

A Good Death: End-of-Life Care at Home for Critically Ill, Ventilator-Dependent Patients

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Disclosures

- None

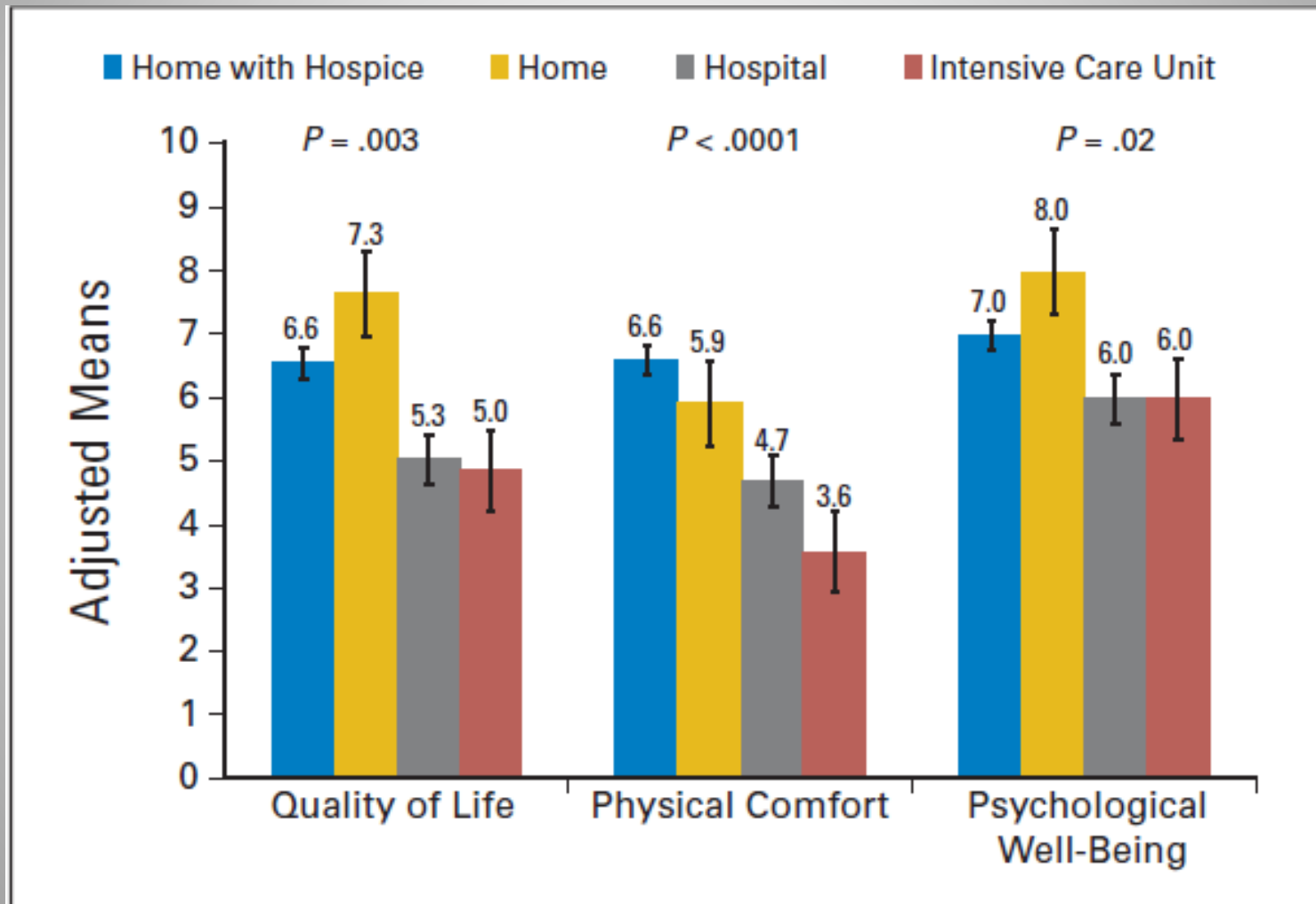
Objectives

- To understand the importance of an interdisciplinary team approach to the withdrawal of mechanical ventilation at the end of life
- Discuss options of where withdrawal of mechanical ventilation can occur
- Discuss potential benefits of withdrawal of mechanical ventilation at home

Where Patients Die

- >2.5 million people die in the US yearly and at least 60% die in hospitals
- Almost 50% of the hospitalized patients have been cared for in the ICU within the 3 days that preceded their death
- Palliative Care literature dating back to the 1980s has shown that people would prefer to die at home, however despite this fact many people die in the hospital

What is the Lasting Memory We Provide?



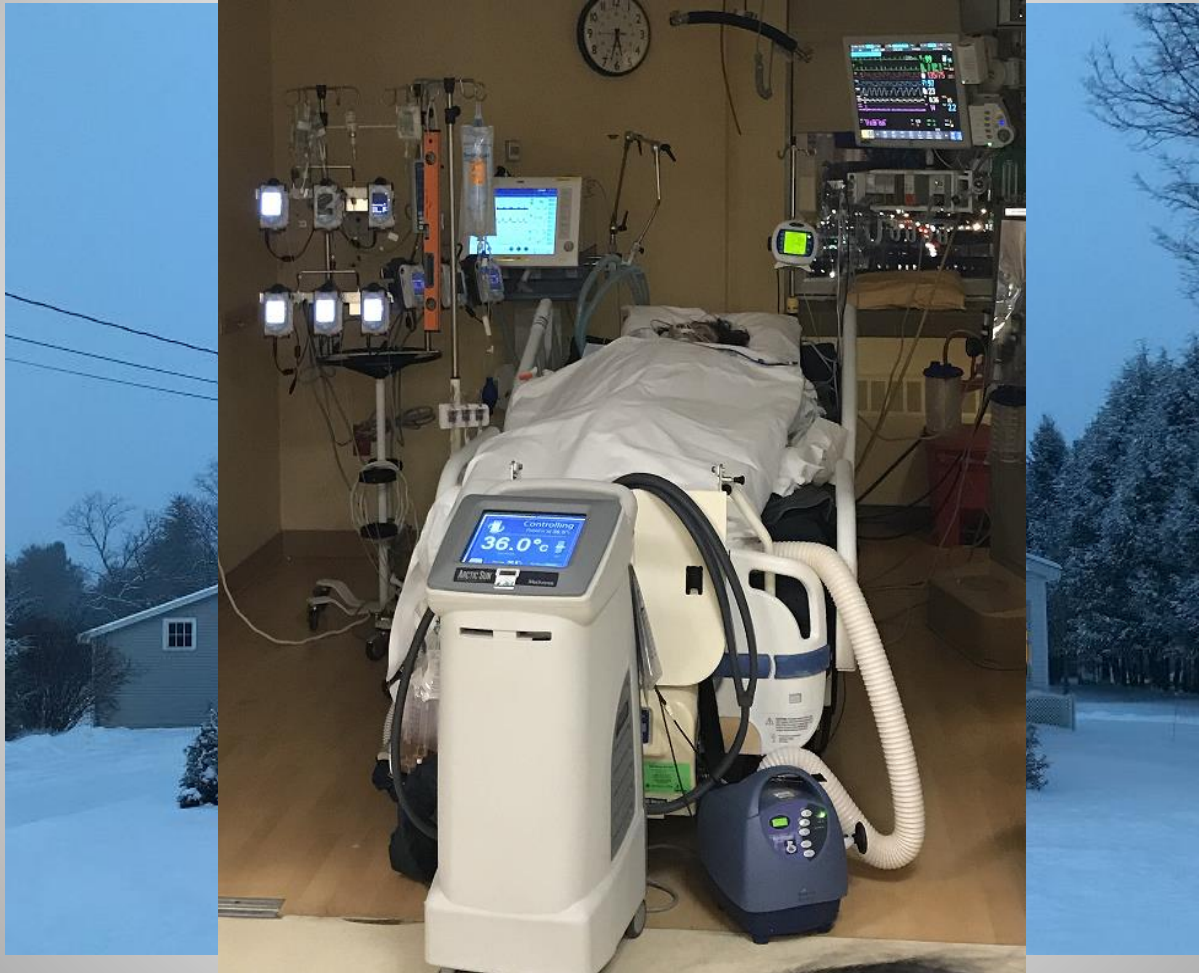
Bereaved Caregivers

Table 4. Bereaved Caregivers' Mental Health Outcomes by Patients' Place of Death

Bereaved Caregivers' Mental Health Outcomes	n	N	%	Patients' Place of Death*											
				Intensive Care Unit			Hospital			Home Without Hospice			Home With Hospice		
				AOR	95% CI	P†	AOR	95% CI	P†	AOR	95% CI	P†	AOR	95% CI	P†
PTSD‡	10	238	4.2	5.00	1.26 to 19.91	.02	0.16	0.009 to 2.94	.22	0.35	0.02 to 7.19	.49	–	Ref	–
GAD§	4	236	1.7	5.35	0.69 to 41.51	.11	0.47	0.03 to 8.31	.61	0.69	0.03 to 15.68	.81	–	Ref	–
PD	9	238	3.8	0.60	0.04 to 9.27	.71	0.95	0.18 to 4.96	.95	0.39	0.02 to 6.75	.52	–	Ref	–
MDD¶	17	229	7.1	2.49	0.86 to 14.22	.08	1.89	0.62 to 5.69	.26	1.34	0.21 to 8.55	.92	–	Ref	–
PGD#	15	142	10.6	5.24	0.62 to 44.36	.13	8.83	1.51 to 51.77	.02	1.98	0.07 to 60.11	.69	–	Ref	–

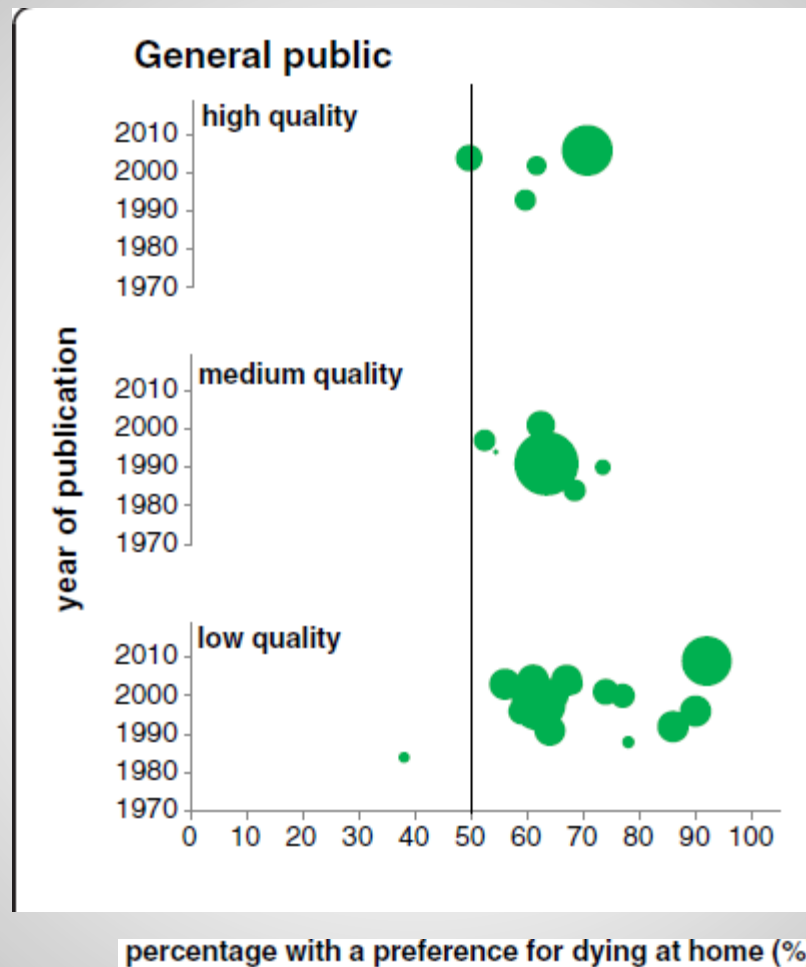
Other Alternatives - Terminal Home Extubation

Where People Prefer to Die



How Many Patients Would Choose To Die At Home If Able?

Variables ^{a,b}	England, N = 1351 n (%)	Flanders, N = 1269 n (%)	Germany, N = 1363 n (%)	Italy, N = 1352 n (%)	Netherlands, N = 1356 n (%)	Portugal, N = 1269 n (%)	Spain, N = 1367 n (%)	All countries, N = 9344 n (%)
Preferred place of death								
Own home	829 (63.0)	883 (71.6)	863 (66.0)	1007 (76.1)	1110 (83.1)	619 (50.3)	848 (66.1)	6159 (68.2)
Home of a relative or friend	15 (1.1)	16 (1.3)	16 (1.2)	8 (0.6)	12 (0.9)	11 (0.9)	13 (1.0)	91 (1.0)
Hospice or palliative care unit	381 (29.0)	122 (9.9)	324 (24.8)	159 (12.0)	140 (10.5)	440 (35.7)	215 (16.8)	1781 (19.7)
Hospital—but not palliative care unit	42 (3.2)	145 (11.8)	45 (3.4)	73 (5.5)	43 (3.2)	101 (8.2)	147 (11.5)	596 (6.6)
Care home	26 (2.0)	65 (5.3)	8 (0.6)	23 (1.7)	22 (1.6)	27 (2.2)	35 (2.7)	206 (2.3)
Elsewhere	23 (1.7)	3 (0.2)	52 (4.0)	54 (4.1)	9 (0.7)	33 (2.7)	24 (1.9)	198 (2.2)



Has anyone else been doing this?

Is anyone thinking about it?

The New Zealand Experience

- Aim: to describe experience of transferring 17 intensive care patients home to die
- Families of patients facing imminent death were approached to discuss transfer home to die
- Two nurses accompany the patient home via ambulance and they are in communication with the ICU by cell phone
- Sedation with morphine and midazolam
- Patients extubated and vasopressors discontinued on arrival to their home

The New Zealand Experience

- 16/17 were intubated and ventilated
- 7/17 were on vasopressors
- Length of time from withdrawal of treatment to death ranged from immediate to 72 hours
- Patients who survived >12 hours were visited either by their family physician, district nurse or hospice nurse
- All families reported this as a positive experience

And From Taiwan

- Aim: to examine prevalence of patients discharged from surgical ICU to home to die and to investigate differences between the home to die patients and the patients who died in the ICU
- 63-81 patients per year were discharged home to die
 - Transported home on the vent, with vasoactives as needed
 - RN accompanied, to extubate and stop vasoactives on site
 - Appropriate sedation given by RN
- No details regarding satisfaction, but the fact that they continued the practice for 5 years suggests it was successful and accepted.

UK Experience and Provider Attitudes

- Aim: to examine health care provider's (HCPs) experience transferring patients home to die from critical care, HCP's views about transfer and characteristics of patients HCPs would hypothetically consider transferring home to die
- Web-based survey sent to lead doctors and nurses in ICUs in England, Scotland, Wales and Ireland in 6/11-7/11
 - Follow up telephone interviews were held with participants with experience of taking patients home to die

UK Experience and Provider Attitudes

- 36% of participants had experience transferring patients home to die in the last 3 years
- 16% of participants did not have experience transferring a patient home to die, but had held discussions about transferring a patient home to die

	1 (strongly disagree)	2 (disagree)	3 (neutral)	4 (agree)	5 (strongly agree)	Median (range), total	Median (range), doctor	Median (range), nurse
Transferring critically ill patients home to die is a good idea in principle but difficult to achieve in reality	0 (0%)	11 (6.5%)	8 (4.7%)	86 (50.9%)	64 (37.9%)	4 (2–5)	4 (2–5)	4 (2–5)
Critical care is a perfectly good place to die	16 (9.4%)	54 (31.8%)	69 (40.6%)	30 (17.6%)	1 (0.6%)	3 (1–5)	3 (1–4)	3 (1–5)
I have limited experience of transferring patients home to die and wouldn't know where to start	8 (4.7%)	60 (35.5%)	42 (24.9%)	45 (26.6%)	14 (8.3%)	3 (1–5)	3 (1–5)	3 (1–5)
It is better for critically ill patients to die in critical care	28 (16.5%)	74 (43.5%)	62 (36.5%)	5 (2.9%)	1 (0.6%)	2 (1–5)	2 (1–4)	2 (1–4)
It would be better to transfer a patient to a hospice than to transfer them home to die	18 (10.5%)	69 (40.4%)	70 (40.9%)	11 (6.4%)	3 (1.8%)	2 (1–5)	3 (1–4)	2 (1–5)
It is satisfying to enable a patient to die at home	0	2 (1.2%)	25 (14.8%)	79 (46.7%)	62 (37.3%)	4 (2–5)	4 (2–5)	4 (2–5)*
We would be able to organise the transfer home to enable someone to die at home	5 (2.9%)	23 (13.5%)	40 (23.5%)	83 (48.8%)	19 (11.2%)	4 (1–5)	4 (1–5)	4 (1–5)
It is unethical to prolong a patient's life, so they can be transferred home to die	11 (6.5%)	43 (25.4%)	54 (32.0%)	50 (29.6%)	11 (6.5%)	3 (1–5)	3 (1–5)	3 (1–5)
It would be too distressing for the patient and relatives to take them out of the familiar critical care environment	25 (14.6%)	90 (52.6%)	45 (26.3%)	9 (5.3%)	2 (1.2%)	2 (1–5)	2 (1–5)	2 (1–5)
Patients will still receive the best possible care if they are transferred home to die	2 (1.2%)	22 (13.1%)	60 (35.7%)	70 (41.7%)	14 (8.3%)	3 (1–5)	3 (1–5)	4 (1–5)*
Transferring critically ill patients home to die is important because patients should be able to die at home if that is their preferred place of death	2 (1.2%)	5 (3.0%)	23 (13.6%)	83 (49.1%)	56 (33.1%)	4 (1–5)	4 (2–5)	4 (1–5)***
It is more important to offer good end-of-life care on the unit than to transfer patients home to die	7 (4.1%)	60 (35.5%)	66 (39.1%)	29 (17.2%)	7 (4.1%)	3 (1–5)	3 (1–5)	3 (1–5)
Critical care staff have more pressing clinical priorities than organising home transfers for dying patients	33 (19.9%)	88 (53.0%)	25 (15.1%)	15 (9.0%)	5 (3.0%)	2 (1–5)	2 (1–5)	2 (1–5)**
Transferring critically ill patients home to die is a feasible option in critical care	5 (3.0%)	8 (4.8%)	46 (27.4%)	85 (50.6%)	24 (14.3%)	4 (1–5)	4 (1–5)	4 (2–5)**
Transferring patients home to die is not worth the risk of dying in the ambulance or having a really bad death at home	21 (12.3%)	83 (48.5%)	45 (26.3%)	18 (10.5%)	4 (2.3%)	2 (1–5)	2 (1–5)	2 (1–5)
Dying in critical care is better than home for patients because of the higher nurse–patient ratios	27 (15.8%)	90 (52.6%)	41 (24.0%)	10 (5.8%)	3 (1.8%)	2 (1–5)	2 (1–4)	2 (1–5)
Taking critical care patients home to die is a waste of health care resources	55 (32.4%)	88 (51.8%)	19 (11.2%)	3 (1.8%)	5 (2.9%)	2 (1–5)	2 (1–5)	2 (1–5)**

Table 2. Responses to question about patient characteristics that respondents would consider (or not consider) transferring, expressed as raw scores and percentages.

	Doctor (%)	Nurse (%)	Total (n (%))
Is unconscious	53.7	69.4*	101 (61.6)
Is conscious	100	100	166 (100)
Is unstable	29.9	45.3	63 (38.2)
Is stable	100	97.6	163 (98.8)
Who is ventilated via an endotracheal tube	34.3	27.9	52 (31.5)
Who is ventilated via tracheostomy	64.7	51.2	96 (57.8)
Who is receiving non-invasive ventilation	66.7	80.2	126 (75.4)
Is self-ventilating breathing oxygen	97.1	93.0	159 (95.2)
Who is self-ventilating breathing air	100	100	167 (100)
Needs cardiovascular support (e.g. inotropes)	45.6	26.7*	57 (34.3)
Has intense nursing needs (e.g. frequent turning and washing)	61.2	88.4***	128 (77.6)
Has high-level emotional needs	82.6	90.6	146 (88.0)
Has relatives with high-level emotional needs	67.6	86.0**	131 (78.9)
Needs regular medication for symptom management (e.g. pain, nausea)	91.3	89.4	150 (90.4)
Lives outside local catchment area	76.8	88.2	135 (81.3)

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

How Many Patients Are Potential Candidates for Death at Home?

- Aim: to determine the size and characteristics of the critical care population who could potentially be transferred home to die
- Retrospective 12 month cohort study from 2011 in two hospital sites in England
- Most patients dying within 5 days of ICU discharge would have been identified for supportive treatment only, and therefore had potential for transfer home to die
- Exclusion criteria: sudden death, patient instability in the 24 hours preceding planned treatment withdrawal, involvement of the coroner or police, complex family dynamics, or physically demanding care needs (unstable spine, morbid obesity, large GI losses, complex wound care)

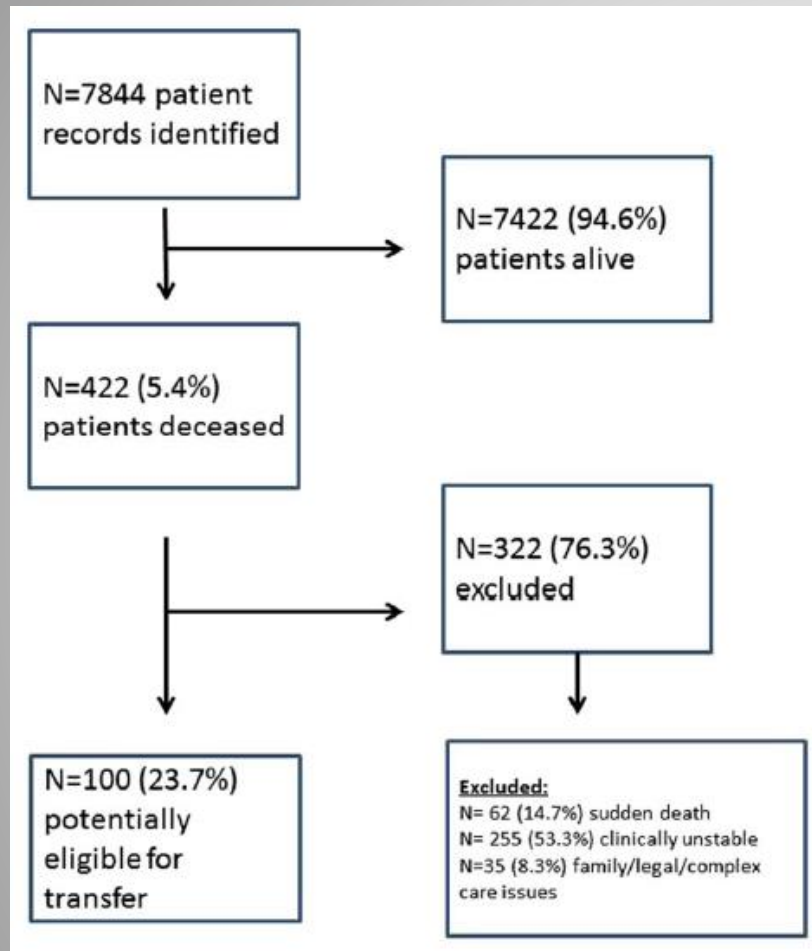


Table 1 Characteristics of patients potentially eligible for transfer

Patient characteristics	
Patients eligible for transfer, n (%)	100 (23.7)
Patient sex, female n (%)	44 (44)
Patient age, mean (SD), range	70.4 years (SD=13.03) 23–92 years
The mean time between discussion about withdrawal of treatment during a family meeting and time of death, mean (SD) hours	36.36 (46.48)
Level of care	
Level 1 care (acute care ward with support from critical care), n (%)	31 (31)
Level 2 care (eg, HDU), n (%)	45 (45)
Level 3 care (eg, ICU), n (%)	24 (24)
Disease category (for majority of patients)	
Respiratory, n (%)	41 (41)
Neurological, n (%)	19 (19)
Cardiac disease, n (%)	19 (19)
Respiratory support	
Self-ventilating breathing room air with no support	13 (13)
Receiving non-invasive ventilation via a mask	18 (18)
Ventilated via an endotracheal tube	20 (20)
Self-ventilating with oxygen via a mask	34 (34)
State (conscious/unconscious)	
Conscious, n (%)	53 (53)
Cardiovascular support	
Dopamine only, n (%)	3 (3)
Receiving multiple inotropes/vasopressors, n (%)	4 (4)
Receiving a single inotrope or vasopressor (excluding 'low dose' dopamine), n (%)	8 (8)
Not receiving any inotropes or vasopressors, n (%)	76 (76)

So Why Aren't People Doing This?

Perceived Barriers

- Safety
- Cost
- Time
- Resources
- Liability
- Access to/sufficient medications
- Supplies
- ICU coverage
- Experience/Comfort
- Theoretical unknown

Our Experience at MMC

Patients

Patient	Sex	Age	Diagnosis	Location	ETT/Trach	Vasopressors	Aware
1	M	64	IPF	Home	Trach	N	Y
2	M	72	COPD	Home	Trach	N	Y
3	F	47	C1 fracture	Home	Trach	N	Y
4	F	61	Diskitis/Osteo	Home	ETT	Y	N
5	F	85	Pneumonia	Home	ETT	Y	Y
6	F	74	COPD, CHF	Home	Trach	N	Y
7	F	91	Hepatic artery injury	Hospice House	ETT	N	Y
8	F	61	Influenza/Staph PNA	Hospital Garden	Trach	N	Y

Our Process

Identify that home death is important to patient



Verify safety of transport and home environment



Arrange: home hospice, medical supplies and meds for transport and at home, ambulance, travel vent



Critical care attending or fellow and ICU nurse accompany patient in ambulance



At home, withdrawal of support, transition to comfort measures by ICU team. Care transferred to hospice nurse.

Hospital team includes ICU team, pharmacy, respiratory therapy, social work, palliative care, chaplain.

Outcomes

- Family satisfaction
 - “You are now honorary members of our family.”
- Staff satisfaction
 - “As we removed the ventilator, a wave of peace came over her face. I knew that we had accomplished her last wish.”

Conclusions

- Home deaths for critically ill mechanically ventilated patients from the intensive care unit are feasible with a committed multidisciplinary team.
- Teamwork, planning, and attention to detail can overcome perceived barriers to transitioning patients from the ICU to home.
- Liberating our patients from life support and allowing death at home is an opportunity for truly patient-centered care.

Thank You

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Questions?

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