: communicative patients only (including symptom burden severity)												
Variable	Total Mod CSI			Burden cluster			Mood cluster			Disturbance cluster		
	β	CI	p-value	β	CI	p-value	β	CI	p-value	β	CI	p-value
Age	-0.04	(-0.18-0.1)	0.534	0.01	(-0.03-0.04)	0.74	0	(-0.05-0.05)	0.87	-0.04	(-0.12-0.03)	0.27
Gender	-0.9	(-5.37-3.58)	0.69	-0.16	(-1.32-1)	0.79	-0.23	(-1.85-1.39)	0.78	-0.5	(-2.99-1.99)	0.6
Home	-2.38	(-6.99-2.23)	0.302	0.76	(-0.43-1.95)	0.21	-2.28	(-3.95--0.61)	<0.01	-0.86	(-3.43-1.71)	0.50
Relative partner	-2.1	(-7.17-2.98)	0.41	0.79	(-0.55-2.13)	0.24	-0.94	(-2.78-0.89)	0.31	-1.9	(-4.73-0.93)	0.18
Relative child	-1.53	(-7.3-4.25)	0.596	0.75	(-0.78-2.28)	0.33	-0.6	(-2.69-1.49)	0.56	-1.62	(-4.84-1.6)	0.32
r-ESAS	0.17	(0.03-0.31)	0.018	0.04	(0.01-0.08)	0.02	0.06	(0.01-0.11)	0.031	0.07	(-0.01-0.15)	0.07

r-ESAS, Revised Edmonton Symptom Assessment System.

Measured caregiver burden was high, specifically concerning time constraints, disturbance of normal life activities, emotional, physical burden, alongside recurring themes of sense of duty, physical and emotional burden, financial strain, restricted day-to-day life, and a perceived need for improved training and education. The emotional burden of caring for patients treated with PMV was noted by Douglas and Daly (2003), who found that about a half (51.2%) of caregivers of PMV patients reported symptoms consistent with some degree of depression at acute hospital discharge with the percentage dropping to 36.4% by six months after discharge. In a qualitative study of 18 caregivers of PMV patients at a specialized weaning center, caregivers reported long-term physical and psychological health changes including alteration to sleep, energy, nutrition, and body weight (Dale et al., 2020). In a study of caregivers of chronically critically ill patients in a long-term acute care hospital, 40% of whom were ventilator-dependent, the caregivers reported anxiety, worries about their relatives' situation, the choices they made and finances and disturbances in everyday life (Lamas et al., 2017). A study of 160 PMV patients and their informal caregivers in Taiwan, equally divided between home and LTCF, also described generally high levels of caregiver physical strain, sleep disturbance, and low back pain, with significantly higher levels of physical strain and somatic complaints among caregivers of home PMV patients (Liu et al., 2017). Unlike our findings, greater financial strain was reported by informal caregivers of patients in LTCF — reflecting the need for families to cover much of the LTCF costs within their local healthcare system.

The Israeli healthcare system provides an obligatory comprehensive healthcare coverage for all citizens, which is delivered by four HMOs (Clarfield et al., 2017). The HMO coverage includes the full cost of care in LTCF for PMV patients, while for home PMV patients and caregivers, the HMO care package includes home visits and telephone coverage by a dedicated team of multidisciplinary specialized health care professionals, all aspects of technical equipment, logistic backup, disposable items, as well as chronic medications. In addition to comprehensive healthcare, it is relevant to note that most older people in Israel still live at home, with only 2.1% residing in any type of long-term care setting (old age homes and skilled nursing facilities), a rate lower than that found in most Organization for Economic Cooperation and Development (OECD) countries (Shnoor and Cohen, 2021; Vinarski-Peretz and Halperin, 2021). The low rate of institutionalization is also true among those who are disabled, among whom almost 80% live in the community (Shnoor and Cohen, 2021). It is most likely that this accomplishment is largely attributable to the active role of family members in the provision of care, which in turn reflects the core value of respect and support of the older population in both the Jewish and Muslim traditions. In addition, the Israeli National Insurance Institute funds the Community Long-term Care Insurance Law, which was implemented in 1988, as well as additional benefits for young people with special needs (Dwolatzky et al., 2017; Gal and Bleikh, 2019). Among other things, these benefits provide a range of possible service options, all related to the direct care of basic functions normally provided by families or paid part-time caregivers, such as personal care and housekeeping. Benefits might also be used to purchase laundry services and absorbent aids for incontinence. These benefits may be used to partially finance a full-time worker. However, eligibility for benefits is determined according to financial means testing, and while the majority of people are indeed entitled to assistance, even maximum benefits are generally insufficient to

completely cover the cost of complex care at home. Consequently, despite significant coverage by both HMO and social security benefits, the extremely complex set of needs surrounding PMV homecare incurs a significant financial burden on both the patient and their family. This would explain the findings among our study population, who unlike those in Taiwan, reported a higher financial strain among caregivers at home rather than at the LTCF.

A large study in the Netherlands comparing aspects of homecare to the LTCF used the Older Persons and Informal Caregiver Survey Minimum DataSet (TOPICS-MDS), which comprises a set of questionnaires for collecting information concerning the physical and mental health of older adults and their primary caregivers. This study found that the subjective burden reported by the caregivers of older adults at home was similar to that of caregivers of older adults at the LTCF (not ventilated), a finding which was also observed in our study, albeit among PMV patients and their informal caregivers (Metzelthin et al., 2017). It is interesting to note that in the current study, 61.4% of the caregivers of PMV patients at the LTCF visited their relatives six to seven times a week, while 8.6% visited only once a week or less.

It has been found that caregivers overrate the severity of impaired quality of life among PMV patients, compared with the patients themselves or nursing staff, measured using the 5-item European Quality of Life scale (EQ-5D) (Hung et al., 2010). This might explain the higher levels of mood strain, which we observed among caregivers of patients in LTCF, many of whom were unable to communicate, and more frequently had suffered with acute and catastrophic changes leading to the initiation of PMV. In contrast, home PMV patients and their caregivers often witnessed a more gradual physical deterioration, along with improved levels of patient communication. The findings of our study synthesize several of the above findings, confirming higher levels of physical, time, and financial burden at home, yet lower mood strain. Greater proximity to the PMV patient at home, alongside the fact that more home patients were able to communicate, might explain the lower levels of caregiver mood strain at home. Although the familial relationship of the caregivers to the patient showed differences between home and LTCF; nonetheless, this factor was not significant after multivariable adjustment.

The dynamic relationship between the dyad of caregiver and the patient being cared for has received increasing recognition over recent years. Thus, for example, Lyons et al (2002) assessed 63 dyads of caregivers and care recipients. The care recipients were older adults with a wide range of both physical and mental impairment. In that study, there was little disagreement between the caregiver and care recipient over the care recipient's needs, but a significant amount of variation in how much the care recipient and the caregiver agreed on their appraisals of caregiving difficulties. Caregivers appeared to report more caregiver difficulties than care recipients did. Relationship strain perceived by the caregiver, but not the care recipient, was significantly associated with this disagreement. Among cancer patients in particular, the caregiver literature has often focused upon the patient-caregiver dyad, emphasizing the bi-directional influence on health outcomes of both the patient and the caregiver (O'Hara et al., 2010; Goldzweig et al., 2016; Kelley et al., 2019). While beyond the scope of the current research, this is an area which may warrant attention, particularly given the extended duration of PMV in certain patient populations, their ability to communicate, and the close and long-term relationship and dependency that exists between patients and informal caregivers.

The finding in the current study that caregiver strain was associated with patients' level of symptoms emphasizes the need for integration of palliative care in the management of PMV patients and their caregivers (Nelson and Hope, 2012; Lamas *et al.*, 2017; Dale *et al.*, 2020). Core elements in such care include alleviation of symptom distress, communication with patients and families about care goals, alignment of treatment with the patients' values and preferences, transitional planning (to LTCF or home), and family support (Nelson and Hope, 2012). Palliative care should be implemented during hospitalization in the intensive care unit (ICU) and continued at the LTCF or home, depending on the site of care. In the ICU setting, growing attention has been evident concerning the need for incorporation of palliative care for PMV patients (Chatterjee *et al.*, 2018; Schorr and Angelo, 2018). Palliative and supportive care should also be tailored to the caregivers' needs (Dale *et al.*, 2020). Palliative care interventions have been shown to decrease depression among caregivers of patients with advanced cancer (Alam *et al.*, 2020). Palliative care can be delivered by either a specialist palliative care consultant, by the interdisciplinary team caring for the patient in the different setting, or by a dedicated social worker. Working in unison, different members of the team will aim to engage and provide emotional support for both the patient and the caregiver, provide information, address financial concerns, as well as enable the possibility of facilitating support groups for caregivers, and if practical, for patients as well (Peres, 2016; Muller-Kluits and Slabbert, 2020). Chaplains can provide pastoral care and emotional support for caregivers, enhance the positive aspects of caregiving, and aid caregivers in spiritual needs (Steinhauser *et al.*, 2016; Cooper, 2018).

Limitations deserve mentioning. Firstly, our study was limited to patients and caregivers in a single LTCF or home hospital, such that the local standards and model of healthcare, as well as local cultural norms, clearly affect both patient and caregiver measures. It is worthy to note that the overwhelming majority of patients and their caregivers were cared for within the urban setting, with only five patients and caregivers living in nearby villages. Thus, our findings may not necessarily reflect the needs of caregivers in rural areas. Secondly, although the modified CSI instrument is a widely accepted and reliable tool in caregiver research; nonetheless, its use among PMV informal caregivers has not been previously described.

Conclusions and implications

In conclusion, we found that while overall caregiver strain was similar for patients treated at home or LTCF, nonetheless different patterns of strain were observed according to the site of care. Recognizing the different challenges faced by caregivers of PMV patients at home compared with LTCF is an important step toward improving healthcare for both patients and their informal caregivers alike. Within this complex dyad of the patient and the caregiver, an appreciation of their palliative care needs is critical, and a necessary step toward the integration of multidisciplinary palliative care as an essential element within standard care, tailored according to the specific care settings. Prioritizing the well-being and resilience of the informal caregiver is crucial, since optimal caregiver status is often the decisive factor in determining whether the PMV patient will be treated in the LTCF or at home.

Acknowledgments. We would like to acknowledge Mrs. Ruth Steiner (RN) for the many hours spent collecting data and interviewing the patients and their caregivers both in the LTCF and at home. We also acknowledge

Ms. Aliza Hammerman-Rozenberg (MA) and Mr. Hananel Giat (BA) for their statistical consultation.

Author contributions. MJM and JS had full access to all study data and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: JS, ELM, and MJM; acquisition of data: MJM, ELM, and JS; analysis and interpretation of data: MJM, ELM, and JS; drafting of the first manuscript and critical revision of the manuscript for important intellectual content: MJM, ELM, and JS; statistical analyses: MJM, ELM, and JS.

Funding. This work was supported by the National Institute for Health Policy Research, Israel (Grant 185/2014).

Conflict of interest. None declared.

Role of the sponsors. The sponsors had no role in the study design, data analysis, preparation, or approval of the manuscript.

Transparency statement. MJM, ELM, and JS affirm the manuscript to be an honest, accurate, and transparent account of the study, and that no important aspects of the study have been omitted.

References

- Adelman RD, Tmanova LL, Delgado D, *et al.* (2014) Caregiver burden: A clinical review. *Journal of the American Medical Association* **311**(10), 1052–1060. doi:10.1001/jama.2014.304
- Alam S, Hannon B and Zimmermann C (2020) Palliative care for family caregivers. *Journal of Clinical Oncology* **38**(9), 926–936. doi:10.1200/JCO.19.00018
- Bar K, Shapira Z and Marcus E-L (2012) Primary caregivers of older adults with dementia: Association between ethnicity, caregiver burden, socio-demographic variables and caregivers' quality of life. *Gerontology and Geriatrics* **39**(1–2), 37–68 [Hebrew].
- Chatterjee K, Goyal A, Kakkera K, *et al.* (2018) National trends (2009–2013) for palliative care utilization for patients receiving prolonged mechanical ventilation. *Critical Care Medicine* **46**(8), 1230–1237. doi:10.1097/CCM.0000000000003182
- Clarfield AM, Manor O, Nun GB, *et al.* (2017) Health and health care in Israel: An introduction. *The Lancet* **389**(10088), 2503–2513. doi:10.1016/S0140-6736(17)30636-0
- Cooper RS (2018) The palliative care chaplain as story catcher. *Journal of Pain and Symptom Management* **55**(1), 155–158. doi:10.1016/j.jpainsymman.2017.03.035
- Cox CE, White DB, Hough CL, *et al.* (2019) Effects of a personalized web-based decision aid for surrogate decision makers of patients with prolonged mechanical ventilation: A randomized clinical trial. *Annals of Internal Medicine* **170**(5), 285–297. doi:10.7326/M18-2335
- Dale CM, Carbone S, Istanbulian L, *et al.* (2020) Support needs and health-related quality of life of family caregivers of patients requiring prolonged mechanical ventilation and admission to a specialised weaning centre: A qualitative longitudinal interview study. *Intensive and Critical Care Nursing* **58**, 102808. doi:10.1016/j.iccn.2020.102808
- Douglas SL and Daly BJ (2003) Caregivers of long-term ventilator patients: Physical and psychological outcomes. *Chest* **123**(4), 1073–1081. doi:10.1378/chest.123.4.1073
- Dwolatzky T, Brodsky J, Azaiza F, *et al.* (2017) Coming of age: Health-care challenges of an ageing population in Israel. *The Lancet* **389**(10088), 2542–2550. doi:10.1016/S0140-6736(17)30789-4
- Evans R, Catapano MA, Brooks D, *et al.* (2012) Family caregiver perspectives on caring for ventilator-assisted individuals at home. *Canadian Respiratory Journal* **19**(6), 373–379. doi:10.1155/2012/452898
- Gal J and Bleikh H (2019) The welfare system: An overview. Taub Center for Social Policy Studies in Israel. A Chapter from the *State of the Nation Report December 2019*, Jerusalem. Available at: <https://www.taubcenter.org.il/wp-content/uploads/2020/12/thewelfaresystemanoverview2019eng74.pdf>.
- Goldzweig G, Baider L, Andritsch E, *et al.* (2016) Hope and social support in elderly patients with cancer and their partners: An actor-partner interdependence model. *Future Oncology* **12**(24), 2801–2809. doi:10.2217/fon-2016-0267

- Hui D and Bruera E** (2017) The Edmonton Symptom Assessment System 25 years later: Past, present, and future developments. *Journal of Pain and Symptom Management* **53**(3), 630–643. doi:10.1016/j.jpainsymman.2016.10.370
- Hung MC, Yan YH, Fan PS, et al.** (2010) Measurement of quality of life using EQ-5D in patients on prolonged mechanical ventilation: Comparison of patients, family caregivers, and nurses. *Quality of Life Research* **19**(5), 721–727. doi:10.1007/s11136-010-9629-1
- Jacobs JM, Cohen A, Rozengarten O, et al.** (2007) Closure of a home hospital program: Impact on hospitalization rates. *Archives of Gerontology and Geriatrics* **45**(2), 179–189. doi:10.1016/j.archger.2006.10.009
- Jacobs JM, Marcus EL and Stessman J** (2021a) Prolonged mechanical ventilation: A comparison of patients treated at home compared with hospital long-term care. *Journal of the American Medical Directors Association* **22**(2), 418–424. doi:10.1016/j.jamda.2020.06.038
- Jacobs JM, Marcus EL and Stessman J** (2021b) Prolonged mechanical ventilation: Symptomatology, well-being, and attitudes to life. *Journal of the American Medical Directors Association* **22**(6), 1242–1247. doi:10.1016/j.jamda.2020.07.037
- Kelley DE, Kent EE, Litzelman K, et al.** (2019) Dyadic associations between perceived social support and cancer patient and caregiver health: An actor-partner interdependence modeling approach. *Psychooncology* **28**(7), 1453–1460. doi:10.1002/pon.5096
- Lamas DJ, Owens RL, Nace RN, et al.** (2017) Opening the door: The experience of chronic critical illness in a long-term acute care hospital. *Critical Care Medicine* **45**(4), e357–e362. doi:10.1097/CCM.0000000000002094
- Lee YW, Hsieh YS, Chang FH, et al.** (2020) Experiences with making difficult decisions of the family caregivers of patients on prolonged mechanical ventilation: A qualitative study. *Annals of Palliative Medicine* **9**(4), 1742–1751. doi:10.21037/apm-19-621
- Liu JF, Lu MC, Fang TP, et al.** (2017) Burden on caregivers of ventilator-dependent patients: A cross-sectional study. *Medicine (Baltimore)* **96**(27), e7396. doi:10.1097/MD.0000000000007396
- Lyons KS, Zarit SH, Sayer AG, et al.** (2002) Caregiving as a dyadic process: Perspectives from caregiver and receiver. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* **57**(3), P195–P204. doi:10.1093/geronb/57.3.P195
- Metzelthin SF, Verbakel E, Veenstra MY, et al.** (2017) Positive and negative outcomes of informal caregiving at home and in institutionalised long-term care: A cross-sectional study. *BMC Geriatrics* **17**(1), 232. doi:10.1186/s12877-017-0620-3
- Muller-Kluit N and Slabbert I** (2020) The role of social workers in addressing caregiver burden in families of persons with disabilities. *South African Health Review* **2020**(1), 137–145.
- Nelson JE and Hope AA** (2012) Integration of palliative care in chronic critical illness management. *Respiratory Care* **57**(6), 1004–1013. doi:10.4187/respcare.01624
- Nonoyama ML, McKim DA, Road J, et al.** (2018) Healthcare utilisation and costs of home mechanical ventilation. *Thorax* **73**, 644–651. doi:10.1136/thoraxjnl-2017-211138
- O'Hara RE, Hull JG, Lyons KD, et al.** (2010) Impact on caregiver burden of a patient-focused palliative care intervention for patients with advanced cancer. *Palliative and Supportive Care* **8**(4), 395–404. doi:10.1017/S1478951510000258
- Peres J** (2016) A time and place: The role of social workers in improving end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care* **12**(3), 185–194.
- Rose L, McKim DA, Katz SL, et al.** (2015) Home mechanical ventilation in Canada: A national survey. *Respiratory Care* **60**(5), 695–704. doi:10.4187/respcare.03609
- Schorr C and Angelo M** (2018) Trends for palliative care use in the prolonged mechanically ventilated patient: Are we moving toward a proactive approach? *Critical Care Medicine* **46**(8), 1374–1375. doi:10.1097/CCM.0000000000003233
- Shnoor Y and Cohen Y** (2021) *The 65+ Population in Israel: Statistical Abstract 2021*. Jerusalem, Israel: Myers-JDC-Brookdale [Hebrew]. Available at: <https://brookdale.jdc.org.il/publication/statistical-abstract-elderly-israel-2021/>.
- Simonds AK** (2016) Home mechanical ventilation: An overview. *Annals of the American Thoracic Society* **13**(11), 2035–2044. doi:10.1513/AnnalsATS.201606-454FR
- Steinhauser KE, Olsen A, Johnson KS, et al.** (2016) The feasibility and acceptability of a chaplain-led intervention for caregivers of seriously ill patients: A Caregiver Outlook pilot study. *Palliative and Supportive Care* **14**(5), 456–467. doi:10.1017/S1478951515001248
- Sviri S, Garb Y, Stav I, et al.** (2009) Contradictions in end-of-life decisions for self and other, expressed by relatives of chronically ventilated patients. *Journal of Critical Care* **24**(2), 293–301. doi:10.1016/j.jcrc.2009.01.011
- Thronton M and Travis SS** (2003) Analysis of the reliability of the modified caregiver strain index. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* **58**(2), S127–S132. doi:10.1093/geronb/58.2.S127
- Vinarski-Peretz H and Halperin D** (2021) Family care in our aging society: Policy, legislation and intergenerational relations: The case of Israel. *Journal of Family and Economic Issues*, 1–17. doi:10.1007/s10834-021-09768-2
- Zilberberg MD, de Wit M and Shorr AF** (2012) Accuracy of previous estimates for adult prolonged acute mechanical ventilation volume in 2020: Update using 2000–2008 data. *Critical Care Medicine* **40**(1), 18–20. doi:10.1097/CCM.0b013e31822e9ff4