Kenia statt Pflegeheim!

Braucht es ExpertInnen oder Amateure in der außerklinischen Intensivpflege?

Michael Tesar

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Eine Reise durch die Versorgungslandschaft in Österreich…

Was braucht es um eine solche Reise zu tun?

Ein Plädoyer für die Expertise

Rechtliche Grundlagen

Ein Blick über den Tellerrand

Impressionen

Der einfachen Lesbarkeit halber, meint der Text Frauen und Männer gleichermaßen.

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Fakten zur außerklinischen Intensivpflege in Österreich

- Ca. 550 Betroffene
- es wäre deutlich mehr, gäbe es professionelle außerklinische Strukturen
- Davon ca. die Hälfte unter 18a
- Derzeit nur in Kärnten eine fachpflegerische, flächendeckende Versorgung und Pflege zu Hause
- 2-3 spezialisierte Einrichtungen für die Entwöhnung innerklinisch
- 3 fachlich adäquate stationäre Einrichtungen in der Langzeitpflege (§20 oder analog)

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TABLE 1 Estimated number of centres, home mechanical ventilation users and prevalence[#]

	Estimated			Actual		Response rate %	
	Centres	Users	Prevalence[¶]	Centres	Users	Centres	Users
Austria	8	300	3.8	7	508	88	100[+]
Belgium	23	500	5	17	501	74	100
Denmark	2	500	9.6	2	503	100	100
Finland	20	450	8.7	16	121	80	27
France[§]	50	10000	17	58	6338	100[+]	63
Germany	54	5000	6.5	22	4220	41	84
Greece	12	70	0.6	5	122	42	100[+]
Ireland	15	155	3.4	14	155	93	100
Italy	70	2200	3.9	44	1928	63	88
Netherlands	4	900	5.6	9	918	100[+]	100[+]
Norway	38	350	7.8	17	377	45	100[+]
Poland	8	40	0.1	17	46	100[+]	100[+]
Portugal	39	933	9.3	20	801	51	86
Spain	35	2500	6.3	15	1400	43	56
Sweden	65	900	10	17	746	26	83
UK	40	2320	4.1	47	2842	100[+]	100[+]
All countries	483	27118	6.6	329	21526	62	79

Data are presented as n, unless otherwise indicated. [#]: actual numbers in completed surveys and estimated percentage response rates; [¶]: prevalence per 100,000 of the population; [+]: actual percentage response is >100%, but 100% used as maximum so as not to spuriously elevate the overall response rate; [§]: France's estimated number of centres includes the number of Associations plus known large prescribing hospitals.

Eur Respir J 2005; 25: 1025–1031
DOI: 10.1183/09031936.05.00066704
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Aufgaben der ReisebegleiterInnen

- Beratung, Case- und Caremanagement, Organisationstalent
- Ansprechperson für Kliniken, Betroffene und Angehörige
- Fortsetzen der Beatmungsentwöhnung (mob. BGA, Protokolle) im interdisziplinären Setting
- Teilhabe am sozialen Leben ermöglichen
- Mögliche Probleme kennen/erkennen und adäquat handeln
- Erfahrung mit Notfallsituationen
- Ersatz der in Ö fehlenden Reha für Beatmete
- Begleitung der An- und Zugehörigen

Wenn einer eine Reise tut…

- Arztbesuch
- Schulbesuchsbegleitung
- Veranstaltungen
- Ambulante Reha
- Arbeit
- Garten

Der Aufwand und das „Gefahrenpotential“ ist immer vorhanden.

Frage: Wer denken Sie, ist der ideale Reisebegleiter?

1. Expertenwissen, Sonderausbildung Intensivpflege, erfahren im Umgang mit beatmeten Menschen?

2. Unerfahrene DGKP, auf Gerätschaften eingeschult, ohne Erfahrungen?

3. PersonenbetreuerIn, ohne fachliche Ausbildung (nicht nostrifiziert), 14 Tage durchgehend beim Klienten, Handlungsfeld analog Heimhilfe?

Handbuch für ReisebegleiterInnen Personenbetreuung und Fachpflege

- Gewerbeordnung, §3b GuKG
- Tätigkeitsprofil analog zur HEIMHILFE
- Übertragung nach Anleitung und Unterweisung nur im Einzelfall und NICHT überwiegend
- Anordnungsverantwortung ÄrzteG bzw. GuKG
- Durchführung nur zulässig, wenn sie kein Fachwissen erfordern und keine Gefahr für die betroffene Person darstellen
- Einlassungs-, Übernahms-, und Durchführungsverantwortung

(vgl. Weiss/Lust; GuKG; 8.Auflage; Manz; 2017)

Handbuch für ReisebegleiterInnen

- §20 GuKG (4):

3. Überwachung und Betreuung schwerstkranker und ateminsuffizienter Patienten mit invasiven und nichtinvasiven Methoden,

4. Mitwirkung an der Überwachung und Funktionsaufrechterhaltung der apparativen Ausstattung (Monitoring, Beatmung, Katheter und dazugehörige Infusionssysteme),

Die Argumentation, dass sich die Gerätschaften in den Jahren im außerklinischen Bereich verbessert haben, ändert aus fachlicher Sicht nicht die Notwendigkeit von Erfahrung, Expertise und entsprechendem Notfallmanagement. Insbesondere bei einem fortgesetzten Weaning, sind diese Kenntnisse unumgänglich.

Pilot, Fluglehrling oder Kofferträger?

Wem würden SIE ihre Flugreise anvertrauen?

Alle 3 haben mit „Fliegen“ zu tun, nicht wahr?

Der Pilot ist erfahren, erkennt (mögliche) Probleme und kann diese lösen

Der Auszubildende kennt die Grundlagen des Fliegens

Der Kofferträger hat ein Flugzeug bestimmt von Innen gesehen

Sowohl der Auszubildende, als auch der Kofferträger sollten kein Flugzeug steuern dürfen, im Sinne der Fluggäste

Warum der Pilot die bessere Option ist…

Table 13. Causes of Death in 47 Home Mechanically Ventilated Pediatric Patients

Cause of Death	No. (%)
Progression of reason for chronic respiratory failure or other underlying condition	16 (34)
Cardiac	10 (21)
Acute respiratory failure	4 (8.5)
Brain death	4 (8.5)
Infectious/sepsis/multiple organ dysfunction syndrome	4 (8.5)
Tracheal bleeding	4 (8.5)
Tracheal obstruction	4 (8.5)
Tracheostomy accident	1 (2)
Total	47 (100)

(Data from Reference 23.)

Table 14. Home Mechanical Ventilation Deaths Described in the FDA Manufacturer and User Facility Device Experience (MAUDE) Database—2010

Reported Cause of Death	No.
Patient passed away in his sleep. Mother says ventilator was functioning but did not alarm.	1
Alleged ventilator malfunction. No additional information.	1
Patient passed away while on ventilator. Ventilator was alarming and would not shut off until plugged in. Allegations of ventilator malfunction.	1
Patient passed away while on ventilator. Mother says no alarm. Sheriff's department investigating.	1
Patient had mucus plug while connected to ventilator, but the ventilator did not alarm.	1
Nurse discovered patient blue while connected to ventilator and began CPR. Ventilator alarmed.	1
Tracheostomy tube became dislodged. Ventilator allegedly did not alarm.	1
Tracheostomy tube became dislodged. Husband unsure if alarm going off or not, "as there were always alarms going off."	1
Caregiver claims patient passed away while on ventilator and alarms were delayed going off.	1
Patient expired while on ventilator. No allegation of ventilator malfunction. No further information.	1
Patient expired while on ventilator. Patient's family alleges ventilator did not alarm at the time of event.	1
Total	11

(Data from Reference 19.)

King et al.; Resp. Care; Juni 2012; Vol 57, No.6

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Eine Reise nach Italien

Care and technical assistance of long-term HMV children need assessment, planning, and resources. A wide variability in pattern of HMV was found throughout Italy. An Italian national ventilation program, as well as a national registry, could be useful in improving the care of these often critically ill children.

Long-term home ventilation of children in Italy: A national survey
Racca et. al; Pediatr. Pulmonol. 2011; 46:566–572.

14% of the patients in our sample were discharged. Clearly, given the gradual improvement in the survival rates for this population, and the consequent increase in the number of patients reaching adulthood (26-28% in the Canadian studies) , we need to develop dedicated pathways for the patients' transition from PPC to the adult services. The approximately 10% annual increase in the number of patients on LTMV-H in the care of the VRCPPC during the period considered confirms the constant increase in the prevalence of this population already reported in the literature.

Rusalen, et al., J Palliat Care Med 2015, 5:6; Long-Term Ventilation at Home and Pediatric Palliative Care: Patients' Characterization in an Italian Regional Survey

Reisen nach Übersee (US, Kanada)

The idea of health and social care integration presupposes the organization into specialist services that is characteristic of many health and social care systems, but privileging patients' experiences re-frames care to be seen as a whole, consisting of interdependent elements. This provides important understandings about what care does and challenges norms about the value assigned to different kinds of care. This study focused on one specific patient popula-tion, but the issues raised are relevant to the increasing numbers of people who are living with long-term conditions and complex care needs, but whose needs are poorly catered for by current care systems.

MacLaren J, Smith P, Rodgers S, Bateman AP, Ramsay P. A qualitative study of experiences of health and social care in home mechanical ventilation. Nursing Open. 2019;6:283–292.

Fig. 4. Perceived barriers to home transition. IMV = invasive mechanical ventilation; NIV = noninvasive ventilation.

Home Mechanical Ventilation in Canada: A National Survey
Louise Rose RN PhD, Douglas A McKim MD FRCPC, Sherri L Katz MD FRCPC;
RESPIRATORY CARE MAY 2015 VOL 60 NO 5

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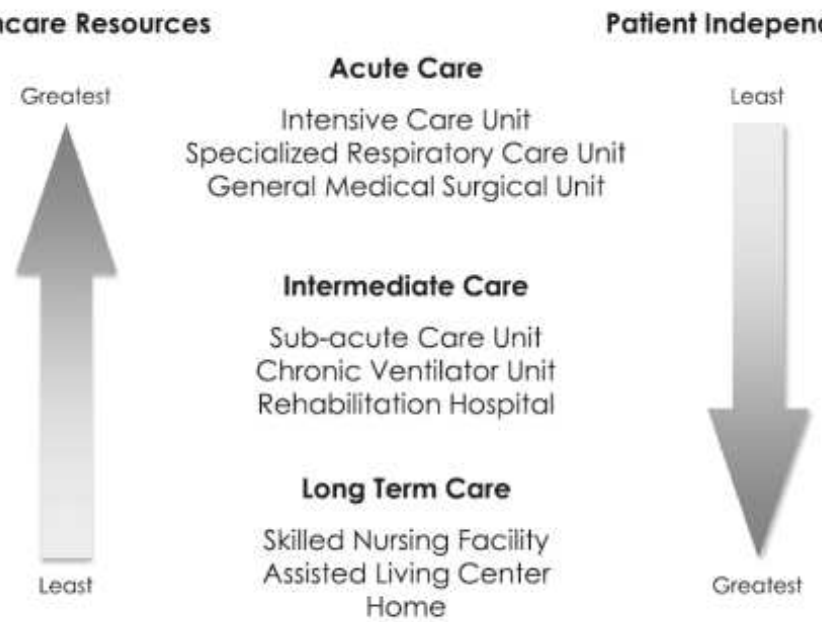

Fig. 1 Potential sites of care for patients requiring PMV. Sites toward the bottom of the figure have fewer medical resources and lower costs but allow greater patient independence and a higher quality of life. PMV, prolonged mechanical ventilation

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…it´s all about the money…

TABLE 4 Impact of caring for child on HMV on household members' employment

N (%)	Overall (*n* = 226)	Invasive ventilation (*n* = 152)	Noninvasive ventilation (*n* = 74)
Household member(s) stopped work to care for child	202 (89)	145 (95)	57 (77)
Household member(s) decreased work to care for child	193 (85)	134 (88)	59 (79)
Amount of work hours decreased			
10%	17 (8)	7 (5)	10 (14)
25%	78 (35)	64 (42)	14 (19()
50%	92 (41)	64 (42)	28 (38)
75%	7 (3)	4 (3)	3 (4)
90%	7 (3)	2 (1)	5 (7)
Unreported	25 (11)	11 (7)	14 (19)
Household member(s) not working/working less caused a financial burden	203 (90)	143 (94)	60 (81)
Household member(s) would work/work more if they did not have to care for child	210 (93)	146 (96)	64 (86)
Household member(s) took unpaid leave to care for child at home or in hospital	188 (83)	136 (89)	52 (70)
Days of unpaid leave household member(s) took in last year, median (IQR)	161 (59-215)	182 (112-215)	71 (0-196)
Household member(s) taking unpaid leave caused a financial burden	183 (81)	134 (88)	49 (66)
Household member(s) changed job(s) to better care for child	187 (83)	137 (90)	50 (68)
Household member(s) felt their professional opportunities were limited because of caring for child	206 (91)	142 (93)	64 (86)

HMV, home mechanical ventilation

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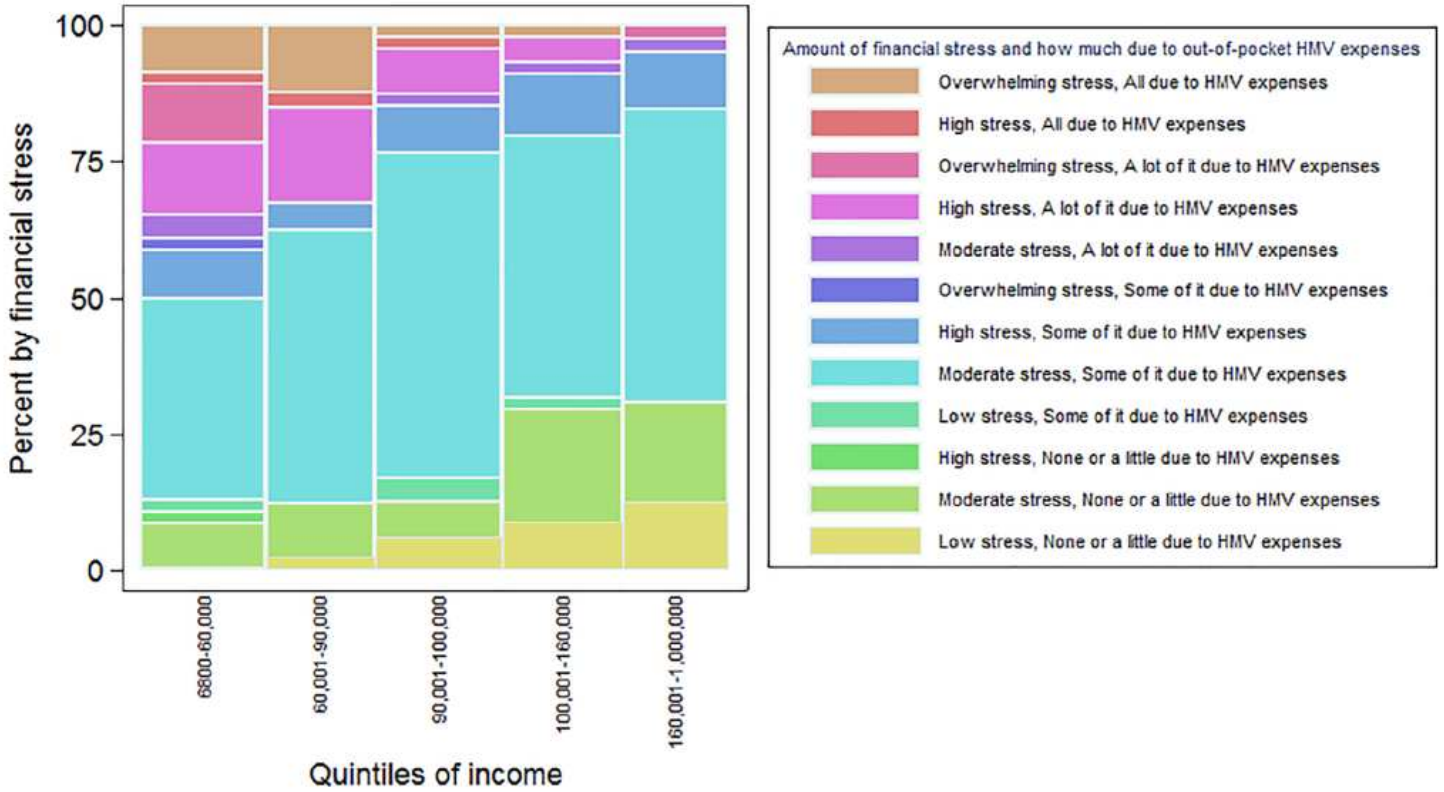

FIGURE 1 Mosaic plot of household finance-related stress and how much of it was caused by HMV-related out-of-pocket expenses by income quintiles

Edwards JD, Panitch HB, Constantinescu A, Miller RL, Stone PW. Survey of financial burden of families in the U.S. with children using home mechanical ventilation. Pediatric Pulmonology. 2018;53:108–116.

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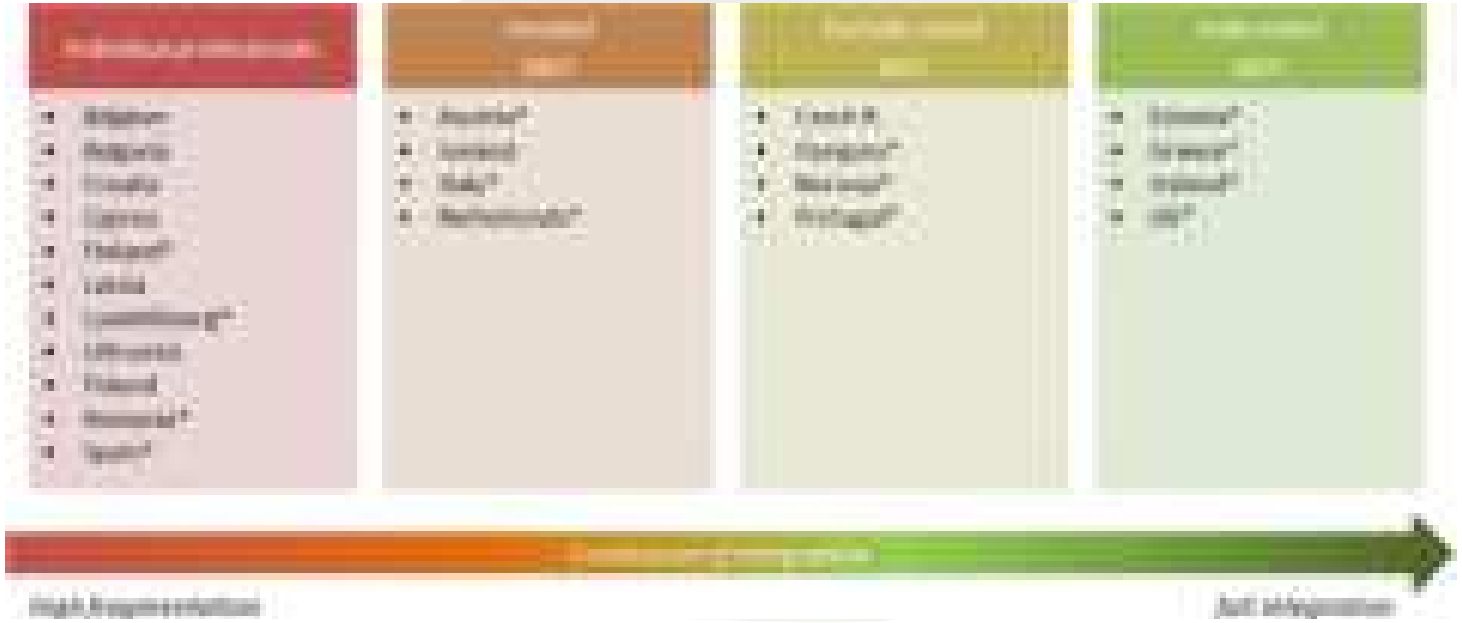
„Reisen“ bedeutet Lebensqualität

In summary, our systematic review suggests that HMV likely provides quality of life benefit and reduced hospitalizations in patients with CRF secondary to NMD, RTD, and OHS. However, small sample sizes, heterogeneity in study design, and variable methodological quality weaken these inferences. With the preferential and proactive implementation of non-invasive over invasive ventilation, the utilization of HMV is likely to expand considerably. Future investigations are clearly needed to better understand the optimal methods for providing care for HMV patients, along with associated caregiver concerns and health economic implications.

MacIntyre et al.; Canadian Respiratory JournalVolume 2016, Article ID 6547180, 10

Half of the analysed countries have a multidisciplinary team with different degrees of team composition, influencing organisational features such as the development of the personalised plan as well as the provision of preventive and curative services. This approach provides indications on the efficiency in performing and organising the delivery of care in terms of family involvement, interactions among professionals and availability of ICT.



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(Data from Reference 23.)

Long-Term Home Mechanical Ventilation in the United States

Angela C King RPFT RRT-NPS

RESPIRATORY CARE • JUNE 2012 VOL 57 NO 6

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Much has been written about how PMV patients require a unique approach to care due to differences in physiology.(1,21-23) However few studies of interventions in this patient population have been published. The ability to standardize illness severity would facilitate the design of cohort studies evaluating interventions to improve process of care and survival. For example, due to issues of high costs and limited resources, hospitals are compelled to discharge PMV patients to various post-ICU settings including respiratory care units, long-term care hospitals (LTCH), or even skilled nursing facilities for continued weaning and management. (24-26) These facilities have been proliferating at a high pace in order to meet increasing demand.(27) While it is possible that these facilities decrease hospital costs, it is not clear whether outcomes are affected. This prognostic model was developed and validated in a population with relatively limited access to post-acute care weaning facilities. Therefore this model provides an acute care baseline against which outcomes from care in different settings can be compared. Variables for the model are measured before most LTCH transfers occur, (25) so illness severity can be standardized before transfer to alternative care settings.

Two prognostic models have been published for PMV patients managed in long-term acute care hospitals,(15,16) but neither have been validated, and only one included long-term follow-up. In one study, existing illness severity scores demonstrated poor discrimination and calibration for hospital mortality in PMV patients at an LTCH. When measured on the day of admission to the LTCH, the area under the ROC curve was less than 0.70 for APACHE II, SAPS II, MPM II and LODS. (28)

A Prognostic Model for One-year Mortality in Patients Requiring
Prolonged Mechanical Ventilation
Shannon S. Carson, MD1
Crit Care Med. 2008 July ; 36(7): 2061–2069.
doi:10.1097/CCM.0b013e31817b8925.

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