SPECIAL ISSUE
PALLIATIVE RESPIRATORY CARE
PART II

- Dyspnea in the Ventilated Patient
- Role of the Respiratory Therapist
- Home Care for Advanced Lung Disease
- The Dying Patient with Lung Cancer
- Multidisciplinary Care
- Death and the Practitioner
- Limitations of Protocols for End-of-Life Care
- Conference Summary

plus

- Annual Indexes
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SPECIAL ISSUE

State-of-the-Art Conference on Palliative Respiratory Care
Part II

CO-CHAIRS

Gordon D Rubenfeld MD MSc
J Randall Curtis MD MPH

CONFERENCE PROCEEDINGS

Dyspnea in the Ventilated Patient: A Call for Patient-Centered Mechanical Ventilation
by John H Hansen-Flaschen—Philadelphia, Pennsylvania

The Respiratory Therapist and Palliative Care
by Melaine Giordano—Dallas, Texas

Palliative Home Care for Advanced Lung Disease
by John H Hansen-Flaschen—Philadelphia, Pennsylvania

Palliation for the Dying Patient with Lung Cancer
by Gerard A Silvestri—Charleston, South Carolina

Organizational Change and Delivery of Multidisciplinary Palliative Care
by Barbara J Daly—Cleveland, Ohio

Death and the Practitioner
by Louisa Viles—Seattle, Washington

The Limitations of Protocols for End-of-Life Care
by Robert A Burt—New Haven, Connecticut

Palliative Care in Respiratory Care: Conference Summary
by Mitchell M Levy—Providence, Rhode Island

BOOKS, FILMS, TAPES, & SOFTWARE

Asthma in the Workplace, 2nd ed (Bernstein IL, Chan-Yeung M, Malo J-L, Bernstein DI, editors)
reviewed by Carrie A Redlich—New Haven, Connecticut

Immunotherapy in Asthma (Bousquet J, Yssel H, editors)
reviewed by N Franklin Adkinson Jr—Baltimore, Maryland
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Close, But No Cigar

BACKGROUND: Although many patients with severe emphysema have undergone lung-volume-reduction surgery, the benefits are uncertain. We conducted a randomized, controlled trial of the surgery in patients with emphysema. Patients with isolated bullae were excluded because such patients are known to improve after bullectomy. METHODS: Potentially eligible patients were given intensive medical treatment and completed a smoking-cessation program and a six-week outpatient rehabilitation program before random assignment to surgery or continued medical treatment. After 15 patients had been randomized, the entry criteria were modified to exclude patients with a carbon monoxide gas-transfer value less than 30 percent of the predicted value or a shuttle-walking distance of less than 150 m, because of the deaths of 5 such patients (3 treated surgically and 2 treated medically). RESULTS: Of the 174 subjects who were initially assessed, 24 were randomly assigned to continued medical treatment and 24 to surgery. At base line in both groups, the median forced expiratory volume in one second (FEV₁) was 0.75 liter, and the median shuttle-walking distance was 215 m. Five patients in the surgical group (21%) and three patients in the medical group (12%) died (p=0.43). After six months, the median FEV₁ had increased by 70 mL in the surgical group and decreased by 80 mL in the medical group (p=0.02). The median shuttle-walking distance increased by 50 m in the surgical group and decreased by 20 m in the medical group (p=0.02). There were similar changes on a quality-of-life scale and similar changes at 12 months of follow-up. Five of the 19 surviving patients in the surgical group had no benefit from the treatment. CONCLUSIONS: In selected patients with severe emphysema, lung-volume-reduction surgery can improve FEV₁, walking distance, and quality of life. Whether it reduces mortality is uncertain.


BACKGROUND: Determining the stage of non-small-cell lung cancer often requires multiple preoperative tests and invasive procedures. Whole-body positron-emission tomography (PET) may simplify and improve the evaluation of patients with this tumor. METHODS: We prospectively compared the ability of a standard approach to staging (computed tomography [CT], ultrasound, bone scanning, and, when indicated, needle biopsies) and one involving PET to detect metastases in mediastinal lymph nodes and at distant sites in 102 patients with resectable non-small-cell lung cancer. The presence of mediastinal metastatic disease was confirmed histopathologically. Distant metastases that were detected by PET were further evaluated by standard imaging tests and biopsies. Patients were followed postoperatively for six months by standard methods to detect occult metastases. Logistic-regression analysis was used to evaluate the ability of PET and CT to identify malignant mediastinal lymph nodes. RESULTS: The sensitivity and specificity of PET for the detection of mediastinal metastases were 91 percent (95% confidence interval, 81 to 100%) and 86% (95% confidence interval, 78 to 94%), respectively. The corresponding values for CT were 75% (95% confidence interval, 60 to 90%) and 66% (95% confidence interval, 55 to 77%). When the results of PET and CT were adjusted for each other, only PET results were positively correlated with the histopathological findings in mediastinal lymph nodes (p<0.001). PET identified distant metastases that had not been found by standard methods in 11 of 102 patients. The sensitivity and specificity of PET for the detection of both mediastinal and distant metastatic disease were 95% (95% confidence interval, 88 to 100%) and 83% (95% confidence interval, 74 to 92%), respectively. The use of PET to identify the stage of the disease resulted in a different stage
from the one determined by standard methods in 62 patients: the stage was lowered in 20 and raised in 42. CONCLUSIONS: PET improves the rate of detection of local and distant metastases in patients with non-small-cell lung cancer.


BACKGROUND: Trauma surgeons use a variety of methods to prevent venous thromboembolism (VT). The rationale for their use frequently is based on conclusions from research on nontrauma populations. Existing recommendations are based on expert opinion and consensus statements rather than systematic analysis of the existing literature and synthesis of available data. The objective is to produce an evidence-based report on the methods of prevention of VT after injury. METHODS: A panel of 17 national authorities from the academic, private, and managed care sectors helped design and review the project. We searched three electronic databases (MEDLINE, EMBASE, and Cochrane Controlled Trial Register) to identify articles relevant to four key questions: methods of prophylaxis, methods of screening, risk factors for VT, and the role of vena caval filters. The initial 4,093 titles yielded 73 articles for meta-analysis. A random-effects model was used for all pooled results. Study quality was evaluated by previously published quality scores. In this article (part I), we report on the question ranked by the experts as the most important, i.e., Which is the best method to prevent VT? and also on the incidence of deep venous thrombosis and pulmonary embolism in trauma patients.

RESULTS: The incidence of deep venous thrombosis and pulmonary embolism reported in different studies varies widely. The pooled rates are 11.8% for deep venous thrombosis and 1.5% for pulmonary embolism. Only a few randomized controlled trials have evaluated the methods of VT prophylaxis among trauma patients, and combining their data is difficult because of different designs and preventive methods used. The quality of most studies is low. Meta-analysis shows no evidence that low-dose heparin, mechanical prophylaxis, or low-molecular-weight heparin are more effective than no prophylaxis or each other. However, the 95% confidence intervals of many of the comparisons are wide; therefore, a clinically important difference may exist. CONCLUSION: The trauma literature on VT prophylaxis provides inconsistent data. There is no evidence that any existing method of VT prophylaxis is clearly superior to the other methods or even to no prophylaxis. Our results cast serious doubt on the existing policies on VT prophylaxis, and we call for a large, high-quality, multicenter trial that can provide definitive answers.


OBJECTIVE: In part II, we describe the results of the literature search and data analysis concerning risk factors for venous thromboembolism and the role of vena caval filters (VCF) in preventing pulmonary embolism. METHODS: The methodology used in part I was used in part II. RESULTS: Spinal fractures and spinal-cord injuries increase the risk for development of deep venous thrombosis (DVT) by twofold and threefold, respectively. Patients with DVT were an average of 9 years older than patients without DVT. No specific age cut-off point for increased risk could be established because data could not be combined across studies. Patients with prophylactically inserted VCF had a lower incidence of pulmonary embolism (0.2%) compared with concurrently managed patients without VCF (1.5%) or historical controls without VCF (5.8%). These results are reported on uncontrolled studies with observational design. CONCLUSION: Spinal injuries, spinal cord injuries, and age are risk factors for development of DVT. Prophylactic placement of VCF in selected trauma patients may decrease the incidence of pulmonary embolism. Future research with well-designed studies is required to provide definitive answers.


OBJECTIVE: Maintaining left ventricular power output (LVP) > 320 mmHg × L/min/m² during resuscitation has been retrospectively associated with faster resolution of acidosis and survival after posttraumatic shock. The purpose of this prospective study was to evaluate the effects of maintaining LVP above this threshold during resuscitation on base deficit clearance, organ failure, and survival. METHODS: This was a study of a consecutive series of critically injured patients (PWR) monitored with a pulmonary artery catheter during initial resuscitation. LVP, calculated as cardiac index (mean arterial pressure-central venous pressure), was maintained > 320 mmHg × L/min/m² via a predefined protocol by using ventricular pressure-volume diagrams. Outcome was assessed by base deficit clearance (< 6 mEq/L in < 24 hours, lowest base deficit in the first 24 hours after admission (24-hr base deficit), organ dysfunctions/patient, and survival. Results were compared with 39 control patients (OXY) with identical enrollment criteria from a previous prospective study who were resuscitated based on oxygen transport criteria. RESULTS: Twenty patients were studied over a 6-month period. Mean LVP during resuscitation in the PWR group was 360 ± 100 mmHg × L/min/m². Admission base deficit was similar between the two groups (PWR 11 ± 4.2 vs. OXY 11 ± 5.8 mEq/L p = 0.66). More PWR patients cleared base deficit in < 24 hours than OXY patients (16 of 20 vs. 17 of 39, p = 0.009, Fisher’s exact test), and the PWR patients had a significantly lower 24-hr base deficit (3.9 ± 3.7 vs. 7.1 ± 4.6 mEq/L).
p = 0.01). Organ dysfunction rate was lower in the PWR group (2.1 ± 1.5 vs. 3.2 ± 1.4 organ dysfunctions/patient, p = 0.007). Survival in the PWR group was 15 of 20, versus 21 of 39 in the OXY group (p = 0.10). CONCLUSION: Prospectively maintaining LVP above 320 mm Hg × L/min/m² during resuscitation is an achievable goal. It is associated with improved base deficit clearance and a lower rate of organ dysfunction after resuscitation from traumatic shock.


Quantitative research is designed to test well-specified hypotheses, determine whether an intervention did more harm than good, and find out how much a risk factor predisposes persons to disease. Equally important, qualitative research offers insight into emotional and experiential phenomena in health care to determine what, how, and why. There are 4 essential aspects of qualitative analysis. First, the participant selection must be well reasoned and their inclusion must be relevant to the research question. Second, the data collection methods must be appropriate for the research objectives and setting. Third, the data collection process, which includes field observation, interviews, and document analysis, must be comprehensive enough to support rich and robust descriptions of the observed events. Fourth, the data must be appropriately analyzed and the findings adequately corroborated by using multiple sources of information, more than 1 investigator to collect and analyze the raw data, member checking to establish whether the participants’ viewpoints were adequately interpreted, or by comparison with existing social science theories. Qualitative studies offer an alternative when insight into the research is not well established or when conventional theories seem inadequate.

Users’ Guides to the Medical Literature: XXIII. Qualitative Research in Health Care B. What Are the Results and How Do They Help Me Care for My Patients?—Giacomini MK, Cook DJ. JAMA 2000;284:478-482.

The second part of this 2-part series on how to interpret qualitative research addresses, “what are the results,” and, “how do they help me care for my patients?” Qualitative analysis is a process of summarizing and interpreting data to develop theoretical insights that describe and explain social phenomena such as interactions, experiences, roles, perspectives, symbols, and organizations. Key results are often illustrated with excerpts from interview transcripts, field notes, or documents. The results of a qualitative research report are best understood as an empirically based contribution to ongoing dialogue and exploration. Empirically based theory evolves from a process of exploration, discovery, analysis, and synthesis. Each concept should be defined carefully in a way that is meaningful to the reader. Concepts should be adequately developed and illustrated when theoretical conclusions are drawn. Arguments should be explained and justified. The qualitative research report ideally should address how the findings relate to other theories in the field. The qualitative study can provide a useful road map for understanding and navigating similar social settings, interactions, or relationships.


This study examined the effect of the prone position on mechanically ventilated patients with hydrostatic pulmonary edema (HPE). Eight patients with acute HPE and mechanically ventilated in the prone position (Group 1) were studied. Six patients with acute HPE and mechanically ventilated in the supine position (Group 2), 20 patients with ARDS (Group 3), and 5 patients with pulmonary fibrosis (PF) (Group 4) served as control patients. Patients with HPE, who after being mechanically ventilated for at least 6 h needed an $F_{O_2}$ ≥ 0.6 to achieve an $S_{O_2}$ of approximately 90%, and did not respond to recruitment maneuvers, were turned to the prone position. Parameters of oxygenation, lung mechanics, and hemodynamics were determined in both the supine and prone positions. All patients with HPE exhibited improvement of oxygenation when they were placed in the prone position. The $P_{A_{O_2}}/F_{O_2}$ ratio increased from 72 ± 16 in the supine position to 208 ± 61 after 6 h in the prone position (p < 0.001); the rise in $P_{A_{O_2}}$ was persistent, without detrimental effect on hemodynamics. Fifteen of 20 patients with ARDS (75%) improved oxygenation when in the prone position. The $P_{A_{O_2}}/F_{O_2}$ ratio increased from 83 ± 14 in the supine position to 189 ± 34 after 6 h in the prone position (p < 0.001). In contrast, 5 of 20 patients with ARDS (25%) and none of the patients with PF responded favorably to prone positioning. Patients with HPE and early ARDS responded better to prone positioning than did patients with late ARDS and PF. Patients with HPE and ventilated in the supine position had a lower $P_{A_{O_2}}/F_{O_2}$ ratio and the duration of mechanical ventilation was longer compared with that of patients in the prone position. Our results show that the prone position may be a useful maneuver in treating patients with severe hypoxemia due to pulmonary edema. The presence of pulmonary edema, as in early ARDS and HPE predicts a beneficial effect of the prone position on gas exchange. In contrast, the presence of fibrosis, as in late ARDS and pulmonary fibrosis, predisposes to nonresponsiveness to prone positioning.


To determine if decreased respiratory frequency (ventilatory rate) improves indices of lung damage, 17 sets of isolated, perfused rabbit lungs were ventilated with a peak static airway pressure of 30 cm H₂O. All lungs were randomized to one of three frequency/peak pulmonary artery pressure combinations: F20P35 (n = 6): ventilatory frequency, 20 breaths/min, and peak pulmonary artery pressure, 35 mm Hg; F35P35 (n = 6), ventilatory frequency, 3 breaths/min, and peak pulmonary artery pressure of 35 mm Hg; or F20P20 (n = 5), ventilatory frequency, 20 breaths/min, and peak pulmonary artery pressure, 20 mm Hg. Mean airway pressure and tidal volume were matched between groups. Mean pulmonary artery pressure and vascular flow were matched between groups F20P35 and F35P35. The F20P35 group showed at least a 4.5-fold greater mean weight gain and a 3-fold greater mean incidence of perivascular hemorrhage than did the comparison groups, all p < 0.05. F20P35 lungs also displayed more alveolar hemorrhage than did F20P20 lungs (p < 0.05). We conclude that decreasing respiratory frequency can improve these indices of lung damage, and that limitation of peak pulmonary artery pressure and flow may diminish lung damage for a given ventilatory pattern.


To assess the interobserver and intraobserver variability in the clinical evaluation of the quasi-static pressure-volume (P-V) curve, we analyzed 24 sets of inflation and deflation P-V curves obtained from patients with ARDS. We used a recently described sigmoidal equation to curve-fit the P-V data sets and objectively define the point of maximum compliance increase of the inflation limb (P_{mm}) and the true inflection point of the deflation limb (P_{tot}). These points were compared with graphic determinations of lower P_{inc} by seven clinicians. The graphic and curve-fitting methods were also compared for their ability to reproduce the
same parameter value in data sets with reduced number of data points. The sigmoidal equation fit the P-V data with great accuracy ($R^2 = 0.9992$). The average of $P_{\text{max}}$ determinations was found to be correlated with $P_{\text{max}}$ ($R = 0.89$) and $P_{\text{max}}$ ($R = 0.76$). Individual determinations of $P_{\text{max}}$ were less correlated with the corresponding objective parameters ($R = 0.67$ and 0.62, respectively). $P_{\text{max}} + 2 \text{ cm H}_2\text{O}$ was a more accurate estimator of $P_{\text{max}}$ (2 SD = ±6.05 cm H$_2$O) than $P_{\text{max}}$ was of $P_{\text{max}}$ (2 SD = ±1.02 cm H$_2$O). There was significant interobserver variability in $P_{\text{max}}$ with a maximum difference of 11 cm H$_2$O for the same patient (SD = 1.9 cm H$_2$O). Clinicians had difficulty reproducing $P_{\text{max}}$ in smaller data sets with differences as great as 17 cm H$_2$O (SD = 2.8 cm H$_2$O). In contrast, the curve-fitting method reproduced $P_{\text{max}}$ with great accuracy in reduced data sets (maximum difference of 1.6 cm H$_2$O and SD = 0.3 cm H$_2$O). We conclude that $P_{\text{max}}$ rarely coincided with the point of maximum compliance increase defined by a sigmoid curve-fit with large differences in $P_{\text{max}}$, seen both among and within observers. Calculating objective parameters such as $P_{\text{max}}$ or $P_{\text{max}}$ from curve-fitted P-V data can minimize this large variability.


Oral mandibular advancement devices are becoming an increasingly important treatment alternative for obstructive sleep apnea (OSA). The first aim of the study was to determine whether a new oral elastic mandibular advancement device (EMA) advances pharyngeal airway closure during sleep in patients with OSA. The second aim of the study was to determine if the polysomnographic response to the oral mandibular advancement device was dependent on the site of airway closure. Overnight polysomnograms were performed in 28 untreated OSA subjects with and without EMA. A third polysomnogram was performed in 12 of the subjects to determine the site of airway closure without the device. Site of airway closure above or below the oropharynx was determined by measuring the respective presence or absence of respiratory fluctuations in oropharyngeal pressure during induced occlusions in non-rapid eye movement (NREM) sleep. Mean apnea-hypopnea index (AHI) was 52.6 ± 28.2 (SD) events/h without the device and 21.2 ± 19.3 events/h with the device. Nineteen subjects (68%) had at least 50% reduction in AHI with the device. The change in AHI with the device (AHI without device - AHI with device) was directly related to the AHI without the device. All three subjects with airway closure in the lower pharyngeal airway had a greater than 80% reduction in AHI with the device. Two of the twelve subjects with airway closure in the velopharynx had a similar therapeutic response. The results show the effectiveness of EMA in the treatment of OSA. The results also indicate that polysomnographic severity of OSA and the site of airway closure should not be used to exclude patients from this oral device treatment.


To investigate the prevalence and behavior of sleep-related breathing disorders (SRBDs) associated with a first-ever stroke or transient ischemic attack (TIA), we prospectively studied 161 consecutive patients admitted to our stroke unit. Complete neurological assessment was performed to determine parenchymatous and vascular localization of the neurological lesion. Stroke subtype was categorized as TIA, ischemic (IS), or hemorrhagic (HS). A portable respiratory recording (PRR) study was performed within 48-72 h after admission (acute phase), and subsequently after 3 mo (stable phase). During the acute phase, 116 patients (71.4%) had an apnea-hypopnea index (AHI) > 10 events/h and 15 (28%) had an AHI > 30. No relationships were found between sleep-related respiratory events and the topographical parenchymatous location of the neurological lesion or vascular involvement. Cheyne-Stokes breathing (CSB) was observed in 42 cases (26.1%). There were no significant differences in SRBD according to the stroke subtype except for the central apnea index (CAI). During the stable phase a second PRR was performed in 86 patients; 53 of 86 had an AHI > 10 and 17 of 86 had an AHI > 30. The CAI had significantly lower than those in the acute phase (16.9 ± 13.8 versus 22.4 ± 17.3 and 3.3 ± 7.6 versus 6.2 ± 10.2, respectively) ($p < 0.05)$ while the obstructive apnea index (OAI) remained unchanged. CSB was observed in 6 of 86 patients. The prevalence of SRBD in patients with first-ever stroke or TIA is higher than expected from the available epidemiological data in our country. No correlation was found between neurological location and the presence or type of SRBD. Obstructive events seem to be a condition prior to the neurological disease whereas central events and CSB could be its consequence.


Varying approaches to measuring the respiratory disturbance index (RDI) may lead to disparate estimates of the severity of sleep-disordered breathing (SDB). In this study, we assessed the impact of varying the use of corroborative data (presence and degree of desaturation and/or arousal) to identify hypopneas and apneas. The relationships among 10 RDIs defined by various definitions of apneas and hypopneas were assessed in 5,046 participants in the Sleep Heart Health Study (SHHS) who underwent overnight unattended 12-channel polysomnography (PSG). The magnitude of the median RDI varied 10-fold (i.e., 29.3 when the RDI was based on events identified on the basis of flow or volume amplitude criteria alone to 2.0 for an RDI that required an associated 5% desatu-
PROGRAM #1
Taking the Mystery Out of Weaning the Pediatric Patient from the Ventilator
Peter Betit, BS, RRT, FAARC, and Richard D. Branson, BA, RRT, FAARC

Learn when to begin the process and how to recognize critical events in weaning a pediatric patient. Also teaches the physiological differences between the adult and pediatric patient and why weaning of the pediatric patient is different. The presentation confronts participants with options in providing assisted ventilation and the correct selection of options that expedite weaning.

Live Videoconference -
March 13, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
April 10, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #2
Pulmonary Rehabilitation:
Standard Care for Chronic Lung Disease Patients
Trina Limberg, BS, RRT, and Thomas J. Kallstrom, RRT, FAARC

Presentation details when to refer a patient for pulmonary rehabilitation and the four elements necessary for the successful operation of a rehabilitation service. Details how to prepare a treatment plan during assessment and how to modify it based on subsequent evaluations as well as how to incorporate rehabilitation techniques into routine bedside therapy sessions.

Live Videoconference -
March 27, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
April 17, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #3
Noninvasive Ventilation:
The Latest Word
Dean R. Hess, PhD, RRT, FAARC, and Richard D. Branson, BA, RRT, FAARC

Learn how to avoid intubation in the acutely ill patient through identification of patients most likely to benefit from noninvasive ventilation. Learn selection and proper fit of full masks or nasal masks and how to select the proper ventilator based on the patient's condition and desired outcomes. Also learn when to make adjustments to achieve the goals of unloading respiratory muscles and achieving good patient/ventilator synchrony.

Live Videoconference -
April 24, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
May 29, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #4
Education of the Patient with Asthma
Tracey Mitchell, RRT, RPFT, and Thomas J. Kallstrom, RRT, FAARC

This program teaches how to ensure that patients understand the disease process of asthma and their care plan for effective disease management. And, it details what patient education materials are available, their context, where to find them, and the best methods of presentation, including new terminologies, analogies, and techniques.

Live Videoconference -
May 22, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
June 19, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #5
ARDS:
The Disease and Its Management
Leonard D. Hudson, MD, and David J. Pierson, MD, FAARC

Presents the four diagnostic criteria for ARDS and the six clinical risk factors that place patients at increased likelihood for developing ARDS. The program will teach viewers how to understand the implications of the lower and upper inflection points on the pressure-volume curve of the respiratory system in ARDS patients; and instruct them in the calculation of estimated required tidal volume.

Live Videoconference -
June 26, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
July 17, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #6
New Respiratory Drugs:
What, When, and How?
Joseph L. Raiu, PhD, RRT, FAARC, and Patrick J. Dunne, MEd, RRT, FAARC

Introduces participants to new formulations such as racemic drug mixtures and single isomers and their effective duration and how they lead to lower costs with improved patient response. Viewers will learn the use of improved anticholinergics in the treatment of asthma patients and learn the uses and effects of inhaled anti-inflammatory agents.

Live Videoconference -
Aug. 14, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
Sept. 11, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #7
Invasive Ventilation:
The Latest Word
Richard Kallet, MS, RRT and Richard D. Branson, BA, RRT FAARC

Learn how proper ventilator management can preclude inflicting harm on the patient and what is essential for the clinician to understand the function and mechanics of newer mechanical ventilators. Also learn how reducing the patient's work of breathing is essential in reducing the additional load on ventilatory musculature, and why reinflating lungs and enhancing the functional area of the lung demands extraordinary means.

Live Videoconference -
Sept. 25, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
Oct. 16, 11:30 a.m. - 12:00 Noon Central Time

PROGRAM #8
Test Your Lungs, Know Your Numbers, Prevent Emphysema
Thomas L. Petty, MD, FAARC and David J. Pierson, MD, FAARC

Reviews the classic signs of COPD with an emphasis on emphysema and a discussion on the measures used to relieve symptoms and slow disease progression. Covers the importance of pulmonary function tests to determine VC, FFC, and FEV1 and why getting patients to know their numbers is the key to early diagnosis and successful treatment.

Live Videoconference -
Oct. 23, 11:30 a.m. - 1:00 p.m. Central Time
Teleconference with Videotape -
Nov. 20, 11:30 a.m. - 12:00 Noon Central Time
ACCREDITATION

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Each program approved for 1 hour of continuing education credit by Continuing Respiratory Care Education (CRCE). Purchase of videotapes only does not earn continuing education credit. Registrants must participate in the live program or the telephone seminar to earn continuing education credits.

NURSING:
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The six-minute walk test is a submaximal exercise test that can be performed even by a patient with heart failure not tolerating maximal exercise testing. To elucidate the clinical significance and prognostic value of the six-minute walk test in patients with primary pulmonary hypertension (PPH), we sought (1) to assess the relation between distance walked during the six-minute walk test and exercise capacity determined by maximal cardiopulmonary exercise testing, and (2) to investigate the prognostic value of the six-minute walk test in comparison with other noninvasive parameters. The six-minute walk test was performed in 43 patients with PPH, together with echocardiography, right heart catheterization, and measurement of plasma epinephrine and norepinephrine. Symptom-limited cardiopulmonary exercise testing was performed in a subsample of patients (n = 27). Distance walked in 6 min was significantly shorter in patients with PPH than in age- and sex-matched healthy subjects (297 ± 188 versus 655 ± 91 m, p < 0.001). The distance significantly decreased in proportion to the severity of New York Heart Association functional class. The distance walked correlated modestly with baseline cardiac output (r = 0.48, p < 0.05) and total pulmonary resistance (r = 0.49, p < 0.05), but not significantly with mean pulmonary arterial pressure. In contrast, the distance walked correlated strongly with peak VO2 (r = 0.70, p < 0.001), oxygen pulse (r = 0.57, p < 0.01), and VO2:VCO2 slope (r = -0.66, p < 0.001) determined by cardiopulmonary exercise testing. During a mean follow-up period of 21 ± 16 mo, 12 patients died of cardiopulmonary causes. Among noninvasive parameters including clinical, echocardiographic, and neurohumoral parameters, only the distance walked in 6 min was independently related to mortality in PPH by multivariate analysis. Patients walking < 332 m had a significantly lower survival rate than those walking farther, assessed by Kaplan-Meier survival curves (log-rank test, p < 0.01). These results suggest that the six-minute walk test, a submaximal exercise test, reflects exercise capacity determined by maximal cardiopulmonary exercise testing in patients with PPH, and it is the distance walked in 6 min that has a strong, independent association with mortality.


Induced sputum cell counts provide a relatively noninvasive method to evaluate the presence, type, and degree of inflammation in the airways of the lungs. Their interpretation requires a knowledge of normal values from a healthy population. The objective was to examine the total and differential cell counts in induced sputum from a sample of healthy adults. A total of 118 healthy nonsmoking adults were studied. None had asthma or airflow obstruction (negative history, FEV1, ≥ 80% predicted, ratio of FEV1 to vital capacity [FEV1/VC] ≥ 80%), methacholine PC20 ≥ 16 mg/mL). Forty-six were atopic. Sputum induction produced an adequate sample in 96 subjects [53 males, mean age (range) 36 (18 to 60) yr]. The expectorator was processed within 2 h; sputum was selected, treated with diethiothreitol, filtered, and examined in a hemocytometer for total cell count and viability and on Wright-stained cytopsins for a differential cell count. The mean, median (90th percentile) total cell count was 4.1, 2.4 (9.7) × 106 cells/g and cell viability was 69.6, 72.0 (89.7)%.

The report assesses Quality of Life (QoL) and its relationship to current symptoms and prospective medical contact among 396 adult patients with asthma. Patients were 16 to 52 yr of age and in the care of family physicians in the northeast of Scotland. All patients had been prescribed asthma medication within the previous 3 mo. Mean %pred FEV1 was 87.4, mean %pred PEF was 85.1: 41% reported respiratory symptoms every week in the month before interview. Patients completed the SF-36, SF-12, and St. George’s Respiratory Questionnaire (SGRQ) scales. Although mean scores on the SF-36 and SF-12 were close to population norms for patients without chronic illness, the presence of any respiratory symptoms in the month before interview was related to significantly lower QoL scores on the SF-36 scales of Physical Functioning, Energy, Mental Health, Pain, and Health Perception: the SF-12 Physical Functioning scale, and the SGRQ Symptoms, Impact and Activities scales. Physician contact for asthma in the 12 mo after interview was significantly related to SF-36, SF-12, and SGRQ scores at time of interview; however, when adjusted for symptoms at time of interview, only the SGRQ scales remained significant predictors of prospective physician contact. We conclude that respiratory symptoms have significant impact on QoL among patients with mild asthma, measured by generic and respiratory QoL scales, but that a specific respiratory scale is better able to discriminate patients who will seek physician care for asthma.


We used national vital statistics data for 1990 through 1995 to examine both national and regional age-adjusted asthma mortality rates for U.S. Hispanics of Mexican, Cuban, and Puerto Rican heritage, as well as for non-Hispanic whites and non-Hispanic blacks. Nationally, Puerto Ricans had an age-adjusted annual asthma mortality rate of 40.9 per million, followed by Cuban-Americans (15.8 per million) and Mexican-Americans (9.2 per million). In comparison, non-Hispanic whites had an age-adjusted annual asthma mortality rate of 14.7 per million and non-Hispanic blacks had a rate of 38.1 per million. Age-adjusted asthma mortality for Puerto Ricans was highest in the Northeast (47.8 per million); this region accounted for 81% of all asthma deaths among Puerto Ricans in the United States. In the U.S., Puerto Ricans had the highest asthma mortality rates among Hispanics, followed by Cuban-Americans and Mexican-Americans. In addition, among Hispanic national groups, mortality rates were consistently higher in the Northeast than the Midwest, South, or West regions. These results further support that Hispanics do not represent a uniform, discrete group in terms of health outcomes, and that further public health research and interventions should take Hispanic national origin into account.

Combined Salmeterol 50 Microg and Fluticasone Propionate 250 Microg in the Diskus Device for the Treatment of Asthma—Shapiro

ABSTRACTS

Respiratory Care • December 2000 Vol 45 No 12
Three hundred forty-nine patients with asthma previously treated with medium doses of inhaled corticosteroids during a 2-wk, single-blind, ran-in period were randomized to treatment with salmeterol 50 microg combined with fluticasone propionate (FP) 250 microg, salmeterol 50 microg, FP 250 microg, or placebo, each given twice daily through a Diskus device for 12 wk. Mean change in FEV₁ at endpoint was significantly (p < 0.001) greater with the salmeterol/FP combination product (0.48 L) than with placebo (-0.11 L), salmeterol (0.05 L), or FP (0.25 L). The combination product significantly increased the area under the 12-h serial FEV₁ curve relative to baseline over that with placebo, salmeterol, or FP at Day 1, Week 1, and Week 12 (p ≤ 0.025). Patients in the combination-product group had a significantly greater probability of remaining in the study without being withdrawn because of worsening asthma than did patients in the placebo, salmeterol, or FP groups (p ≤ 0.002). The combination product significantly increased (p < 0.001) morning PEF at endpoint (33.5 L/min) as compared with placebo (-14 L/min), salmeterol (-1.16 L/min), or FP (15.2 L/min). The combination product significantly (p ≤ 0.011) reduced asthma symptom scores and supplemental albuterol use, and significantly increased the percentage of nights with no awakenings as compared with placebo, salmeterol, and FP (p ≤ 0.016). Combination treatment with salmeterol 50 microg and FP 250 microg given twice daily from the Diskus device provided better asthma control and greater improvement in pulmonary function than did the individual agents, and may simplify the management of asthma in patients who need both classes of drugs for optimal control of their disease.


The outcome of asthma and/or nonspecific bronchial hyperresponsiveness (BHR) associated with nasal polyposis (NP) is uncertain. Over a 4-yr period, we investigated the long-term changes of pulmonary function and BHR in 46 patients with NP. Each subject was assessed for nasal symptoms and tested for allergy skin prick tests, serum total IgE, spirometry, and carbachol challenge at baseline before initiating any treatment (T0). Nasal symptoms evaluation, spirometric measurements, and carbachol challenge were repeated at T1 and at T2 (respectively, 12.7 ± 0.9 and 47.9 ± 2.2 mo after T0). In addition, bronchodilator response was measured at T2. At T0, 25 patients exhibited BHR and 16 of 25 were asthmatic. All patients were treated first with topical steroids for 6 wk (beclomethasone 600 microg/d). Eighteen patients were successfully treated with topical steroids (topical steroids responders). Intranasal ethmoidectomy was performed in 28 patients who did not improve with topical steroids alone (topical steroids nonresponders). Nasal score improved at T1 and remained improved at T2 as compared with T0 in both groups (p < 0.005). Topical steroids nonresponders demonstrated a significant decrease of FEV₁, FEV₁/FVC ratio, and FEF₂₅-₇₅ at T1 (p < 0.05) and at T2 (p < 0.0005), whereas no significant change was observed in FEV₁ and FEV₁/FVC ratio in responders. ΔFEV₁ (%) between T2 and T0 was not related to the presence of asthma, BHR, or atopy. Bronchodilator response at T2 was similar in the two groups. BHR did not significantly change over the 4-yr follow-up period in the two groups. No change in pulmonary symptoms and/or asthma severity occurred. Our results show that nonreversible airflow obstruction appears over a 4-yr follow-up period in topical steroids nonresponders patients with NP requiring nasal surgery. The long-term contribution of these changes to the development of respiratory symptoms in patients with NP remains to be documented.


Aspiration of foreign material into the lungs has been implicated in the etiology of a variety of pulmonary disorders. Although aspiration is a common clinical problem, its diagnosis represents a major challenge due to the lack of sensitive and/or specific tests. In this study, we evaluated the sensitivity and specificity of a novel diagnostic method in a murine model of milk aspiration. Under light anesthesia, BALB/c mice received either single or repeated intranasal instillation of milk. Control animals received sterile physiologic saline or were infected with respiratory pathogens in a similar manner. After isolation and cannulation of the trachea, mouse lungs were lavaged with PBS at various time points after the last aspiration event. Cells were recovered for Oil Red O (ORO) staining as well as immunocytochemistry for milk proteins: alpha-lactalbumin and beta-lactoglobulin. After single aspiration of milk, a large number of alveolar macrophages displayed a strong immunoreactivity for alpha-lactalbumin for 2-96 h. After single and repeated aspiration, the percentage of positive cells for alpha-lactalbumin was significantly higher when compared with ORO staining at 24, 48, and 72 h (p < 0.05). No immunoreactivity for milk proteins was found in alveolar macrophages obtained from our control groups. These findings demonstrate that immunocytochemical staining of milk proteins within alveolar macrophages represents a novel, sensitive, and specific test for the diagnosis of aspiration in a murine model.


Forced expiratory flows (FEF) can be measured in infants from lung volumes initiated near total lung capacity. In order to establish reference values and to evaluate lung growth, we obtained measurements in 155 healthy subjects between 3 and 149 wk of age. Forced vital capacity (FVC) was highly correlated with body length; however, after accounting for length, age was also significant. When subjects were divided at the median age (40 wk) younger compared with older subjects had a significantly larger slope for length (3.7 versus 2.8; p = 0.002). The flow parameters (FEF₅₀, FEF₇₅, FEF₉₀, and FEF₂₅₋₇₅) were highly correlated with length, and those infants whose mothers smoked had lower flows. For FEF₅₀, male subjects had lower flows than female subjects. The relationship between FEF and volume was assessed using FEV₁/V/FVC, which decreased with increasing length. Smaller subjects emptied their lung volume proportionately faster. We conclude that our study provides reference values for this age group and demonstrates that smoke-exposed infants and male subjects have decreased FEF. In addition, our findings indicate that lung volume increases most rapidly during the first year of life and that airways are large relative to lung volume very early in life.


Postpneumonectomy pulmonary oedema (PPO) develops in approximately 5% of patients undergoing pneumonectomy or lobectomy, and has a high associated mortality (>50%). In its extreme form, PPO follows a clinical and histopathological course indistinguishable from acute respiratory distress syndrome. Perioperative fluid overload, impaired lymphatic drainage following node dissection and trauma caused by surgical manipulation have been implicated in the pathogenesis of PPO. However, PPO more probably represents the pulmonary manifestation of a parenchymal injury consequent upon inflammatory processes induced by the surgical procedure, which involves collapse and re-expansion of the oper-

Daytime sleepiness, impaired cognitive performance and dysphoric mood are often present in patients with obstructive sleep apnoea syndrome (SAS). This prospective controlled study evaluates the effects of treatment with continuous positive airway pressure (CPAP) during 1 yr on daytime functioning in a large group of patients with SAS. The authors studied 80 patients (mean±SEM 49±1 yrs) with SAS with a mean apnoea-hypopnoea index of 60±2 h-1, and 80 healthy control subjects matched for sex and age (46±1 yrs). Measurements were obtained at the beginning of the study and 12±1 months later, and included: daytime sleepiness (Epworth scale), depression and anxiety (Beck tests), vigilance (Steer-Clear) and reaction time (Psychomotor Vigilance Test 192). Drug, coffee and alcohol intake, as well as the sleep schedule, were also recorded. Results showed that, before treatment, patients were more somnolent (p<0.001), anxious (p<0.01) and depressed (p<0.001) than control subjects. Also, they had a longer reaction time (p<0.05) and poorer vigilance (p<0.01). The use of CPAP improved significantly the levels of somnolence (p<0.0001) and vigilance (p<0.01), but failed to modify anxiety and depression. Reaction time changes were minor. Variables with a potential confounding effect did not change during the study. These results provide firm evidence to substantiate the use of continuous positive airway pressure in patients with sleep apnea syndrome.


Investigation and treatment of sleep apnoea/hypopnoea syndrome (SAHS) is placing increasing demands on healthcare resources. This workload may be reduced by using split-night studies instead of the standard full-nights of diagnostic polysomnography and continuous positive airway pressure (CPAP) titration. Split-night studies involve polysomnography in the first half of the night followed, if there is an abnormal frequency of apnoeas and hypopnoeas, by CPAP titration for the remainder of the night. The authors’ database of all patients prescribed a CPAP trial 1991-1997 was used to compare long-term outcomes in all 49 (46 accepting CPAP) patients prescribed split-night studies with those in full-night patients, matched 1:2 using an apnoea/hypopnoea index (AHI) of ≤5 and Epworth score of ≤3 units. Classical symptoms of SAHS were the main reason for the split-night studies (n=27). There were no differences between the groups in long-term CPAP use, median nightly CPAP use (split-night 6.0 h x night, IQR 3.8-7.4, full-night; 6.2 h x night, IQR 3.7-7.0, p=0.9), post-treatment Epworth scores and frequency of nursing interventions/clinic visits required. The median time from referral to treatment was less for the split-night patients (13 months, IQR 11-20 months) than for full-night patients (22 months, IQR 12-34 months; p=0.003). Split-night studies, in selected patients, result in equivalent long-term continuous positive airway pressure use to full-night studies with shorter treatment times and less healthcare utilization.


The objective of this study was to compare the long-term safety of a fixed combination of fenoterol hydrobromide (50 microg) and ipratropium bromide (20 microg) delivered using a metered dose inhaler (MDI) formulated with a non-chlorinated propellant, hydrofluoroalkane134a (HFA-MDI), with delivery using the conventional chlorofluorocarbon propellant (CFC-MDI). The study was designed according to Safety Assessment of Marketed Medicines (SAMM) guidelines, to reflect as far as possible the use of MDIs under normal prescribing conditions. Two thousand and twenty-seven patients with chronic airways obstruction (CAO) were enrolled from 99 centres in France, 95 centres in Germany and 24 centres in Italy. Following a 2-week run-in period, patients were randomized on a 2:1 basis (1,348 patients to HFA-MDI, 679 patients to CFC-MDI) to receive a flexible dose regimen of the combination (2 puffs, 2-4 times a day, as prescribed by the investigator) during a 12-week open label phase. The overall incidence of adverse events was comparable between both groups. In addition, the incidence of respiratory side effects was also similar, with CAO exacerbations or bronchitis the most frequently recorded events. The safety profile of the HFA formulation was comparable to those of the marketed CFC-MDIs used in Germany and France/Italy. No clinically significant differences were detected between HFA134a or CFC driven inhalers on the switch from CFC- to HFA-MDI (2 weeks before randomisation versus 2 weeks after randomization). There was a trend for taste complaints to be reported more frequently by patients in the HFA-MDI group (0.7% before randomisation versus 3.4% after randomisation). This, however, was an expected finding as the HFA134a formulation does have a different taste to the CFC formulation. No difference between formulations was observed in the incidences of coughing or paradoxical bronchospasm. The incidence of falls in FEV1 >15% within 15 min following inhalation at each of the clinic visits was 1.2% for both CFC- and HFA-MDIs. In conclusion, administration of a fenoterol/ipratropium bromide combination via hydrofluoroalkane-metered dose inhaler is as safe as delivery by the currently available chlorofluorocarbon-metered dose inhaler, in an extended population of patients with CAO under normal prescribing conditions.


Several threshold values for predicting weaning outcome from mechanical ventilation have been proposed. These values, however, have been obtained in nonhomogeneous patient populations. The aim of the present study was to determine the threshold values in chronic obstructive pulmonary disease (COPD) patients and compare them to those reported for nonhomogeneous patient populations. The initial weaning trial included 81 COPD patients. Fifty-three of them underwent a successful weaning trial, whereas 28 failed it. The latter were enrolled into the present investigation, and were restudied during a subsequent successful trial. The weaning indices used were those reported in the literature. The threshold values obtained were within 10% of those reported for a nonhomogeneous patients population only for tidal volume and effective compliance. The classification error was <20% for maximal inspiratory pressure (MIP), occluded inspiratory pressure swing (DPi)/MIP, rapid and shallow breathing (respiratory frequency/tidal volume), and compliance, rate, oxygenation, pressure index (CROP), whereas the area under the receiver operating characteristic curves was >0.9 only for DPi/MIP and CROP. In conclusion, the threshold values obtained in chronic obstructive pulmonary disease patients who failed the first weaning attempt differed from those previously reported. Although a gold standard weaning index is not available for chronic obstructive pulmonary disease patients, the oc-
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The function of the diaphragm and other respiratory muscles during exercise in chronic obstructive pulmonary disease (COPD) remains controversial and few data exist regarding respiratory muscle pressure generation in this situation. The inspiratory pressure/time products of the oesophageal and transdiaphragmatic pressure, and the expiratory gastric pressure/time product during exhaustive treadmill walking in 12 patients with severe COPD are reported. The effect of noninvasive positive pressure ventilation during treadmill exercise was also examined in a subgroup of patients (n=6). During free walking, the inspiratory pressure/time products rose early in the walk and then remained level until the patients were forced to stop because of intolerable dyspnoea. In contrast, the expiratory gastric pressure/time product increased progressively throughout the walk. When patients walked the same distance assisted by noninvasive positive pressure ventilation, a substantial reduction was observed in the inspiratory and expiratory pressure/time products throughout the walk. When patients walked with positive pressure ventilation for as long as they could, the pressure/time products observed at exercise cessation were lower than those observed during exercise cessation after free walking. It is concluded that, in severe chronic obstructive pulmonary disease, inspiratory muscle pressure generation does not increase to meet the demands imposed by exhaustive exercise, whereas expiratory muscle pressure generation rises progressively. Inspiratory pressure support was shown to substantially unload all components of the respiratory muscle pump.

**Development of Severe Hypoxaemia in Chronic Obstructive Pulmonary Disease Patients at 2,438 m (8,000 ft) Altitude**—Christensen CC, Ryg M, Refvem OK, Skjonsberg OH. Eur Respir J 2000;15:635-639.

The arterial oxygen tensions (P_{aO_2}) in chronic obstructive pulmonary disease (COPD) patients travelling by air, should, according to two different guidelines, not be lower than 7.3 kPa (55 mm Hg) and 6.7 kPa (50 mm Hg), respectively, at a cabin pressure altitude of 2,438 m (8,000 ft). These minimum in-flight P_{aO_2} values are claimed to correspond to a minimum P_{aO_2} of 9.3 kPa (70 mm Hg) at sea-level. The authors have tested whether this limit is a safe criterion for predicting severe in-flight hypoxaemia. The authors measured arterial blood gases at sea-level, at 2,438 m and at 3,048 m (10,000 ft) in an altitude chamber at rest and during light exercise in 15 COPD patients with forced expiratory volume in one second (FEV_{1}) <50% of predicted, and with sea-level P_{aO_2} >9.3 kPa. Resting P_{aO_2} decreased below 7.3 kPa and 6.7 kPa in 53% and 33% of the patients, respectively, at 2,438 m, and in 86% and 66% of the patients at 3,048 m. During light exercise, P_{aO_2} dropped below 6.7 kPa in 86% of the patients at 2,438 m, and in 100% of the patients at 3,048 m. There was no correlation between P_{aO_2} at 2,438 m and pre-flight values of P_{aCO_2}, FEV, or transfer factor of the lung for carbon monoxide. In contrast to current medical guidelines, it has been found that resting arterial oxygen tension >9.3 kPa at sea-level does not exclude development of severe hypoxaemia in chronic obstructive pulmonary disease patients travelling by air. Light exercise, equivalent to slow walking along the aisle, may provoke a pronounced aggravation of the hypoxaemia.

The aim of this study was to investigate the association between daily changes in respiratory health and air pollution in 489 adults, aged 50-70 yrs, with and without chronic respiratory symptoms, living in urban and nonurban areas in the Netherlands. Subjects were selected from the general population with a screening questionnaire. During three consecutive winters starting in 1992/1993, peak expiratory flow (PEF) and respiratory symptoms were registered in a daily diary. Daily measurements of particles with a 50% cut-off aerodynamic diameter of 10 microm (PM10), black smoke (BS), sulphate, sulphur dioxide (SO2) and nitrogen dioxide (NO2) were conducted. The difference in PM10, BS and sulphate concentrations between urban and nonurban areas was small, but there was more contrast in the concentrations of SO2 and NO2. In symptomatic subjects from urban areas, PM10, BS, sulphate and SO2 concentrations were associated with the prevalence of large decrements in morning PEF (>20% below the median). BS in particular was also associated with upper respiratory symptoms (URS). The magnitude of the effect estimates was in the order of an 80% increase in PEF decrements and a 20% increase in URS for a 40 microg × m⁻³ increase of the same day BS concentration. In symptomatic subjects from nonurban areas, no consistent associations between air pollution and health indicators were observed. However, the differences in effect estimates between urban and nonurban symptomatic panels were small and nonsignificant. In non-symptomatic adults from both areas, no consistent pattern of associations with air pollution was found. In conclusion, air pollution effects were only found in symptomatic adults in the urban areas.


It is not clear how airway pathology relates to the severity of airflow obstruction and increased bronchial responsiveness in cystic fibrosis (CF) patients. The aim of this study was to measure the airway dimensions of CF patients and to estimate the importance of these dimensions to airway resistance using a computational model. Airway dimensions were measured in lungs obtained from CF patients who had undergone lung transplantation (n=12), lobectomy (n=1), or autopsy (n=4). These dimensions were compared to those of airways from lobectomy specimens from 72 patients with various degrees of chronic obstructive pulmonary disease (COPD). The airway dimensions of the CF and COPD patients were introduced into a computational model to study their effect on airway resistance. The inner wall and smooth muscle areas of peripheral CF airways were increased 3.3- and 4.3-fold respectively compared to those of COPD airways. The epithelium was 53% greater in height in peripheral CF airways. The sensitivity and maximal plateau resistance of the computed dose/response curves were substantially increased in the CF patients compared to COPD patients. The changes in airway dimensions of cystic fibrosis patients probably contribute to the severe airflow obstruction, and to increased bronchial responsiveness, in these patients.


According to a recent hypothesis, airway smooth muscle regulates airway calibre mostly at high lung volume, whereas the mucosa and adventitia dimensions dominate at low lung volumes. It was thought that if inhaled steroids decrease the thickness of airway wall in asthma, then forced vital capacity (FVC), which reflects the functional changes at low lung volume, should decrease less during induced bronchoconstriction than flow at high volume. The study was conducted in 31 mild asthmatics under control conditions and during a methacholine challenge before and after 4-weeks treatment with inhaled fluticasone propionate (1.5 mg daily,

Study objective: To describe the clinical course and prognostic factors in patients with HIV admitted to the ICU. DESIGN: Prospective, observational. SETTING: A university-affiliated medical center. METHODS: We included 169 consecutive ICU admissions, from April 1995 through March 1999, of 141 adults with HIV. Data collected included APACHE (acute physiology and chronic health evaluation) II score, CD4+ lymphocyte count, serum albumin level, in-hospital mortality, and the development of organ failure, systemic inflammatory response syndrome (SIRS), and ARDS. RESULTS: The ICU admission rate of hospitalized patients with HIV infection was 12%. The most common reason for ICU admission was respiratory failure, occurring in 65 patient admissions. Mechanical ventilation was required in 91 admissions (54%), ARDS developed in 37 admissions (22%), Pneumocystis carinii pneumonia was diagnosed in 24 admissions (14%), and SIRS developed in 126 admissions (75%). One or more organ failures developed in 131 admissions (78%). The actual and predicted mortality rates were 29.6% and 45.2%, respectively, with a standardized mortality ratio of 0.65. The most frequent immediate cause of death was bacterial infection. The CD4+ lymphocyte count (median, 27.5 cells/μL vs 59 cells/μL; p = 0.0310) and serum albumin level (median 2.2 g/dL vs 2.6 g/dL; p = 0.0355) of nonsurvivors were lower and the APACHE II score (median, 30 vs 21; p < 0.0001) was higher, compared to those of survivors. A higher APACHE II score (odds ratio [OR], 1.11; 95% confidence interval [CI], 1.05 to 1.16) and a transfer from another hospital ward (OR, 3.03; 95% CI, 1.20 to 7.68) were independently associated with increased mortality. The median number of organ failures that developed in survivors was one, compared to four in nonsurvivors (p < 0.0001). CONCLUSIONS: The outcome of HIV-infected patients admitted to the ICU has improved over the years. The CD4 count does not correlate with in-hospital mortality. Higher APACHE II scores and a transfer from another hospital ward are associated with a poor outcome.


Objective and design: To relate UK national trends since 1950 in smoking, in smoking cessation, and in lung cancer to the contrasting results from two large case-control studies centred around 1950 and 1990. Setting: United Kingdom. Participants: Hospital patients under 75 years of age with and without lung cancer in 1950 and 1990, plus, in 1990, a matched sample of the local population: 1465 case-control pairs in the 1950 study, and 982 cases plus 3185 controls in the 1990 study. Main outcome measures: Smoking prevalence and lung cancer. Results: For men in early middle age in the United Kingdom the prevalence of smoking halved between 1950 and 1990 but the death rate from lung cancer at ages 35-54 fell even more rapidly, indicating some reduction in the risk among continuing smokers. In contrast, women and older men who were still current smokers in 1990 were more likely than those in 1950 to have been persistent cigarette smokers throughout adult life and so had higher lung cancer rates than current smokers in 1950. The cumulative risk of death from lung cancer by age 75 (in the absence of other causes of death) rose from 6% at 1950 rates to 16% at 1990 rates in male cigarette smokers, and from 1% to 10% in female cigarette smokers. Among both men and women in 1990, however, the former smokers had only a fraction of the lung cancer rate of continuing smokers, and this fraction fell steeply with time since stopping. By 1990 cessation had almost halved the number of lung cancers that would have been expected if the former smokers had continued. For men who stopped at ages 60, 50, 40, and 30 the cumulative risks of lung cancer by age 75 were 10%, 6%, 3%, and 2%. Conclusions: People who stop smoking, even well into middle age, avoid most of their subsequent risk of lung cancer, and stopping before middle age avoids more than 90% of the risk attributable to tobacco. Mortality in the near future and throughout the first half of the 21st century could be substantially reduced by current smokers giving up the habit. In contrast, the extent to which young people henceforth become persistent smokers will affect mortality rates chiefly in the middle or second half of the 21st century.


Objectives: To determine whether use of an oral nicotine inhaler can result in long term reduction in smoking and whether concomitant use of nicotine replacement and smoking is safe. Design: Double blind, randomised, placebo controlled trial. Four month trial with a two year follow up. Setting: Two university hospital pulmonary clinics in Switzerland. Participants: 400 healthy volunteers, recruited through newspaper advertisements, willing to reduce their smoking but unable or unwilling to stop smoking immediately. Intervention: Active or placebo inhaler as needed for up to 18 months, with participants encouraged to limit their smoking as much as possible. Main outcome measures: Number of cigarettes smoked per day from week six to end point. Decrease verified by a measurement of exhaled carbon monoxide at each time point compared with measurement at baseline. Results: At four months sustained reduction of smoking was achieved in 52 (26%) participants in the active group and 18 (9%) in the placebo group (p < 0.001; Fisher's test). Corresponding figures after two years were 19 (9.5%) and 6 (3.0%) (p = 0.012). Conclusion: Nicotine inhalers effectively and safely achieved sustained reduction in smoking over 24 months. Reduction with or without nicotine substitution may be a feasible first step towards smoking cessation in people not able or not willing to stop abruptly.


Objective: To determine the relation between extent of restrictions on smoking at home, at school, and in public places and smoking uptake and smoking prevalence among school students. Design: Cross sectional survey with merged records of extent of restrictions on smoking in public places. Setting: United States. Participants: 17 287 high school students. Main outcome measures: Five point scale of smoking uptake; 30 day smoking prevalence. Results: More restrictive arrangements on smoking at home were associated with a greater likelihood of being in an earlier stage of smoking uptake (p < 0.05) and a lower 30 day prevalence (odds ratio 0.79 (95% confidence interval 0.67 to 0.91), p < 0.001). These find-
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ings applied even when parents were smokers. More pervasive restrictions on smoking in public places were associated with a higher probability of being in an earlier stage of smoking uptake (p<0.05) and lower 30 day prevalence (0.91 (0.83 to 0.99), p=0.03). School smoking bans were related to a greater likelihood of being in an earlier stage of smoking uptake (0.89 (0.85 to 0.99), p<0.05) and lower prevalence (0.86 (0.77 to 0.94), p<0.001) only when the ban was strongly enforced, as measured by instances when teenagers perceived that most or all students obeyed the rule. Conclusions: These findings suggest that restrictions on smoking at home, more extensive bans on smoking in public places, and enforced bans on smoking at school may reduce teenage smoking.


Objective: To assess the impact of the Massachusetts tobacco control programme, which, since its start in January 1993, has spent over $200m—"the highest per capita expenditure for tobacco control in the world"—on an extra tax of 25 cents per pack of cigarettes. Design: Population based trend analysis with comparison group. Subjects: Adult residents of Massachusetts and other US states excluding California. Main outcome measures: Per capita consumption of cigarettes as measured by states' tax sales records; prevalence of smoking in adults as measured by several population-based telephone surveys. Results: From 1988 to 1992, decline in per capita consumption of cigarettes in Massachusetts (15%) was similar to that in the comparison states (14%), corresponding to an annual decline of 3.4% for both groups. During 1992-3, consumption continued to decline by 4% in the comparison states but dropped 12% in Massachusetts in response to the tax increase. From 1993 onward, consumption in Massachusetts showed a consistent annual decline of more than 4%, whereas in the comparison states it levelled off, decreasing by less than 1% a year. From 1992, the prevalence of adult smoking in Massachusetts has declined annually by 0.43% (95% confidence interval 0.21% to 0.66%) compared with an increase of 0.03% (-0.06% to 0.12%) in the comparison states (p<0.001). Conclusions: These findings show that a strongly implemented, comprehensive tobacco control programme can significantly reduce tobacco use.


Objective: To test the efficacy of behavioural counselling for smoking mothers in reducing young children’s exposure to environmental tobacco smoke. Design: Randomised double blind controlled trial. Setting: Low income homes in San Diego county, California. Participants: 108 ethnically diverse mothers who exposed their children (aged < 4 years) to tobacco smoke in the home. Intervention: Mothers were given seven counselling sessions over three months. Main outcome measures: Children’s reported exposure to environmental tobacco smoke from mothers in the home and from all sources; children’s cotinine concentrations in urine. Results: Mothers’ reports of children’s exposure to their smoke in the home declined in the counselled group from 27.30 cigarettes/week at baseline, to 4.47 at three months, to 3.66 at 12 months and in the controls from 24.56, to 12.08, to 8.38. The differences between the groups by time were significant (p=0.002). Reported exposure to smoke from all sources showed similar declines, with significant differences between groups by time (p=0.008). At 12 months, the reported exposure in the counselled group was 41.2% that of controls for mothers’ smoke (95% confidence interval 34.2% to 48.3%) and was 45.7% (38.4% to 53.0%) that of controls for all sources of smoke. Children’s mean urine cotinine concentrations decreased slightly in the counselled group from 10.93 ng/mL at baseline to 10.47 ng/mL at 12 months but increased in the controls from 9.43 ng/mL to 17.47 ng/mL (differences between groups by time p=0.008). At 12 months the cotinine concentration in the counselled group was 55.6% (48.2% to 63.0%) that of controls. Conclusions: Counselling was effective in reducing children’s exposure to environmental tobacco smoke. Similar counselling in medical and social services might protect millions of children from environmental tobacco smoke in their homes.


BACKGROUND: The Palliative Medicine Unit at University Hospital of Trondheim, Norway, started an intervention programme that aims to enable patients to spend more time at home and die there if they prefer. Close cooperation was needed with the community health-care professionals, who acted as the principal formal caregivers, and a multidisciplinary consultant team coordinated the care. We did a cluster randomised trial to assess the intervention’s effectiveness compared with conventional care METHODS: Community health-care districts in and around Trondheim, Norway, were defined as the clusters to be randomised. We enrolled 434 patients (235 assigned intervention and 199 conventional care [controls]) in these districts who had incurable malignant disease and an expected survival of 2-9 months. Main outcomes were place of death and time spent in institutions in the last month of life. FINDINGS: 395 patients died. Of these, more intervention patients than controls died at home (54 [25%] ) vs 26 [15%], p<0.05). The time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7.2 vs 14.6%, p<0.05). Hospital use was similar in the two groups. INTERPRETATION: The palliative-care intervention enabled more patients to die at home. More resources for care in the home (palliative care training and staff) and an increased focus on use of nursing homes would be necessary, however, to increase time at home and reduce hospital admissions.


Objectives. To perform a systematic investigation of medications associated with adverse sedation events in pediatric patients using critical incident analysis of case reports. Methods. One hundred eighteen case reports from the adverse drug reporting system of the Food and Drug Administration, the US Pharmacopoeia, and the results of a survey of pediatric specialists were used. Outcome measures were death, permanent neurologic injury, prolonged hospitalization without injury, and no harm. The overall results of the critical incident analysis are reported elsewhere. The current investigation specifically examined the relationship between outcome and medications: individual and classes of drugs, routes of administration, drug combinations and interactions, medication errors and overdoses, patterns of drug use, practitioners, and venues of sedation. Results. Ninety-five incident fulfilled study criteria and all 4 reviewers agreed on causation; 60 resulted in death or permanent neurologic injury. Review of adverse sedation events indicated that there was no relationship between outcome and drug class (opioids; benzodiazepines; barbiturates; sedatives; antihistamines; and local, intravenous, or inhalation anesthetics) or route of administration (oral, rectal, nasal, intramuscular, intravenous, local infiltration, and inhalation). Negative outcomes (death and permanent neurologic injury) were often associated with drug overdose (n = 28). Some drug overdoses were attributable to prescription/transcription errors, although none of 39 overdoses in 34 patients seemed to be a decimal point error. Negative outcomes were also associated with drug combinations and interactions. The use of 3 or more sedating medications compared with 1 or 2 medications was strongly
ABG Analysis Clinical Assessment Software — Reviews the guidelines used in the interpretation of arterial blood gases, including the evaluation of oxygenation status, causes of abnormal arterial blood gases, and interpretation of the ABG abnormalities. CAI Software. Requires Windows 3.1 or higher. Item PEL8 $65.00 (multi-installation license is an additional $65.00)

Advanced Ventilator Management Clinical Assessment Software — Requires the user to relate ventilator settings to a variety of clinical conditions involving weaning procedures, the treatment of a head injury patient, an asthmatic, a patient with a flail chest, a COPD patient, and a premature infant. CAI Software. Requires Windows 3.1 or higher. Item PEL10 $65.00 (multi-installation license is an additional $65.00)

Aerosol Therapy Clinical Assessment Software — Presents clinical scenarios involving the use of aerosol therapy requiring the user to troubleshoot various aerosol-generating devices including situations where aerosol output is inadequate or intermittent. CAI Software. Requires Windows 3.1 or higher. Item PEL9 $65.00 (multi-installation license is an additional $65.00)

Basic Ventilator Management Clinical Assessment Software — Presents clinical scenarios relating to the management of patients receiving mechanical ventilation including situations where the user is required to troubleshoot various alarm conditions and correct malfunctioning equipment, and react appropriately. CAI Software. Requires Windows 3.1 or higher. Item PEL11 $65.00 (multi-installation license is an additional $65.00)

IPPB Therapy Clinical Assessment Software — Presents scenarios relating to reviewing physician orders, obtaining pertinent patient information, proper technique, calculation of medication, and patient instruction. CAI Software. Requires Windows 3.1 or higher. Item PEL12 $65.00 (multi-installation license is an additional $65.00)

Oral Intubation Clinical Assessment Software — Provides an overview of the guidelines for selecting the proper size of endotracheal tube as well as laryngoscope parts, supplies, use of oral airway, and positioning techniques. CAI Software. Requires Windows 3.1 or higher. Item PEL7 $65.00 (multi-installation license is an additional $65.00)

Oxygen Therapy Clinical Assessment Software — Requires the user to make recommendations for the correct method of oxygen administration for various types of patients. Also includes a review of the hazards of oxygen administration, bubble humidifiers, E cylinder and Bourdon gauge and a cylinder duration calculation, and the effect of patient-breathing pattern on the FIO2 delivered via nasal cannula. CAI Software. Requires Windows 3.1 or higher. Item PEL13 $65.00 (multi-installation license is an additional $65.00)

Respiratory Pharmacology Clinical Assessment Software — Requires the user to calculate various drug dosages as well as recommend the appropriate drug for a variety of patient conditions including croup, asthma, drug overdose, and pulmonary edema. CAI Software. Requires Windows 3.1 or higher. Item PEL14 $65.00 (multi-installation license is an additional $65.00)

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associated with adverse outcomes (18/20 vs 7/10). Nitrous oxide in combination with any other class of sedating medication was frequently associated with adverse outcomes (9/10). Dental specialists had the greatest frequency of negative outcomes associated with the use of 3 or more sedating medications. Adverse events occurred despite drugs being administered within acceptable dosing limits. Negative outcomes were also associated with drugs administered by nonmedically trained personnel and drugs administered at home. Some injuries occurred on the way to a facility after administration of sedatives at home; some took place in automobiles or at home after discharge from medical supervision. Deaths and injuries after discharge from medical supervision were associated with the use of medications with long half-lives (chloral hydrate, pentobarbital, promazine, promethazine, and chlorpromazine). Conclusions. Adverse sedation events were frequently associated with drug overdoses and drug interactions, particularly when 3 or more drugs were used. Adverse outcome was associated with all routes of drug administration and all classes of medication, even those (such as chloral hydrate) thought to have minimal effect on respiration. Patients receiving medications with long plasma half-lives may benefit from a prolonged period of postsedation observation. Adverse events occurred when sedative medications were administered outside the safety net of medical supervision. Uniform monitoring and training standards should be instituted regardless of the subspecialty or venue of practice. Standards of care, scope of practice, resource management, and reimbursement for sedation should be based on the depth of sedation achieved (ie, the degree of vigilance and resuscitation skills required) rather than on the drug class, route of drug administration, practitioner, or venue.


BACKGROUND: Injured patients with pulmonary failure often require prolonged length of stay in an intensive care unit (ICU), which includes weaning from ventilatory support. In the last decade, noninvasive ventilation modes have been established as safe and effective. One method for accomplishing this mode of ventilation uses a simple bilevel ventilator. Because this ventilator has been successfully used in hospital wards, we postulated that bilevel ventilators could provide sufficient support during weaning from mechanical ventilation of injured patients in a non-ICU setting. METHODS: A retrospective review of trauma patients (August 1996-January 1999) undergoing bilevel positive pressure ventilation as the final phase of weaning was conducted. Before ward transfer with bilevel ventilation, conventionally ventilated ICU patients were changed to bilevel ventilation and were required to tolerate this mode for at least 24 hours. All patients had a tracheostomy as a secure airway. Outcomes analyzed included ICU length of stay, hospital length of stay, duration of mechanical ventilation, weaning success, complications, and survival. RESULTS: Fifty-one patients (39 men, 12 women) with a mean age of 53 received more than 24 hours of bilevel positive pressure ventilation. The Mean Injury Severity Score was 29, with blunt mechanisms of injury occurring in 90%. Chest or spinal cord injuries that affected pulmonary mechanics were present in 75% of patients. Ventilator-associated pneumonia was treated in 43% of patients. Mean ICU length of stay and hospital length of stay were 21 and 34 days, respectively. Weaning was successful in 89% of patients, whereas 11% were discharged to skilled nursing facilities still receiving bilevel positive pressure ventilation. Two patients died, neither from a pulmonary nor airway complication. Of the remaining 49 patients, 12 were weaned in the ICU and 37 were transferred to the ward with bilevel ventilatory support. The average length of ward ventilation was 6.5 ± 5.4 days (n = 37). CONCLUSIONS: Implementation of a program using bilevel ventilation to support the terminal phase of weaning seriously injured patients from mechanical ventilation was successful. After initiating this mode in the ICU, it was satisfactorily continued in standard surgical wards. Because this method enabled the withdrawal of ventilatory support in a non-ICU setting, its major advantage was reducing ICU length of stay.


BACKGROUND: Pulmonary hypertension is usually due to an underlying cardiac or pulmonary condition. An association between unexplained pulmonary hypertension and bilateral leg edema in primary care patients was found previously. We undertook this study to identify the frequency of obstructive sleep apnea (OSA) in ambulatory, adult patients with pulmonary hypertension who initially presented with bilateral leg edema. METHODS: Twenty ambulatory adults with bilateral leg edema, with echocardiocardiographic evidence of pulmonary hypertension (estimated pulmonary artery systolic pressure >30 mm Hg), and without left ventricular dysfunction or with no clinically apparent pulmonary disease were enrolled from a suburban family practice and an inner-city family practice during a 3-year period. Spirometric assessment, pulse oximetry, rheumatologic evaluation, polysomnography, and questionnaire information regarding risk factors for pulmonary hypertension were obtained for each subject. RESULTS: Fifteen patients (75%) completed the study. Almost all of the subjects were obese. Nine (60%) of the 15 had OSA. None of the subjects demonstrated an obstructive pattern on spirometric evaluation results, but 9 (60%) had a restrictive spirometry pattern, consistent with their obesity. None of the subjects had daytime hypoxemia. Systemic hypertension was present in two-thirds of the subjects with OSA, and was absent in all of the subjects who lacked OSA. CONCLUSIONS: Bilateral leg edema in obese primary care patients is associated with both OSA and modest pulmonary hypertension. If these findings are generalizable, then bilateral leg edema may be an important clinical marker for underlying OSA.


Objective. To evaluate the bias, precision, and blood loss characteristics of an ex vivo in-line point-of-care testing blood gas and electrolyte monitor designed for use in critically ill newborn infants. Study Design. Study participants included consecutive neonates with an umbilical artery catheter (UAC) in use for clinical laboratory testing. The in-line monitor (VIA LVM Blood Gas and Chemistry Monitoring System, VIA Medical, San Diego, CA) was directly connected to the participant’s UAC and the monitor’s determinations of pH, PCO2, PO2, sodium, potassium, and hematocrit (Hct) were compared with those simultaneously drawn and measured with a standard bench top laboratory instrument (Radiometer 625 ABL; Radiometer America, Inc, Westlake, OH). The bias (the mean difference from the reference method) and precision (1 standard deviation of the mean difference) performance criteria of the in-line monitor were derived using standard laboratory procedures. Results. Sixteen neonates monitored for a total of 37 days had a total of 229 paired blood samples available for comparison by the 2 methods. Bias and precision performance characteristics of the in-line monitor were similar to reports of other point-of-care devices (ie, pH: -0.003 ± 0.024; PCO2: 0.35 ± 2.84 mm Hg; PO2: 0.39 ± 7.30 mm Hg; sodium: 0.52 ± 2.34 mmol/L; potassium: 0.17 ± 0.18 mmol/L; and Hct: 0.61 ± 2.80%). The range of values observed for each parameter included much of the range anticipated among critically ill neonates (ie, pH: 7.15-7.65; PCO2: 25-75 mm Hg; PO2: 25-275 mm Hg; sodium: 127-150 mmol/L; potassium: 2.6-5.5 mmol/L; and Hct: 32%-60%). Mean blood loss (± standard deviation) per sample with the in-line monitor was approximately one-tenth that of the reference method: 24 ± 7 μL versus 250 μL, respectively. There was
no evidence of hemolysis and no patient related safety issues were identified with use of the in-line monitor. Conclusions. Repeated laboratory testing of critically ill neonates using an ex vivo in-line monitor designed for use in neonates provides reliable laboratory results. The blood loss and hemolysis data obtained suggests that this monitoring device offers potential for reducing neonatal blood loss-and possibly transfusion needs during the first weeks of life. Before this promising technology can be routinely recommended for care of critically ill neonates, greater practical experience in a variety of clinical settings is needed.


Background. Despite improved treatment regimens for asthma, the prevalence and morbidity from asthma are increasing, especially among underserved, minority children. Objective. The purpose of this study was to identify barriers to the treatment of asthma among urban, minority children as perceived by parents. Methods. Parents were recruited from 4 schools located in low-income, urban areas with high rates of asthma hospitalizations. Focus groups involving parents of children 5 to 12 years old with asthma were conducted using a standardized questionnaire. Parents' comments were analyzed to identify barriers, and 3 independent raters coded parents' comments to assess reliability of interpretation. Results. Forty parents who represented 47 children participated in the focus groups. All parents described their racial background as black. Parents' average age was 36.8 years, 92% were females, 70% were nonmarried, and 38% had less than a high school education. Forty-five percent of children had intermittent or mild asthma and 55% had moderate to severe asthma. The most frequent types of barriers identified by parents were patient or family characteristics (43%), followed by environmental (28%), health care provider (18%), and health care system (11%). Parents were specifically concerned about the use, safety and long-term complications of medications, the impact of limitation of exercise on their child's quality of life, and their own quality of life. Conclusions. In contrast with the widespread beliefs that access to medical care, health insurance, and continuity of care are the major barriers to quality asthma care, the barriers most frequently reported by parents were related to patient and family characteristics, health beliefs, or to their social and physical environment. To improve asthma management and health outcomes for urban, minority children with asthma, it is critical to tailor education about asthma and its treatment, and address quality of life issues for both children and parents.


The effect of patient education on morbidity in asthmatics and COPD patients has not previously been investigated in a single study. We randomized 78 asthmatics and 62 COPD patients after ordinary outpatient management. Intervention consisted of educational group sessions and individual sessions administered by a trained nurse and physiotherapist. A self-management plan was developed. The utilization of health resources and absenteeism from work was self-reported monthly. During the 12-month follow-up, approximately two (p=0.001) and three (p=0.001) times as many uneducated asthmatics and COPD patients, respectively, visited their general practitioner (GP) compared with educated. The mean reduction in GP consultations for the educated were 73% (p=0.001) and 85% (p=0.0001) for the asthma and COPD group, respectively, compared with uneducated. Fifty percent of uneducated asthmatics reported absenteeism from work compared with 24% of the educated (p=0.06). The mean reduction in days off work for the educated was 69% (p=0.03), compared with uneducated. A positive correlation was observed between St George's Respiratory Questionnaire total score and number of GP visits for both the asthma and COPD group (p<0.001). We conclude that patient education in asthmatics and COPD patients reduced the need for GP visits and kept a greater proportion of patients independent of their GP. Patient education among asthmatics also reduced the number of days off work and appeared to increase the proportion of patients not reporting absenteeism from work at all. Increasing number of GP visits was correlated with decreased health-related quality of life as measured by the SGRQ for both the asthmatics and the COPD patients.


Upper airway dryness is a frequent side-effect of nasal continuous positive airway pressure therapy (nCPAP) in obstructive sleep apnoea (OSA). In this situation, heated or non-heated passover humidifiers are often added to the nCPAP-therapy. The efficacy of these two models in terms of increasing the absolute humidity of the inspired air in vivo has so far not been established. The present investigation was therefore designed to compare various heated and non-heated passover humidifiers in terms of the their ability to increase the absolute humidity in the inspired air during nCPAP. In six healthy test individuals, nCPAP-therapy at pressures of 5 mbar and 10 mbar was simulated, and the relative humidity and temperature of the air within the tube at the junction between CPAP and mask were measured. In each test person, measurements were carried out both with and without the two heated (HC 100, Fischer&Paykel Inc., New Zealand and HumidAir, ResMed Ltd., Australia) and two non-heated (Oasis and Humidifier, both from Respironics Inc, U.S.A.) passover humidifiers under steady-state conditions. The absolute humidity was calculated from the relative humidity and temperature measurements. The mean (SD) absolute humidity (gm⁻³) in the steady-state was significantly (p<0.05) higher with each of the humidifiers than that calculated when no humidifier was used. The relevant figures were as follows: no humidifier: 10.3 (1.8) gm⁻³ (at 5 mbar)/9.8 (1.8) gm⁻³ (at 10 mbar); Humidifier: 16.4 (0.97)/15.6 (1.26); Oasis: 17.3 (0.97)/16.7 (0.93); HC100: 26.5 (1.40)/26.2 (1.23); HumidAir: 31.8 (2.50)/30.9 (2.64). The mean increase in absolute humidity (gm⁻³) with the aid of the heated humidifiers was 16.3 (5 mbar) gm⁻³/16.4 (10 mbar) gm⁻³ with HC100 and 21.6/21.1 with HumidAire, and in both cases was clearly and significantly (p=0.028) higher in comparison with the non-heated humidifiers—6.2/5.8 with Humidifier and 7.2/6.9 with Oasis. In terms of the absolute humidity achieved within the CPAP tube system, the heated humidifiers were clearly superior to the non-heated humidifiers. These results were, however, obtained under laboratory conditions, and therefore cannot be translated unreservedly to the situation represented by long-term CPAP-treatment. Furthermore, it is possible that the smaller humidification capacity of the non-heated humidifiers may still suffice to meet the requirements of clinical use in terms of effectively preventing dry airways under CPAP treatment. This point, however, needs further investigation on the basis of long-term clinical studies.
Part II of Two Special Issues

Palliative Respiratory Care

Containing the papers and discussions from a Journal Conference sponsored by the American Association for Respiratory Care and held May 19-21, 2000.
Conference faculty members—front row, from left: Gerard A Silvestri MD MS, Joshua O Benditt MD, Gordon D Rubenfeld MD MSc, Mitchell M Levy MD, J Randall Curtis MD MPH, Louisa Viles MSW. Back row, from left: John H Hansen-Flaschen MD, Harold L Manning MD, Melaine (Tudy) H Giordano MS RN CPFT, Helen M Sorenson RRT, John E Heffner MD, Robert A Burt JD, Joseph J Fins MD. Not pictured: Barbara J Daly PhD RN (did not attend)

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Dyspnea in the Ventilated Patient: A Call for Patient-Centered Mechanical Ventilation

John H Hansen-Flaschen MD

Introduction

What Is Known about Controlling Dyspnea during Mechanical Ventilation
What Is Not Known
A Pragmatic Approach for Respiratory Therapists

Key words: palliative care, terminal care, dyspnea, lung diseases, obstructive, interstitial, ventilators, mechanical, ventilator weaning, ventilation, artificial, intubation, intratracheal, respiratory insufficiency. [Respir Care 2000;45(12):1460–1464]

In recent years, most research on mechanical ventilation has focused on improving physiologic measures of cardiopulmonary function and increasing short-term survival. By comparison, remarkably little research has aimed at improving the subjective experience of patients undergoing mechanical ventilation. Less than 10 studies published in English report measurements of dyspnea during mechanical ventilation. These reports demonstrate that many endotracheally intubated patients can communicate the severity of their dyspnea by means of conventional measures such as numeric and visual analogue scales. They also suggest that dyspnea is common during mechanical ventilation and that adjustments of tidal volume, inspiratory flow, and level of ventilatory assistance may alleviate dyspnea in some instances. Much remains to be learned about the incidence, characteristics, and treatment of dyspnea during mechanical ventilation. In the meantime, respiratory therapists can help usher in a new era of “patient-centered mechanical ventilation” by routinely asking patients during bedside visits whether they are experiencing dyspnea. Therapists should ask two questions: “Are you short of breath right now?” and, if yes, “Is your shortness of breath mild, moderate, or severe?” The response can be recorded in the medical record using a 4-point scale: 0 = no shortness of breath, 1 = mild, 2 = moderate, 3 = severe, X = unable to answer. If the answer is 2 or 3, the therapist should endeavor to reduce dyspnea by adjusting ventilator settings within predetermined limits or by seeking additional assistance. By this approach, patient comfort can become a new parameter for routine adjustment of ventilator settings in the management of respiratory failure.

Introduction

More than 40 years after widespread adoption of positive-pressure mechanical ventilation for acute respiratory failure, this life-sustaining therapeutic intervention is still...
monary complications, and avoiding preventable errors. These advances have produced measurable improvements in survival from such conditions as respiratory distress of premature newborns and the acute respiratory distress syndrome.

By comparison, remarkably little research has aimed at improving the experience of patients undergoing mechanical ventilation. While the same can be said for other major medical interventions, such as chemotherapy and hemodialysis, research on the experience of mechanical ventilation has lagged in particular because of obstacles to communicating with patients who are endotracheally intubated. Only in the past several years have scientific techniques been developed for eliciting and measuring symptoms from supine, physically restrained patients who cannot talk because of endotracheal intubation. These communication techniques—and the scientific insights likely to derive from them—have the potential to promote a new approach to mechanical ventilation that aims not only at improving the safety and survival of patients but also at reducing their distress and fear. This approach might be called “patient-centered mechanical ventilation” to emphasize the importance of adjusting ventilator support partly in response to preferences expressed by the patient.

Some might argue that patient-centered mechanical ventilation is not an important objective relative to optimizing patient safety and survival: “Patients who recover from respiratory failure should be thankful just to be alive. Most have little or no memory of their experience during mechanical ventilation anyway.” At least 3 responses can be raised to counter that argument. First, most of us would rather not experience severe, sustained, avoidable distress, even if we might not remember it afterwards. Second, the duration of mechanical ventilation is often prolonged by administration of sedating drugs and analgesics administered at doses that are sufficient to sustain placidity and amnesia but may be excessive to relieve distress. Third, long-term amnesia may not be as complete or as protective as some intensivists imagine. Recent research has revealed a disturbingly high prevalence of anxiety disorders, depression, and post-traumatic distress disorder in survivors of acute respiratory failure. Post-traumatic distress disorder in particular can persist for years after intensive care and appears to relate directly to memory of adverse experiences during acute care.

This article briefly reviews what is known and not known about the experience of dyspnea during mechanical ventilation for respiratory failure and suggests a straightforward, empirical approach to patient-centered mechanical ventilation in anticipation of additional research on this subject.

What is Known about Controlling Dyspnea during Mechanical Ventilation

1. Dyspnea can be elicited and measured during conventional mechanical ventilation.

Drawing from research on pain, respiratory behavioral scientists have developed several techniques for measuring the severity of dyspnea experienced at the time of inquiry. The modified Borg scale, which employs several brief descriptive terms, is widely used to measure dyspnea during progressive exercise testing. Dyspnea at rest is often measured using visual analog or numeric intensity scales (Fig. 1). Because these scales require limited effort by the subject, they can be used to measure dyspnea experienced by physically restrained, mechanically ventilated patients who are alert and comprehending.

Bouley et al used a visual analog scale to compare dyspnea experienced by 9 patients with chronic obstructive pulmonary disease during 3 modes of weaning from mechanical ventilation: synchronized intermittent mandatory ventilation (SIMV), T-piece, and pressure support ventilation (PSV). They were able to measure dyspnea repeatedly during weaning in each of the patients. The patients differed from one another in the relationship between dyspnea scores and physiologic measures, suggesting that the severity of a patient’s dyspnea cannot be estimated by an observer from such measures as respiratory rate or tidal volume (V T). No difference was observed in dyspnea between the 3 weaning modes.

Knebel et al used a visual analog scale to compare dyspnea and anxiety measured simultaneously by 21 subjects in acute respiratory failure during SIMV or PSV weaning from mechanical ventilation. They also found that dyspnea could be measured reproducibly at frequent intervals by this technique. Dyspnea and anxiety scores tracked closely together, suggesting that they are highly interrelated during weaning from mechanical ventilation. Like Bouley et al, they found no difference in dyspnea between weaning modes.

In 1999, Powers and Bennett reported studies of reliability and validity for 5 measures of dyspnea in 28 patients receiving mechanical ventilation. Horizontal and vertical visual analog scales, a numeric scale, the modified Borg scale, and a faces scale were studied. All 5 methods
showed acceptable test-retest reliability and criterion validity. In agreement with Bouley et al, they found that dyspnea scores did not correlate with physiologic variables, thereby reinforcing the notion that dyspnea must be measured directly, not inferred from other routine measures in patients receiving mechanical ventilation.

Considered together, these three studies convincingly demonstrate that selected patients receiving mechanical ventilation can communicate across the barrier of endotracheal intubation to convey the degree of dyspnea they are experiencing at the time of measurement. None of several established measurement techniques has been shown to be superior in this setting. We use a 1 to 10 horizontal numeric intensity scale (see Fig. 1) printed on 8 × 10 inch paper using 72-point Arial font. If the patient’s arms are restrained, the examiner holds the card 2 to 3 feet from the patient’s eyes and moves a pointing finger from 0 to 10 along the scale. The patient is then asked to nod affirmatively when the appropriate number is reached.

2. Dyspnea is commonly reported by patients undergoing mechanical ventilation for respiratory failure.

Research published to date suggests that some degree of dyspnea is remarkably common among communicative patients receiving mechanical ventilation for respiratory failure, not only during active ventilator weaning but also under maintenance conditions when the patient appears calm and adequately ventilated. Restoration of adequate arterial blood gas tensions and patient-ventilator synchrony does not necessarily alleviate dyspnea. For example, Knebel et al reported a mean visual analog scale score of 32.2 on a scale of 0 to 100 for clinically stable patients in respiratory failure during maintenance mechanical ventilation shortly before initiation of a weaning trial. Respiratory adverse events also commonly occur and may contribute to the development of post-traumatic stress disorder in survivors.

3. Under some circumstances, dyspnea can be reduced by appropriate adjustment of mechanical ventilation.

Certain modes of positive-pressure mechanical ventilation such as inverse ratio and pressure-controlled mechanical ventilation are known to cause respiratory distress requiring deep sedation, especially if acute hypercapnia is imposed. Limited published experience suggests that ventilator settings in other modes can have a favorable or detrimental effect on dyspnea as well.

Manning et al studied the effects of $V_T$ on air hunger in medically stable, mechanically-ventilated, high-level quadriplegics. In hypercapnic, spontaneously breathing normal subjects and hypercapnic ventilator-dependent patients, others have also shown that dyspnea increases when $V_T$ is reduced appreciably from spontaneously adopted, most comfortable levels. When 5 subjects were ventilated at constant, elevated partial pressure of carbon dioxide, air hunger decreased as breath size was increased to each patient’s usual level. Generalization from such small studies is difficult; nevertheless, these findings suggest that an increase in the volume of ventilator-assisted breaths to the patient’s preferred volume might reduce dyspnea in some patients undergoing mechanical ventilation.

The effect of ventilator-supplied inspiratory flow rates on the sensation of dyspnea has also received limited attention. In a study of 10 tracheally intubated and mechanically ventilated normal subjects, Manning et al found that respiratory discomfort increased as inspiratory flow was reduced to 70% or increased to 300% of each subject’s most comfortable, spontaneous inspiratory flow. Air hunger was not appreciably increased at an inspiratory flow of 200% of the most comfortable level, suggesting that there is a “comfort zone” for inspiratory flow around each patient’s spontaneously preferred level.

The level of ventilatory assistance is a third variable that appears to influence the experience of dyspnea in mechanically ventilated patients. Leung et al measured the inspiratory time product and other related measures as indices of patient-ventilator synchrony and dyspnea in 11 medically stable, intubated patients during 4 modes of mechanical ventilation: assist-control, SIMV, PSV, and a combination of SIMV with PSV. As a general rule, increases in ventilatory assistance produced progressive decreases in inspiratory muscle effort and dyspnea. These careful measurements suggest that respiratory discomfort can be decreased in some instances by increasing the IMV rate or pressure support or both to a level that is experienced as comfortable by the patient.

What Is Not Known

1. What do mechanically ventilated patients mean when they report shortness of breath?

Dyspnea is a complex respiratory sensation that encompasses various qualities and characteristics depending on psychological as well as physical variables. Recent research has revealed a number of distinct descriptors of dyspnea, such as air hunger or chest tightness, that tend to be used repeatedly under reproducible circumstances across diverse cultures and languages. These studies have not yet been extended to patients undergoing mechanical ventilation. To what extent, for example, does anxiety or dread influence the description of breathing discomfort in this setting? If anxiety is a major amplifier of dyspnea experienced during mechanical ventilation, might pharmacologic anxiolysis appreciably reduce breathing distress for some patients in respiratory failure?
Measurement of dyspnea in patients receiving mechanical ventilation may be further confounded by other closely associated sources of distress, notably the discomfort of translaryngeal endotracheal intubation. Remarkably little is known about the prevalence, nature, and severity of pain or other discomfort associated with endotracheal intubation, although indirect and anecdotal evidence suggests that this is a common and important source of distress. Patients who can talk freely may be able to differentiate dyspnea from throat discomfort. However, those who are constrained by endotracheal intubation to identifying a single number on a rating scale may fold throat pain and other disagreeable sensations into their rating of "dyspnea." Obviously, if much of the distress measured with a dyspnea scale derives from the throat, readjustments of ventilator settings will have a limited beneficial effect. Additional research is needed on measurements of respiratory discomfort associated with various types of intubation for respiratory failure and on the relative contributions of these sensations to dyspnea measured by conventional techniques.

2. What is the incidence and range of severity of dyspnea under various circumstances of mechanical ventilation?

Studies to date have focused on controlled conditions and medically stable, fully communicative normal volunteers or patients. The incidence and severity of dyspnea across the spectrum of acute and chronic respiratory failure and the range of assisted ventilatory modes are largely unknown. To what extent does respiratory discomfort contribute to agitation in delirious patients who are unable to answer questions about discomfort? Do patients with asthma respiratory failure experience more dyspnea during mechanical ventilation than patients with a comparable degree of airway obstruction caused by chronic obstructive pulmonary disease? Are patients more comfortable determining respiratory rate, ventilator $V_T$, and inspiratory flow themselves? Do patients ventilated noninvasively by nasal or face mask experience less dyspnea than those who are ventilated by endotracheal intubation? Do patients experience less dyspnea after replacement of a translaryngeal tube by a tracheostomy? Answers to these and other related questions will be useful in further refining the management of respiratory failure to reduce patient distress without adversely affecting other outcomes.

3. Can the need for sedation and analgesia be reduced by adjusting mechanical ventilation to minimize patient dyspnea?

Intravenous analgesics and sedating drugs are widely used during mechanical ventilation to quell agitation and to alleviate patient distress. Unless patient distress is measured routinely, the potential exists to systematically overdose these agents. As a result, the duration of mechanical ventilation can be greatly prolonged while accumulated sedating drugs gradually clear from the body. Depending on which agents are used, continuous intravenous sedation can also add several hundred dollars or more to the daily cost of caring for patients in respiratory failure.

Dyspnea is but one of several types of distress commonly experienced by patients during mechanical ventilation, together with pain, anxiety, and delirium. Thus, it is unknown to what extent regular measurements of dyspnea may allow for reductions in the amount of sedating drugs needed to maintain patient comfort and safety. To what extent can agitation and, hence, the need for sedation be reduced by periodic adjustments of mechanical ventilation to the lowest achievable level of patient discomfort?

4. Can the incidence or severity of post-traumatic stress disorder be reduced in survivors of respiratory failure by minimizing respiratory distress during mechanical ventilation?

Clinical investigators have just begun to gauge the extent and severity of post-traumatic stress disorder and other psychological or cognitive sequelae experienced by patients who survive mechanical ventilation for respiratory failure. It is clear that many patients experience flashbacks and nightmares for years after recovery and that at least some of these experiences are related to adverse respiratory events during mechanical ventilation or shortly after extubation. The degree to which these psychological aftereffects can be minimized by judicious use of sedating drugs or optimum management of ventilatory assistance remains entirely unknown.

A Pragmatic Approach for Respiratory Therapists

While awaiting additional research, RTs can advance the goal of patient-centered mechanical ventilation by routinely asking conscious, mechanically ventilated patients whether they are experiencing dyspnea. This assessment should be done by protocol at the time therapists visit patients for scheduled reassessment and recording of ventilator settings. As a matter of routine, therapists should ask two questions: "Are you short of breath right now?" and, if yes, "Is your shortness of breath mild, moderate or severe?" The response can be recorded in the medical record using a 4-point scale such as $0 = $no shortness of breath, $1 = mild, $2 = moderate, $3 = severe, $X = unable to answer. If the answer is 2 (moderate), or 3 (severe), the therapist should endeavor to reduce respiratory discomfort by readjusting ventilator settings within limits, as determined by protocol. During maintenance mechanical ventilation, the protocol might test, for example, varying $V_T$. 


inspiratory flow rates, and pressure support settings. During ventilator weaning, a change from 2 (moderate) to 3 (severe) might trigger readjustment to a higher level of ventilatory support. As changes are made, the patient should be asked, “Is your shortness of breath less, more, or unchanged?” and the settings should be readjusted accordingly. After adjustment is completed, the patient should be asked again to rate shortness of breath from mild to severe, and the new level should be recorded. The therapist should recheck physiologic parameters and consider arterial blood gas testing to verify that the new ventilator settings are tolerable. Finally, if the patient continues to report an unacceptable level of dyspnea despite ventilator adjustment, the therapist should advise the nurse so that other therapies can be considered. In addition to administration of additional analgesic or sedating medication, nonpharmacologic therapies for dyspnea such as mechanical chest wall vibration and facial stimulation using a fan can be considered.14–16

Under certain circumstances, use of a 10-point or visual analog scale might be more appropriate to provide additional discrimination in dyspnea scores between measurements. This approach might be useful, for example, during prolonged weaning from mechanical ventilation when some dyspnea must be tolerated by the patient to achieve the intended respiratory muscle training effect.

The approach described above should not require more than an additional 2 or 3 minutes at the bedside, on average, across all patients seen in a day. Many patients will be unable to answer; others may report no or mild shortness of breath. Time required to reduce dyspnea by readjustment of the ventilator should shorten as experience is gained. The degree to which this approach might reduce use of sedating drugs and analgesics is unpredictable but can be tested scientifically.

By adding a straightforward assessment of dyspnea to routine bedside care, and by responding appropriately to the discovery of moderate or severe dyspnea, RTs can usher in a new era of patient-centered mechanical ventilation to the enduring benefit of patients in respiratory failure.

Discussion

Benditt: That was great. I really enjoyed that. Several years ago, the son of a patient of mine with COPD who was an engineer devised a system for communication for ventilated patients: it involved a touch pad that you could place one finger on and move the cursor around the screen where a number of predetermined responses could be chosen. He came and showed it to us in the respiratory department, but I haven’t heard anything since.

Hansen-Flaschen: I think we’re all in agreement that the obstacle to communication is a fundamental feature of the experience of conscious people who are mechanically ventilated, and you’d like to think there are technical approaches that would help to overcome that. The biggest problem I see is we don’t like to spend a lot of time at the bedside, whether physicians or respiratory therapists. Some nurses spend time in there, but we’re in the room for 90 seconds, and we are often focused on other goals. If the patient can’t get our message with a clip

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board and a pen in clear coherent writing very quickly, we cut them off and we leave. So the technology will have to communicate quickly.

Pierson: I think it’s really sobering how few studies there are in the literature dealing with the patients’ experience of mechanical ventilation, and specifically with respiratory distress, because this is in the context of dozens of papers comparing different modes, pressure-wave forms, pressure-triggering versus flow-triggering, and so on. If this were a conference on the technical aspects of mechanical ventilation (of which we’ve had several), there would be hours of discussion of the relative merits of things such as inspiratory flow and pressure-wave forms, for which the literature mainly consists of the use of what are perhaps pretty poor surrogates for patient experience, having to do with pressure-time constants, rates of rise of various things, triggering sensitivity, and so forth. One message that I hear is that we need to look more directly at what the patient is experiencing, and we have perhaps just been assuming that our measures of things that are much easier to assess are telling us that kind of information. I think perhaps they are not.

Hansen-Flaschen: “Patient-centered mechanical ventilation” would be the current vogue term for an approach that says “Without compromising this individual’s opportunity to recover, let’s choose the mode and set the settings to the patient’s comfort.” And to do that we would simply need to establish a reasonable, even rough, communication across the transaryngeal tube or the tracheostomy. Then, with communications established, we would have to take a few extra moments to set the ventilator to maximize the patient’s comfort.

Manning: About two years ago, I was asked to give a talk on the same topic, so it was reassuring to me to see that you found the same paucity of evidence that I did. I remember thinking to myself, “What am I going to say after the first 5 minutes and I’ve reviewed all the relevant studies?” You raise the question about how often there is clinically relevant dyspnea in the intensive care unit [ICU] and whether the things we do can affect that. Although I don’t think there are any data that bear directly on that, I think—extrapolating from studies done in normal subjects—it’s clear that it is possible to induce extreme discomfort by an adverse pattern of mechanical ventilation. There have been lots of studies in normal subjects, using various models of experimentally-induced dyspnea, and they’ve all had a common finding, that when you deviate from what the subject wants, dyspnea results, and it can often be severe. The general notion has been referred to as neuroventilatory dissociation. Under any given set of circumstances, the brain is sending out motor signals to the respiratory muscles and receiving different types of afferent feedback, and it expects a certain result. If it doesn’t get that, discomfort results. It’s kind of like the rest of life: if you don’t get what you want, you’re unhappy. So I think the discomfort can be severe, and, again, I don’t know how prevalent it is.

I think you can do a little experiment in yourself to convince yourself what a pattern of ventilation that’s different from what you want causes. If you’re sitting here breathing with a relatively low respiratory rate and a relatively small tidal volume, you’re perfectly comfortable. If you now go for a two mile run and have increased ventilatory requirements, if you try to reproduce the same breathing pattern, even for a matter of 10 seconds, which is far too short to have your arterial carbon dioxide tension rise or your arterial oxygen tension drop, you’ll experience severe discomfort. In fact, I suspect that if you voluntarily try to constrain your tidal volume just sitting here for 10 or 15 seconds you’ll find that it’s uncomfortable. I think the observation is that when you get a pattern of ventilation that’s very different from what your brain wants under the circumstances—and that’s going to be based on many things, many pieces of information that your brain is integrating—if you get a pattern of ventilation that’s different, it causes significant discomfort.

Curtis: John, that was a really nice summary. I really liked your protocol as well; in fact, it would be great to see that in print because I think a lot of people need to see that, and it would be a good thing for teaching purposes. I guess I’ll challenge you to think about how that might change once a decision is made to withdraw life support. Are there different questions that we should be asking, and for those patients who are intermittently following some commands but not clearly communicative, should we be in the ICU trying to tell these people that we’re withdrawing life-support and explain that to them?

Hansen-Flaschen: Those are two really tough questions that I want to do a little thinking about myself. My first thought is that even after the decision to limit life-support I would think that people still want to be able to communicate their discomfort and have someone react to it, and they still want to know what’s going to happen next. There’s nothing about passing that threshold that would take away someone’s fear. How much should we tell a patient about a decision to withdraw mechanical ventilation? If the person is completely conscious and interactive and at a high level of understanding, I really don’t see any way to move forward without engaging them.
I’ve been impressed though, that confusion and delirium are ubiquitous in the type of patients you’re describing. Whereas psychiatrists teach themselves to assume that someone is competent and understanding and capable until they very convincingly prove otherwise, I have learned to suspect that patients are not clear-minded after several days of intensive care. I am not somebody who likes to walk in on a patient who’s breathing 60 times a minute and has been up for two straight nights and ask them “Do you want us to intubate you or not?” Particularly if the person is not clear-minded and not able to make a dispassionate judgment, the affirmative answer might simply mean “I’m short of breath: help me out here.” My answer to the second question is that I tend not to engage patients in decisions to limit life-support at the time that we’re making them unless I’m pretty confident that they have a full understanding and full judgment and full awareness, which is very unusual.

Fins: I really liked your question because it was so full of meaning. Is it the ventilator or is it you? Not only are you getting important diagnostic information, you’re acknowledging the presence of a human being on the other side of that piece of plastic, which we so often discount. I can just imagine the sense of vulnerability and isolation that even an intermittently thinking person would have in that situation. Eric Cassell has written about the nature of suffering. What he talks about, and what you have done in your attempt to find out and acknowledge the thinking person there, and giving them information about what’s going to happen that day, is relieve the suffering, which he describes as a fundamental threat to the self—the uncertainty of it all. He distinguishes that very clearly from pain, which is a physiologic phenomenon, and suffering, which is “When will this end? Will anyone be here to see me?” And with that simple question you’re really addressing that profound isolation, and you’ve acknowledged that person on the other side of the tube. I think it’s really laudatory.

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Hansen-Flaschen: I think a lot of us have a goal of using less sedating and analgesic drugs in mechanically ventilated patients. If we’re going to do that, we need to substitute some kind of discipline on communicating with our patients. My discipline right now is to ask what bothers them, and tell them what’s coming ahead. Will that be part of the strategy that will allow us to be more confident about using lower doses of sedating drugs?

Rubenfeld: That was running through my mind too—the lightening of sedation—and I know you’ve recently given this some thought. Do you have any comments on the interaction between arguments to use less sedation in the ICU and the role of the ventilator or even the role of substituting our interaction with the patient for lower doses of narcotics?

Hoffner: I think the theme of communication is important, and we used that over the years as one of the arguments to consider tracheotomy earlier than in the 1970s and 1980s, when delaying tracheotomy as long as possible was in vogue. Enhancing communication is a real value of the procedure. Tracheotomy earlier in the course of ventilated patients may improve comfort and decrease the need for heavy sedation, which has been identified as a risk factor for pneumonia. Tracheotomy is a “comfort” measure that may have adjuvant benefits that go beyond comfort in decreasing sedation and decreasing the attendant complications of sedation such as nosocomial pneumonia. In the last decade, speech therapists have included communication for ventilated patients as a part of their practice. I have gotten a lot of assistance from speech therapists for ventilated patients and have them come in as consultants to advise us as to how to assist patients to communicate their needs, but it still remains an incredible challenge.

Hansen-Flaschen: I agree on both points. For the last 10 or 15 years, in comparing translaryngeal intubation against tracheostomy, people have focused on the standard complications—the injury to the larynx, the bleeding, and things like that, and have not been able to find much of a difference. We’ve got to put that aside now. We put a tracheostomy in for the patient’s comfort—so the question here is which approach promotes greater comfort, greater communication, and less need for sedation and analgesia? When you ask the question that way, empirically before the studies are done, I think you tend toward earlier tracheostomy than we were practicing before. So I agree with you.

Rubenfeld: Thank you very much. I had at least two “Ah Ha!” experiences during your talk. I think patient-centered mechanical ventilation would make a really stupendous editorial. I recently reviewed some of this literature too, for a talk at ATS [American Thoracic Society], and came to the same sorts of conclusions—that the outcomes measured in studies in mechanical ventilation are really disappointing. If we don’t have compelling evidence (and I would say we don’t) that these different modes and triggering, etc., reduce the duration of mechanical ventilation or improve survival, then comfort really becomes a primary goal. It may be the case that what you and Hal [Manning] have suggested, which is that we simply ask patients which of the modes is most comfortable, may be an approach to it. The comment I wanted to make, because David [Pierson] has actually been struggling for an argument for
Hansen-Flaschen: How many outcome studies have compared noninvasive mechanical ventilation and translaryngeal intubation with mechanical ventilation? How many of those included a rigorous measurement of dyspnea? Or even the need for sedating drugs and analgesia? We’re missing one of the most important outcome measures for ICU interventions by passing this by.

Levy: What really illustrates the importance of what you’re talking about is the recent data that were presented by Jesse Hall’s group at ATS and were published in the New England Journal of Medicine.1 Everybody was very excited because of the huge difference in outcomes between two groups—one of which had daily discontinuation of continuous infusion of sedation, but what got lost in the presentation at the session was the percent days awake per patient. They found that in the control group patients spent 9% of their ICU days awake, while in the stop group it was 85%. The feeling in the room was that this is great. People were awake. A few of us stood up and said, “Oh, wait a minute. Are we sure this is really good?” And it’s particularly true since we don’t have a good way to communicate with them. So the assumption that being awake 85% of the time is a good thing is really suspect.

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Hansen-Flaschen: I think that a tube through the larynx is really uncomfortable. We have to be sure we don’t go over to the other side and cause a lot of pain there in a campaign to stomp out sedation.

Manning: One last point. I would caution against saying that small tidal volumes are uncomfortable. I think it would be fairer to say that a smaller tidal volume than the person desires produces discomfort. For some reason, patients with muscular disease often seem to desire large tidal volumes. I took care of a couple of high level quadriplegics, including a couple who were in the study, and some of them wanted tidal volumes in the 1.5–2 L range, which resulted in chronic end-tidal carbon dioxide tensions of 10–15 mm Hg. What the reason for that was I’m not sure, but the fact is that, if you give them a smaller tidal volume than they desire, they become very short of breath. But I don’t think we can make the blanket statement that patients who get small tidal volumes are going to be more dyspneic.
The Respiratory Therapist and Palliative Care

Melaine Giordano MS RN CPFT

Introduction

Just the Facts
Where Is the Respiratory Therapist?
Palliative Care Education
Principles of Palliative Care
Symptom Management
Assessment Skills
Geriatric Education
Ethical Issues
Cultural Issues
Grief and Bereavement
Effective Communication
Where Do We Go from Here?

Key words: respiratory therapist, palliative care, end-of-life care, education, geriatric. [Respir Care 2000;45(12):1468–1474]

“The art of living well and dying well are one.”
—Epicurus

Introduction

End-of-life care has become a prominent topic in the public sector as well as within the health care community. Numerous stories depicting the plight of the dying can be readily accessed in the media. Mitch Albom’s best-selling novel, Tuesdays with Morrie, tells the story of a young man’s last 14 visits with an older professor whom he had befriended as a college student and who was on his end-of-life journey.1 Mitch’s mentor, Morrie Schwartz, experienced a “good death,” living out his final days with dignity in his own home surrounded by people he loved. The heartfelt book was a success; it remains on the best seller list and was made into a television movie.

Not all end-of-life stories are as gratifying as the one portrayed by Mitch Albom. For many people the end-of-life journey is a living nightmare. The dramas of prolonged futile life-sustaining measures (often against the patient’s or family’s wishes), lengthy illnesses with slow deterioration, uncontrolled pain in the final days of life, and the loss of bodily functions are often in the news and frequently witnessed by respiratory therapists (RTs).2

No one profession is more intimately involved with end-of-life care than the health care professionals. This is especially true for those who are employed in acute care or long-term care facilities, as over 75% of all deaths (in excess of 1.7 million) in the United States occur in health care facilities.2

There are over 100,000 RTs in the United States who evaluate, treat, educate, and care for people with pulmonary disease and/or pulmonary complications. RTs can be found working throughout the health care continuum, including acute care facilities, rehabilitation units, long-term care facilities, home health agencies, physician offices, and medical equipment companies. However, 75.5% of RTs work in acute care settings, particularly in critical care areas such as the intensive care unit (ICU), emergency department, recovery room, or neonatal unit, where end-of-life care is a daily event.3

Yet RTs are curiously absent in publications dealing with palliative care and end-of-life care (Table 1), despite the fact that lung disease is the fourth leading cause of death in the United States.4–7 The search terms I used in the MEDLINE review for this report were “palliative care,”

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A version of this paper was presented by Ms Giordano during the Respiratory Care Journal Conference, Palliative Respiratory Care, held May 19–21, 2000, in Cancún, Mexico.

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THE RESPIRATORY THERAPIST AND PALLIATIVE CARE

Table 1. MEDLINE Citations to Articles on Palliative Care and Related Topics According to Different Types of Caregiver

<table>
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<tr>
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<td>Clergy</td>
<td>5</td>
</tr>
<tr>
<td>Social worker</td>
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</tr>
<tr>
<td>Volunteers</td>
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</tr>
<tr>
<td>Physical therapist</td>
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</tr>
<tr>
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<td>Physician</td>
<td>223</td>
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<tr>
<td>Nurse</td>
<td>289</td>
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“end-of-life care,” and “hospice,” coupled with the professional terms “physician/doctor,” “respiratory therapist/respiratory care practitioner/RT/respiratory therapy, nurse/nursing,” and “physical therapy/physical therapist.” The physicians, volunteers, physical therapists, nurses, social workers, and family members are the individuals consistently portrayed as members of the multidisciplinary palliative care team.2,8-17

Once I completed the MEDLINE search, I called fellow long-time RTs to ask their opinions on the role of the RT in palliative care. To my amazement, the response was “not much, as most RTs are not involved in hospice care, unless they work in the home care setting.” This misconception is detrimental to the respiratory profession, as everything points to the fact that RTs are intimately involved in providing palliative care.

Just the Facts

Over 350,000 deaths (1 in 7 deaths) in 1997 were the result of lung disease: lung cancer accounted for 156,900 deaths, chronic obstructive pulmonary disease (COPD) 109,029, and pneumonia/influenza 82,448.4-7,18 While mortality rates for heart disease, stroke, and cancer have steadily decreased in the last 20 years, mortality rates for lung disease have been increasing. Lung cancer is the leading cause of cancer deaths in women, surpassing deaths from breast cancer and increasing 249% from 1973 to 1994.5 Deaths from COPD increased 119% from 1979 to 1997.4,7 Death from respiratory-related disease processes is evident in nearly all age groups, especially the 65 years and older cohort.5,18 The number of respiratory-related deaths will continue to increase with the aging population, lifestyle choices (smoking), and environmental pollution.

More chilling is the prevalence of lung disease in the American population. Over 164,000 new cases of lung cancer were diagnosed in 1997—28% of cancers.5 It is estimated that 16 million (the numbers may be as high as 35 million) suffer from COPD.4,7

Pulmonary diseases are often chronic and life-limiting, requiring care over a period of years, in a variety of health care settings.6,19,20 Individuals with lung cancer have relative short life expectancies: 5-year survival is less than 15%. The median survival for COPD is 10 years for patients who have lost two thirds of “normal” expected lung function at diagnosis.19 Through the course of the lung disease, individuals will suffer with such symptoms as dyspnea, anxiety, pain, fatigue, anorexia, and/or confusion. Palliative care interventions are needed at various junctures of the disease process, and often the end stage of COPD continues for years.20-24

Where Is the Respiratory Therapist?

Studies conducted across the health care continuum have repeatedly demonstrated that the care provided by RTs improves patient outcomes and is cost-effective.25-28 Because of reimbursement constraints, RTs are not readily accessible outside of the acute care setting, such as in home care or long-term care settings.3,17,28 This is unfortunate, because it denies patients with pulmonary disorders access to the practitioners (RTs) who are the best educated and skilled in the delivery of respiratory care.29-35 Comparative reviews of nursing and respiratory education curriculums show that RTs’ pulmonary education exceeds that of nurses (Fig. 1).34,35

Palliative Care Education

The question is, “Are RTs adequately educated and skilled in palliative care?” As with most health professions, the palliative care that RTs provide would be greatly enhanced by thorough instruction about the end of life. In early 2000, Rabow et al reported that in a review of 50 top-selling medical textbooks (multiple specialties) only 2% of the total pages were devoted to end-of-life care.36

It is not necessary to reinvent the wheel, as many resources have addressed the “ideal” needed education components for health care providers (Table 2). The following are highlights of an “ideal” palliative care curriculum.2,9,11-13,15,17,20,36-51

Principles of Palliative Care

As demonstrated earlier, the terms “hospice care” and “palliative care” are thought to be mutually exclusive end-of-life care concepts. They are not. Hospice is the terminal
or “dying” component of palliative care. The World Health Organization defines palliative care as “the study and management of patients with active, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.” Notice that this definition does not delineate a time frame for which care is to be rendered.

The absence of life expectancy criteria in palliative care is significant in the care of those with chronic disease processes, since chronic disease is characterized as a progressive deterioration of health, with periods of exacerbation, lasting for years before death ensues. Keep in mind that chronic-disease-related deaths account for nearly 72% of all deaths in the United States.

RTs are intimately involved in the care of the chronically ill, across the health care spectrum, providing care and education and advocating for patients and families. No doubt the quality of life of individuals who are suffering from the end stages of chronic disease would be greatly enhanced by palliative care delivered by RTs, care that addresses the physical, emotional, psychological, and spiritual needs of the dying and their loved ones. However, we could do a better job for our patients by enhancing our knowledge of palliative care.

Early in our education we are taught to preserve life by using the latest in medical technology. RTs must understand that the palliative care they provide must be guided by patients’ and families’ health care wishes and not by the technological equipment that is at our disposal. This is not to say that we should hasten death, but, unfortunately, so often we turn to life-extending technology to provide end-of-life care that is not congruent with the wishes of the patient. An awareness of the wishes of the patient will allow RTs to deliver palliative care that is beneficial to patients and additionally to be viable members of the interdisciplinary care team.

**Symptom Management**

Symptom management is the hallmark of palliative care. Symptoms such as pain, fatigue, weakness, anorexia, constipation, confusion, dyspnea, anxiety, depression, and anger are frequently encountered by those with life-limiting illnesses. Perhaps the two most distressing symptoms, particularly with pulmonary patients, are pain and dyspnea. Uncontrolled pain and dyspnea are quite disturbing to patients, as well as to those witnessing the distress. As mentioned in other papers from this conference, the RT can have a positive effect in assessing and controlling dyspnea, pain, and other symptoms associated with the end of life. An area of study that the RT should be familiar with is the utilization of “alternative” medicine techniques for symptom management, such as music therapy, massage therapy, pet therapy, biofeedback, aromatherapy, body positioning, and communication.

**Assessment Skills**

RTs spend a tremendous amount of time at the patient’s bedside, which allows the RT to establish a trusting relationship with the patient and, frequently, the patient’s family. These relationships provide a unique opportunity for thoughtful and insightful assessments of the patient’s physical, functional, environmental, and psychological status. Information obtained from these relationships will enhance the care provided to the patient and will, hopefully, reflect the desires of the patient. An additional consequence of obtaining reliable clinical information is being recognized as a competent and indispensable member of the health care team.

**Geriatric Education**

Medical technology has helped to postpone death: persons surviving to age 65 years today can expect to live, on average, another 18 years. Yet as one ages the probability increases of developing lengthy chronic illness. The aging trend is especially important to the future of the health care system, because older people suffer from comorbid illnesses, proportionately access more health care services, are often economically deprived, and experience

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Table 2. Components of a Curriculum in Palliative Care for Respiratory Therapists

<table>
<thead>
<tr>
<th>Number</th>
<th>Component</th>
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<tbody>
<tr>
<td>1</td>
<td>Principles of palliative care</td>
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<td>2</td>
<td>Assessment skills</td>
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<td>3</td>
<td>Geriatric education</td>
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<tr>
<td>4</td>
<td>Ethical issues</td>
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<td>7</td>
<td>Grief and bereavement</td>
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<tr>
<td>8</td>
<td>Effective communication</td>
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</tbody>
</table>

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**Fig. 1.** Comparison of clinical and classroom instruction in 4 core topics (mechanical ventilation, aerosol therapy, metered-dose inhaler use and instruction, and oxygen administration) in nursing and respiratory schools. (Adapted from Reference 34.)
functional, sensory, and cognitive declines.\(^{57,58}\) Additionally, the older population currently accounts for over 78% of all deaths in the United States.\(^{18,56}\)

Providing quality care to the chronically and terminally ill will be one of the great challenges of the 21st century. The old adage, "You ain't see nothin' yet!" certainly applies here, as the graying of the population will cause future mortality numbers to soar.

Currently, health care professionals are poorly instructed in geriatric care. Few education programs, medical, or nursing programs offer direct teaching in the care of the geriatric patient.\(^{40-51,57,58}\) Failure to educate RTs (both students and practitioners) in the core essentials of geriatric care (Table 3) will doom the profession to languish behind health professionals who have pursued the knowledge and skills needed to deliver effective and efficient care to older patients.

### Ethical Issues

One of the most difficult assignments that RTs encounter is withdrawing life-support from a patient they have cared for. It is a highly charged emotional event for the health care team, as well as for the patient's loved ones. Clearly, the RT must be educated in the precarious nature of end-of-life decisions made by the patients, families, medical colleagues, and their own personal feelings regarding these decisions.

Medical decisions in end-of-life care, even when they differ from one's own personal values or beliefs, must be respected, since these are the patient's and/or family's wishes based on cultural, religious, ethnic, and personal perceptions. As many of us know, death is not always a "bad" thing. Helping patients achieve a "good death" in their last journey can be a fulfilling experience for the RT, health care team, and the patients' loved ones.

### Cultural Issues

Medical decisions made by our patients and families may be inconsistent with our own values; however, these decisions should be honored whenever possible. Cultural and ethnic values as well as our own personal experiences and perceptions form health care beliefs. Developing an awareness of the cultural practices of your community will not only enhance your understanding of their health care beliefs and rituals; it will also strengthen your acceptance of the cultural differences.

### Grief and Bereavement

The death of a loved one, whether it is unexpected or anticipated, is a painful and distressing event. Not unlike our patients' families, we experience sorrow over the loss of the patients we come to know. There are no magic formulas to deal with the grief that is felt at the loss of life, nor are there defined time tables to the period of mourning experienced by individuals.

However, there are many resources available to increase your understanding of death, dying, and the bereavement process, for all age groups (see Appendix). An understanding of the dynamics of death and loss will provide the RT with the resources to reconcile his or her personal feelings as well as provide support to patients and families.

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**Table 3. Core Essentials of Geriatric Care**

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<td>V.</td>
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<td>VII.</td>
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<td>B.</td>
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<td>D.</td>
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<td>Dementia</td>
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<td>IX.</td>
<td>Psychology of aging</td>
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Effective Communication

As mentioned earlier, RTs provide direct patient care, and providing this care necessitates a great deal of time at the bedside or at the patient’s home. These bedside/home encounters allow the formation of relationships and trust, which in turn can facilitate open flow of communication between the RT and the patient and the patient’s loved ones. The RT can utilize these relationships to communicate effectively to the patient and caregivers regarding respiratory health care education. Additionally, the RT often serves as an advocate for the patient by communicating the concerns or wishes of the patient or family or caregivers to other health care team members. Effective communication between all health care team members and the patient and family is essential in the provision of palliative care. Failure to include all members can result in misunderstandings and missed opportunities to fulfill the desires of the patient.

Where Do We Go from Here?

Members of the respiratory care community must commit themselves to providing quality palliative care at the end of life. Education and research are the keys to succeeding with this goal. Curriculums may be overcrowded, yet how can the education system overlook palliative care—care that the practitioner provides on a daily basis? Respiratory research has been technology-driven, but today it is imperative to research effort towards the efficacy of RTs in the delivery of palliative care and measures to improve the palliative care that is provided by the RT. The patients we care for deserve the best-educated and skilled providers to provide health care in their end-of-life journeys.

REFERENCES
35. Bohman J. Curriculum comparison between the associate degree nursing program and associate degree respiratory care programs in Oregon. Breath Sounds 1994;8:4-5.
Appendix

Palliative Care Advocacy Groups

American Academy of Hospice and Palliative Medicine (AAHPM)
4700 W Lake Avenue
Glenview IL 60025-1485
847/375-4712
http://www.aahpm.org

(Originally organized as the Academy of Hospice Physicians in 1988, AAHPM is dedicated to the advancement of hospice/palliative medicine and its practice, research, and education.)

The Association for Death Education and Counseling
342 North Main Street
West Hartford CT 06117-2507
860/586-7503
http://www.adec.org

(A multidisciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling, and care of the dying.)

Community-State Partnerships to Improve End-of-Life Care
Midwest Bioethics Center
1021-1025 Jefferson Street
Kansas City MO 64105
800/344-3829
816/221-1100
http://www.midbio.org

(A coalition working to promote policy change and support for high-quality, comprehensive end-of-life care.)

Hospice Foundation of America
2001 S Street NW, #300
Washington DC 20009
800/854-3402
http://hospicefoundation.org

(A not-for-profit organization that provides leadership in the development and application of hospice and its philosophy of care.)

Last Acts
The Robert Wood Johnson Foundation
PO Box 2316
Princeton NJ 08543-2316
609/243-5951
http://www.lastacts.org

(An unprecedented national effort to raise awareness of the need to improve care of the dying and to share issues and ideas at the national, state, and local levels.)

The National Hospice and Palliative Care Organization
1700 Diagonal Road, Suite 300
Alexandria VA 22314
703/243-5900
http://www.nho.org

(Dedicated to advancing the philosophy and practice of hospice care to meet the unique needs of each terminally ill person and his or her family and to serve as a voice and resource for its members.)

Partnership for Caring: America's Voices for the Dying
1035 30th Street NW
Washington DC 20007-3823
800/989-9455
http://www.partnershipforcaring.org

(A coalition of individual consumers, consumer organizations, health care professionals, and health care organizations advocating for needed changes in professional and public policy and health care systems to improve care for dying persons and their families.)
**Discussion**

**Benditt:** That was really great. I appreciated that very much. As the medical director of respiratory care at our hospital, I have felt this problem really keenly. I’m really fortunate to have a terrific therapist working with me—Louis Boitano. I have encouraged the staff of our department to concentrate on their assessment skills, because I think that’s the initial step in getting them ready to really assume the role of a practitioner—of someone who can assess and then treat. Obviously, regulation issues are involved, as well as the support of respiratory care directors. RT assessment skills are really crucial and are the first step in moving forward.

**Tudy Giordano:** You can alleviate a lot of problems down the road if you have a therapist whom you trust and who you know is assessing the older patients correctly. They (along with family members) are the ones who deal with and know the disease process, and they know the patient and family. Appropriate assessment of an older person, whether in the terminal phase or into the chronic phase is very important. If you don’t know what the normal physiological changes are in an older person, you will not be able to accurately assess the health status of that patient. Take, for example, pneumonia identification. As you age, your normal basal temperature is lower. So when an older patient comes to the emergency room with temperature of 98.6°F, you might think nothing’s wrong with them and send them home, but they might have a flaring case of pneumonia.

**Heffner:** That was a very stimulating presentation. If there’s one thing I’ve been impressed with about respiratory therapists, it’s that they’re wonderful patient advocates and are also fairly fluid in the application of their skills. In a lot of the medical centers we look to respiratory therapy for ECMO [extra corporeal membrane oxygenation] directors and hemodynamic monitoring personnel. Could we anticipate that respiratory therapists could assume, as part of their domain, expertise in assessing dyspnea and communication needs? They could supply us with the needed skills to advocate for patients and promote the fulfillment of their needs.

**Tudy Giordano:** I would hope so. The RT has the clinical skills to assess the patient and, in turn, report their findings to the appropriate physician. I remember a patient in the home who was failing terribly. It wasn’t until I kept calling the physician saying, “You need to see this gentleman in your office or you’ll be seeing him in your hospital on a vent.” So, yes, I think I averted an emergency admission for the man. It was a simple phone call, but it was the assessment that did it. I knew what to look for. I don’t think your average nurse would have identified the signs and symptoms of impending respiratory failure that this particular man was demonstrating. The assessment skills of a therapist are invaluable. I know there are therapists who are better than others, but you know which ones those are. Use them. They want to be used.

**Silvestri:** I want to also say that I think there is tremendous variation with palliative care among respiratory therapists. I’m medical director at our facility. We have a hundred full timers and respiratory therapists for our children and adult hospital. We have completely adopted Jamie Stoller’s therapist-driven protocols and have assessors all over the place. We have them in the sleep lab; we have them going into the home now; and they have an incredibly active role in palliative care. I just don’t think it’s been documented. Probably if you went out and looked, if you asked the respiratory therapists at Cleveland Clinic Foundation if they believed they were a vital part of the palliation team as a respiratory therapist, they’d probably uniformly say, “Yes.” At least I hope they would.

**Tudy Giordano:** They would say, “In the hospital.”

**Silvestri:** In the hospital, but also respiratory therapists are now being hired in droves by home care companies, and they’re setting up continuous positive airway pressure and bilevel positive airway pressure in the home and doing all kinds of care. Now, they may not be doing some of the things you’d like to see them doing.

**Tudy Giordano:** I’d like to see them set up the home nebulizer units, ventilator management, and instruct patients in their disease processes and appropriate treatment, including medication administration. But that’s not always happening.

**Silvestri:** I think you’d be surprised at how many are.

**Rubenfeld:** Let me just follow up on that. This is a great question for some empirical study. This is one of the great opportunities for respiratory care in the future. In our area they are active, and I think one of the reasons for this conference is that they are active in skilled nursing facilities, and you pointed that out. RTs are active in the home setting, the acute care hospital, and the outpatient clinic. How much they’re active, and what sorts of different places, I don’t know.

**Tudy Giordano:** I think you’d be surprised at how little they are out there. I can tell you a story about an encounter I had at a skilled nursing facility. I did not go in as a therapist or a nurse. I went in as a long-term care ombudsman. I was a volunteer for the state of Texas, and I went into nursing homes to take complaints from patients and help them resolve their complaints.
After I had left the program, I got a call from the director of the program, who said, "Would you come back and look at this resident who is on a ventilator?" I said, "Yes, I'd love to." She said, "We're having a little trouble trying to wean her off the vent." And they were having a lot of trouble. I went to the facility and found a non-responsive woman in her late 60s. I pulled back the sheets and saw that she had finger marks where they had been rolling her without a draw-sheet. The facility claimed that the reason she had those bruises was because of the steroids she'd been ingesting. After reviewing her chart, I found that she was being given 10 mg of Valium intervenous Q4, BuSpal, and Hakey. I asked, "Why are you doing that?" They replied they were trying to wean her off the vent. There wasn't a therapist employed at this particular facility. I think you'd be very shocked if you knew what was happening in long-term care facilities.

**Sam Giordano:** I want to comment on the penetration of respiratory therapists into alternative care settings. The fact is, it's sort of like the surf out there. The tide did come in, but because of the institution of the prospective payment system and skilled nursing, we estimate that about 70% of the therapists who were employed there 12-18 months ago are no longer there. Indeed, about half a dozen of the major national skilled nursing chains have filed Chapter 11.

This change is the result of inadequate reimbursement—clear and simple. It's not related to clinical outcomes whatsoever. In terms of home care, because of the ratcheting down of payments brought about by the Balanced Budget Act of 1997, there's been a terrific retreat in terms of the number of home health agencies. Fewer exist, and positions have been cut—not just for respiratory therapists but for nurses also.

The squeeze also hit home with medical equipment providers, many of whom generally hire respiratory therapists. Moreover, because of these cuts (primarily in oxygen reimbursement), they've also had to eliminate positions. The AARC commissioned a survey to identify the number of respiratory therapists working in each care setting. The numbers are being crunched as we speak, and we should be able to present that report late this summer.1 This will be the first time that a comprehensive human resources study was ever done for respiratory therapists. Previous efforts were limited to therapists in hospital and education settings.

**REFERENCE**


**Tudy Giordano:** I can tell you that being in the jobs I've had—acute care, long-term care, rehab, and home care—they didn't hire me as a therapist. They hired my knowledge as a therapist, but I was hired as a nurse. It was the knowledge I had as a therapist that they wanted. The RT offers an immense amount of knowledge to the health care team. Wouldn't you rather send out a respiratory therapist than a diabetes nurse to see your patients (not to say anything had about diabetes nurses)? Nurses don't have the clinical expertise the respiratory therapist has. In nursing school I think I got maybe an hour devoted to "respiratory care."

**Curtis:** There's been a big push recently to put more palliative medicine curriculum into medical schools and medical textbooks.1 I wonder if you think there needs to be a similar push in the training of respiratory care practitioners, and if so whether you think there will be a big barrier or resistance to doing that on the part of schools.

**Tudy Giordano:** I'm speaking strictly from my own desire for knowledge. If I was offered that knowledge when I came through a nursing school (I was an OJT [on-the-job trainee]) I would have loved to have gained better understanding of end-of-life care. I remember taking care of my very first patient who I knew (naively) was dying. She was a postop craniotomy and had a tracheostomy. I'd drag those tanks down in the middle of the night—big H cylinders—and change out the trach mask. She'd blink her eyes, and I kept thinking, "What's going on with her? What's she doing? Does she hear me?" All the while I was wishing I knew more. I know I could have been a better therapist and a nurse had I been trained in palliative care.

**Levy:** Is there resistance in the schools?

**Tudy Giordano:** Probably. I think the curricula are crammed. Helen [Sorenson] and I are gerontologists. We've had a very difficult time getting geriatrics included in the curriculum. Respiratory care curricula include neonatal and pediatrics, but who are the vast majority of patients the RT cares for? Older people and dying patients.

**Pierson:** One thing evident on one of your slides was the tremendous number of hours of training on mechanical ventilation that respiratory therapists get in school. Coming back to Gordon's [Rubenfeld] presentation on the withdrawal of life-sustaining

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Sam Giordano MBA RRT FAARC, Executive Director, American Association for Respiratory Care, Dallas, Texas.
treatment, and particularly the discontinue of ventilatory support and airway protection, I would bet that those things are actually physically done in the United States by respiratory therapists more often than they are done by doctors. Perhaps at least that aspect of palliative care should be incorporated into some of the mechanical ventilation training, and also in the physical assessment skills, on which they also get a fair number of hours. Clearly, it is something respiratory therapists are very much involved in the present day. It’s just that it is not acknowledged as such, and they’re not instructed in it.

**Tudy Giordano:** I kind of get that Rodney Daingerfield thought: “I don’t get no respect.” I do think the RT feels that way a lot of times—the little scenario we talked about, calling the respiratory therapist in to take out the vent—you have cared for this patient, you know this patient and the family, and now all they want is for me to come “take the garbage out.” It can be very hard for a therapist. But they do have the skills and knowledge, as Dave [Pierson] clearly pointed out. In their knowledge base, they are the ones who know airway maintenance.
Palliative Home Care for Advanced Lung Disease

John H Hansen-Flaschen MD

Introduction
Prognosis
Advance Medical Planning
Hospice Home Care
Symptom Management
Dying at Home

Key words: palliative care, terminal care, treatment refusal, dyspnea, advance directive, living will, hospice, obstructive lung disease, interstitial lung disease, respiratory tract disease, hypertension, pulmonary, life support, mechanical ventilation. [Resp Care 2000;45(12):1478–1486]

Although chronic lung disease is the fourth leading nontraumatic cause of death in the United States, remarkably little research has been published on the palliative care of this group of patients. Recent identification of 6 attributes of a “good death,” derived from interviews with terminally ill patients and their caregivers, provides a framework for an empirical approach to the medical care of patients who die because of chronic lung disease. Palliation begins with frank disclosure of a poor prognosis based on statistical evidence and expressed without undue “framing.” Given the uncertainty of prognosis for most chronic lung diseases, medical advance planning for end-of-life care should be encouraged when the median survival of a group of similarly affected patients is one year or less. Medical advance planning is best pursued on an outpatient basis as a 3-way conversation between patient, closest family member, and physician. Discussions should cover home versus institutional care, selection of home and institutional care providers, preferences for initiation and continuation of life support, and response of home caregivers to frightening untoward events—the “what ifs.” Hospice referral should be considered when a terminally ill patient is generally confined to bedroom or bed and is declining. Symptom management should address dyspnea, cough, pain, insomnia, anxiety, depression, and delirium. Because sustained dyspnea at rest is distressing to caregivers as well as to patients, and is difficult to manage, the option of terminal hospital care should be kept open, even for those who express a preference to die at home.

Introduction

Current definitions of palliative care refer to medical or nursing interventions that alleviate symptoms without im-
Palliative Home Care for Advanced Lung Disease

Rather than the duration of further survival. Life-prolonging interventions are generally foregone in favor of patient comfort and hygiene. The therapeutic armamentarium and the "rules" of care change accordingly.

Until the past few years, surprisingly little has been written on the subject of palliative care for patients with advanced lung disease, especially considering that chronic obstructive pulmonary disease (COPD) and related diseases are the fourth leading nontraumatic cause of death in the United States, across all age groups.\(^2\) Research on palliation of advanced lung disease has been almost as scarce. Only in the past decade have scientific techniques been developed for evaluating symptoms, clinical decision-making, and quality of life in chronically or terminally ill patients. Until those techniques are applied in carefully designed therapeutic trials, the palliative care of patients with advanced lung disease will remain largely empiric.

This article outlines an approach to the palliative home care of patients who are dying of advanced lung disease. The recommendations that follow focus primarily on the role of physicians; however, respiratory therapists (RTs) and nurses also play key roles in comprehensive palliative care of this patient group.

Prognosis

Consideration of palliative care begins with a frank discussion about prognosis. For at least 2,500 years, the thoughtful provision of an accurate medical prognosis has been one of the most important and difficult services provided by physicians. In the 5th century BC, Hippocratic physicians distinguished themselves from other competing schools of health care largely by offering their patients a prognosis that was based on an understanding of disease as a natural process. At that time, a physician's reputation was determined largely by his ability to predict the outcome of an illness or injury. Even to this day, patients judge physicians to a considerable extent by how well or poorly we address the question of prognosis.

Yet remarkably, for many years, until the mid 1960s, physicians in the United States routinely withheld a poor prognosis from their patients to spare them the pain of bad news. The doctor, the close family, and usually also the patient knew or sensed what was to come, yet all refrained, by convention or agreement, from discussing the subject of death with one another. Today, routine disclosure of diagnosis and prognosis is the standard of practice across North America and Western Europe. However, many physicians in Eastern Europe, South America, and the Far East continue to withhold or soften disclosure of a fatal prognosis. Some people who come from those regions still expect physicians in western nations to do the same.

Thus, physicians who advocate full disclosure are sometimes asked by family members to refrain from revealing knowledge of a terminal condition to a patient. Occasionally, a patient indicates directly or through a family member the desire not to hear bad news. How should a physician respond to those requests? One approach is to consider the adverse effects on the patient or the physician-patient relationship of withholding material information. Might the withholding of the diagnosis or prognosis undermine the patient's trust in the physician? Will the patient or others be placed unknowingly at risk from certain behaviors that are not appropriate for the diagnosis or prognosis? Will the physician be restrained from answering questions about the purpose of proposed or potential future medical interventions? Will the patient not be able to participate in important decisions about his or her medical care or personal affairs?

Under some circumstances, the answers to these and other related questions may be "No." For example, if the physician is asked as a one-time consultant to provide an opinion on a specific issue not directly related to a terminal condition or prognosis, or if a hospitalized patient requires urgent attention for severe distress or is cognitively impaired, disclosure of the overall prognosis might not be immediately relevant to the task at hand. In such situations, it may be reasonable for the physician not to volunteer information about prognosis, while still reserving the authority to answer questions honestly and completely if asked directly by the patient.

If the withholding of information about diagnosis or prognosis is likely to compromise a continuing relationship between physician and patient, the physician should ask why he or she is being asked not to provide the information. The discussion that ensues may lead to a mutually acceptable plan. If not, the physician might best serve the patient by declining to enter into an ongoing professional relationship: "I feel so strongly about this that I am probably not the right doctor for your relative. If you wish, I will see him this once to answer his questions and yours."

Most patients do want to know the diagnosis and the future implications of their respiratory disease. Unfortunately, relative to cancer, the prognosis for many chronic progressive lung diseases is highly uncertain.\(^3-5\) COPD in particular progresses at a slow rate that varies considerably among individuals and within individuals over time. Most patients who suffer from COPD die, not from intractable respiratory failure, but instead from other intercurrent acute or chronic conditions such as cardiovascular disease or pneumonia. For that reason, the 95% confidence interval around the median survival of a group of patients with a given respiratory condition may be so broad as to preclude an accurate prediction of survival for an individual patient.

Estimation of prognosis begins with identification of a cumulative survival curve for a group of patients who are most comparable to the individual patient. The expected median survival can be adjusted to a limited extent by additional knowledge about the patient, such as age, cur-
rent performance status, rate of progression of disease, or intercurrent illness. For example, the median survival for patients with the usual interstitial pneumonitis form of idiopathic pulmonary fibrosis is about 2.9 years. If a patient with advanced idiopathic pulmonary fibrosis also has severe, 3-vessel coronary artery disease and uncontrolled angina, the median survival for a similarly afflicted group of patients is likely to be less than 2 years. This information should be presented to the patient in a straightforward manner that is not framed to encourage a false impression. For example, “About half of patients with your condition will live longer than 2 years, and some will live 4–5 years or longer. Half live less than 2 years. And some may die within weeks or months.” Information about prognosis for a terminal condition is so important and so readily misinterpreted that it is useful to test the patient’s comprehension later in the conversation, “I want to be sure that you understand. How would you explain your prognosis to someone else?”

**Advance Medical Planning**

Frank disclosure of a poor prognosis opens the door for additional discussions with patients and family members regarding palliative and terminal care. The most appropriate month or day may not be predictable, but the desirability of a transition to palliation as the primary goal of care can be anticipated for most patients who have progressive, irreversible lung disease. Unfortunately, physicians tend to delay substantive discussions regarding terminal care. A recent survey of Canadian pulmonologists revealed that those clinicians often initiated discussions about mechanical ventilation late in the progression of advanced lung disease, if at all.

For more than 20 years, the primary tool in the United States for planning care near the end of life has been the medical advance directive. These legal documents were introduced in the late 1970s as a way for physicians to obtain protection from litigation and prosecution in the event that life-supporting medical therapy is withheld or withdrawn at the request of a patient or designated surrogate. Thousands of court cases later, the fear of legal sanction that gave rise to these documents is no longer justified in the United States, provided that physicians act in the best interests of their patients with full regard for their expressed or imputed wishes. From a current perspective, conventional written directives perform a limited planning function at best. Standardized, preprinted forms, signed at the kitchen table and filed away in safe deposit boxes, frequently enter late into medical decision-making, if at all. Except for some patients who fall unexpectedly into permanent unconsciousness, standardized medical directives often serve to validate rather than to drive decisions made for patients by others.

The legal approach to advance planning for pre-terminal health care is giving way to a medical approach that is constrained but not dictated by legal concerns. The medical approach described below, which emphasizes continuing communication between physician, patient, and proxy, is derived from the author’s personal experience as well as the recent medical literature. This approach is appropriate for patients who have an appreciable chance of dying from a chronic or progressive lung disease within the next year, and for patients with advanced lung disease who are contemplating a major therapeutic intervention such as lung transplantation or lung volume reduction surgery.

Medical advance planning begins in earnest with a 3-way conversation between the patient, the patient’s designated medical proxy, and the patient’s principle physician (whether generalist or specialist). If the patient raises the issue of advance planning during a brief outpatient or hospital visit, the physician should propose that such a meeting be scheduled separately so that sufficient time is available for discussion. If the patient does not raise the subject, the physician should do so. In a recent survey of pulmonary rehabilitation patients, virtually all of the study participants expressed interest in discussing end-of-life decisions with their physicians. The issue can often be raised without implying that death is imminent by stating simply, “It is wise to hope for and expect the best, but it is also wise to prepare for the worst.”

Older patients are often receptive to advance planning for end-of-life care. In contrast, many younger adults are reluctant to discuss their own deaths or to plan for terminal care. Resistance is encountered not only in young adults who unexpectedly acquire a fatal disease such as cancer, but also in many who have always known that they are expected to die prematurely from an inherited disease such as cystic fibrosis or muscular dystrophy. The physician may raise the subject of advance medical planning with a young adult to a response of silence or a conversation-ending statement such as, “I don’t want to talk about that.” Patients should not be drawn reluctantly into advance medical planning. Instead, the physician might respond to initial resistance by saying, “If you want to talk with me about dying and what you would want, let me know, and we’ll set up a special time.” Under some circumstances, when important decisions are pressing, the physician might propose to the reluctant patient a separate meeting with close family members to help the physician plan his or her role in terminal care.

In the event that a 3-way meeting does take place in an outpatient setting, the physician should begin the discussion with a brief statement about the purpose of the meeting and the patient’s current condition or prognosis. Then the physician should turn to the patient with an open-ended invitation to speak: “I expect that you have been thinking about this meeting. What are your thoughts?” Other helpful, open-ended questions include, “What are your hopes for the future?” and “What are your greatest concerns and fears?”
Table 1. Components of a “Good Death”

Recent qualitative research has identified 6 attributes of a good death as commonly perceived by terminally ill patients and their caregivers:
1. Pain and symptom management. People fear dying unattended in distress.
2. Clear decision-making. Patients feel empowered by participating in treatment decisions.
3. Preparation for death. Many patients want to know what to expect during the course of their illness. They want to plan for the events that precede and follow death.
4. Completion. Completion includes faith and spiritual experiences, and also life review, resolution of conflicts, spending time with family and friends, and saying goodbye.
5. Contributing to others. Many people want to contribute to the well-being of others, even as they decline and die.
6. Affirmation of the whole person. Terminally ill patients appreciate empathic caregivers who understand their current condition in the context of their lives, values, and preferences as whole and unique persons.

Answers to these broad questions remind physicians that patients with advanced lung disease often have other concerns that may be more important to them than the technical aspects of medical care during their final days of life. The patient’s surrogate is given an opportunity to speak next. Finally, the physician raises or clarifies specific medical decisions that should be considered in advance.

Recent qualitative research focusing on patients enrolled in human immunodeficiency virus or oncology clinics and their caregivers has identified 6 concerns commonly associated with a “good death” (Table 1). While individual values and concerns may vary, knowledge of these commonly expressed themes can help physicians to formulate a framework for planning terminal care.

Table 2. Issues for Advanced Medical Planning

1. Discuss the most appropriate location for terminal care: the patient’s or a family member’s home versus an institutional setting.
2. Identify preferred providers for terminal home or institutional care:
   A. Home care organization
   B. Acute care hospital
   C. Skilled nursing facility
3. Determine patient preferences for initiation and termination of life-support:
   A. Should mechanical ventilation be initiated in the event of respiratory failure?
   B. Terminal withdrawal of life-support in the event of irreversible impaired consciousness?
   C. Terminal withdrawal versus institutional care in the event of prolonged dependency on mechanical ventilation?
4. Plan for anticipated “what ifs.” For example:
   A. “What if I find him unconscious on the kitchen floor?”
   B. “What if she starts coughing up blood again?”

Depending on the circumstances, 4 practical issues are often appropriate for shared decision-making between patient, family, and physician in meetings devoted to advance planning for terminal care (Table 2). First, is the patient likely to die at home or in an institutional setting? Many who express a desire to die at home considerably underestimate the associated effort and expense and the degree of expertise necessary to ensure their comfort and hygiene. Victims of advanced lung disease may be confined to bed on and off or continuously for weeks or months before they die. For some or much of this time, they cannot be left unattended. With rare exceptions, health insurance policies do not provide for prolonged, continuous bedside care at home. Because of work or family commitments or their own health care needs, many family members are ill-equipped to provide this level of home care for longer than a few days. Consequently, the physician should focus this component of medical advance planning on the caregiver(s). What level of care can they realistically support at home?

Often the appropriate answer is an open one that anticipates possible or probable conversion from home to institutional care at some time during the progression of the illness. Three-way agreement on this point helps to allay the guilt of family members if a patient who prefers home care ultimately dies in a hospital or a nursing home. This point also sets the stage for a second goal of medical advance planning, which is to identify preferred providers for home or institutional skilled nursing care. By preparing in advance, the patient and family members establish a relationship with one or more selected organizations that are then prepared to provide service on short notice. For a patient who is expected to die, a full service home care organization that includes an accredited hospice is generally most appropriate (see below).

Because patients with advanced lung disease rarely experience sudden cardiac arrest, discussions regarding cardiopulmonary resuscitation with this group of patients should focus primarily on ventilatory support. There are limited choices to consider, and these should be laid out in the same manner that a physician describes options for the treatment of lung cancer. A patient with advanced emphysema might, for example, be given the following options as a starting point for discussion:

1. Home care only.
2. Hospitalize if indicated for comfort care, but do not initiate mechanical ventilation or other major life support.
3. Initiate appropriate life-support, to be continued only so long as the physician and the proxy both believe there is a reasonable chance for recovery to functional independence.
4. Indefinite life-support so long as the patient retains cortical brain function, to be continued in a long-term nursing facility if necessary.
These options encompass a spectrum in the timing and circumstances of a transition from life-sustaining to palliative care that can be refined by further discussion. If the patient favors a limited trial of life-support (third option), the role of the patient, the proxy, and the physician in the decision to abandon the trial is clarified. If the patient chooses indefinite ventilatory support (fourth option), the potential impact of that decision on the patient’s financial resources and family should be discussed openly.

If the planning session predates major surgery, such as lung transplantation or lung volume reduction surgery, the physician should discuss the special considerations that apply to intraoperative and immediate postoperative care. In the perioperative period, the need for cardiopulmonary resuscitation or other life-supporting interventions often has a more favorable prognostic significance than at other times. Indeed, many surgeons and anesthesiologists consider perioperative life-support an integral component of the surgical procedure itself. If, as is often recommended, the patient’s general plans are to be suspended temporarily at the time of surgery, the transition back to the general plans should be discussed in advance.

Family members who provide home care for terminally ill patients are often concerned about certain “what ifs.” “What should I do if I find him unconscious on the kitchen floor?” “What if she starts coughing up blood again?” Not every eventuality can be anticipated and planned. Nevertheless, home caregivers appreciate guidance in advance on how they should respond if an uncontrolled or frightening situation develops suddenly or at an inconvenient hour. Who should be called? Should the patient be transported urgently to an emergency room? How should the patient’s preferences be communicated to emergency personnel? This planning is essential to respect the wishes of those patients who want to limit life-support, and particularly those who prefer to die at home.

Shortly after completion of initial discussions, the patient (ideally) or the proxy or physician should write a brief summary of the decisions that were made in the form of a letter or declaration. In addition to defining the role of the proxy and the primary physician in medical decision-making should the patient become incapacitated, the document lays out goals of therapy, limitations on treatment that can be identified in advance, and outcomes to be avoided. If circumstances warrant, the document can then be modified in form, with the help of an attorney, to meet the requirements of applicable state laws. In addition to the patient, both the proxy and the physician might also sign the document, indicating that they will do their best to ensure that the patient’s stated wishes are fulfilled. Copies should be filed by all 3 participants in readily assessable locations. If surgery is planned, a copy should be provided to the surgeon for further discussion during a preoperative meeting.

This approach offers several advantages. Unlike a standardized form completed at home, an advance planning agreement reached by 3-way discussion benefits from the guidance and advice of the physician and is tailored to the patient’s disease. Just as importantly, the initial discussion opens lines of communication among the 3 key decision-makers that can be continued for the duration of the patient’s life. During the planning discussion, the patient can ensure that both the proxy and the primary physician are in agreement with the plan. The 3-way discussion, as documented in the summary statement, serves as a foundation for negotiations between proxy and physician at the time decisions must be made, thereby maintaining focus on the patient’s preferences. Also, a written advance directive prepared in this way empowers the principle physician to play an active role in medical decisions if the patient is hospitalized under the care of another physician.

Hospice Home Care

As an alternative to terminal hospitalization, patients with advanced lung disease should be encouraged to consider hospice home care. The hospice movement developed in the United States primarily as an extension of medical oncology. Even today, many hospices report that most of their patients suffer from incurable cancer, even though terminally ill patients with diagnoses other than cancer are more likely to need specialized home care and professional assistance. Although most hospices welcome patients with other diagnoses, they receive relatively few referrals of patients with advanced lung disease. Indeed, patients with COPD constituted only 3.1% of a representative group of Medicare beneficiaries enrolled in hospice programs in 1990. The reason is unclear, but may relate in part to common misperceptions about hospice among physicians who care for patients with advanced lung disease.

Prior to enrollment in a hospice home care program, Medicare and most other insurers require that the patient sign an agreement indicating understanding and acceptance of the hospice approach to palliative health care. Also, the referring physician and the hospital medical director both must certify that the patient is expected to die within 6 months.

Because of the uncertainties associated with determining such a prognosis, in 1996 an expert committee of the National Hospice Organization issued criteria to help physicians identify patients with nonmalignant terminal illnesses, including advanced lung disease. In 1997 the Health Care Financing Administration codified the guidelines into auditables criteria by which Medicare intermediaries are to judge the appropriateness of hospice referral (Table 3).

Students and practitioners of respiratory medicine recognize inconsistencies within the Health Care Financing Administration hospice review policy for pulmonary diseases. The criteria are not evidence-based. Indeed, prog-
Table 3. United States Health Care Financing Administration’s Medical Review Policy for Hospice Referral

<table>
<thead>
<tr>
<th>Patients will be considered to be in the terminal stage of pulmonary disease (life expectancy of 6 months or less) if they meet the following criteria. The criteria refer to patients with various forms of advanced lung disease who eventually follow a final common pathway for end-stage pulmonary disease. (1 and 2 must be present. Documentation of 3, 4, and 5 will lend supporting documentation).</th>
</tr>
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<tbody>
<tr>
<td>1. Severe chronic lung disease as documented by both A and B:</td>
</tr>
<tr>
<td>A. Disabling dyspnea at rest, poorly responsive or unresponsive to bronchodilators, resulting in decreased functional capacity such as bed-to-chair existence, fatigue, and cough (documentation of FEV₁ after bronchodilator &lt; 30% of predicted is objective evidence of disabling dyspnea, but is not necessary to obtain).</td>
</tr>
<tr>
<td>B. Progression of end-stage pulmonary disease, as evidenced by increasing visits to the emergency department or hospitalizations for pulmonary infections and/or respiratory failure or increasing physician home visits prior to initial certification. (Documentation of serial decrease of FEV₁ &gt; 40 mL/min is objective evidence for disease progression, but is not necessary to obtain.)</td>
</tr>
<tr>
<td>2. Hypoxemia at rest on room air, as evidenced by PCO₂ &lt; 55 mm Hg or oxygen saturation ≤ 88% on supplemental oxygen, determined either via arterial blood gas measurement or oxygen saturation monitor, or hypercapnia, as evidenced by PCO₂ &gt; 50 mm Hg.</td>
</tr>
<tr>
<td>3. Right heart failure secondary to pulmonary disease (ie, not secondary to left heart disease or valvuleplasty).</td>
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<tr>
<td>4. Unintentional weight loss of &gt; 10% of body weight over the preceding 6 months.</td>
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<tr>
<td>5. Resting tachycardia: heart rate &gt; 100/min.</td>
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 FEV₁ = forced expiratory volume in the first second. PO₂ = partial pressure of oxygen. PCO₂ = partial pressure of carbon dioxide.

Palliative Home Care for Advanced Lung Disease

Nonspecific criteria derived from the guidelines failed to distinguish patients enrolled in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) who died within 6 months after hospital discharge from those who did not. Nevertheless, these criteria are used currently by the Office of Inspector General in an active campaign to reduce fraud and abuse by hospice organizations. Fortunately, there is no penalty to patients for failing to die within 6 months.

The Health Care Financing Administration review policy notwithstanding, patients with terminal advanced lung disease should be considered for hospice home care when their health is declining and they are largely confined to the bedroom or bed by weakness or extreme exertional dyspnea despite optimal treatment. At that point in the progression of chronic respiratory disease, many patients benefit from the specialized home care assessment and assistance provided by experienced hospice personnel.

In the United States, certified home hospices receive a fixed, daily payment from Medicare Part A for the comprehensive care of qualifying patients (approximately $100 per day for routine hospice home care and approximately $560 per day for short-term continuous home care). All medical expenses other than physician’s fees are covered by the payment, including the cost of medications, supplies, durable medical equipment, and long-term oxygen. Home assessment, education, and counseling are provided by nurses, social workers, dietary counselors, pastoral counselors, and therapists as appropriate. Telephone consultation and coordination of care is often available 24 hours a day. Home health aides are typically provided for 2 or 3 hours a day. Home nursing care may be available for up to 24 hours a day during a medical crisis. Some hospices provide volunteers for transportation to a doctor’s office or to cover family caregivers for short trips out of the house. Brief hospitalizations for symptom control and up to several days of inpatient respite care to provide caregivers with personal time may also be covered by the hospice program.

Hospice coverage lapses during longer-term residential care or acute care hospitalization for reasons other than palliation of the major illness. However, home hospice care can be renewed. Medicare covers unlimited extension of hospice service, provided the patient is recertified as terminally ill at periodic intervals. Many private insurers provide comparable coverage.

The flexibility of the Medicare hospice benefit serves many terminally ill patients well. Unfortunately, Medicare capitulated payments for hospice services work against some patients with advanced lung disease who are dependent on unusually expensive therapies. The high cost of home mechanical ventilation and of drugs such as nebulized tobramycin, transplant immunosuppression drugs, dornase alfa, and epothelin (prostacyclin) effectively preclude enrollment in hospice, especially for those who already incur the expense of home oxygen. Continuous intravenous prostacyclin infusion is especially problematic in that patients with severe pulmonary hypertension risk sudden death if this drug is discontinued, even momentarily. Thus, most Medicare patients with pulmonary hypertension must relinquish their hospice benefit for life in order to receive the current drug of choice for their disease, because few hospice organizations can afford the cost of this treatment in addition to other hospice services.

Terminaly ill patients who are unwilling to enroll in a hospice program may obtain some of the same benefits from a visiting nurse agency, although most insurers restrict the quantity and duration of palliative home care services available by this route.

Symptom Management

As revealed in Table 1, most terminally ill patients identify freedom from pain and other forms of distress as an essential component of a “good death.” In addition to counseling and medical advance planning, alleviation of symptoms is the primary objective of palliative care for advanced lung diseases, as for other chronic, fatal illnesses.
Symptoms of particular concern to patients with advanced lung disease include dyspnea, cough pain, insomnia, anxiety, depression, and delirium.24,25

Dyspnea, defined as a subjective experience of breathing discomfort, is the most persistent and distressing symptom experienced by most patients who die of advanced lung disease.26 As respiratory impairment progresses, dyspnea occurs with minimal exertion, and ultimately at rest. Nearly all of the COPD patients in the SUPPORT group study experienced dyspnea during the last 3 days of life.25 Compared with pain, dyspnea remains poorly understood at a cellular or biochemical level. No specific receptors or chemical blockers of the sensation of dyspnea have been identified. No medication or surgical intervention reliably eliminates dyspnea in conscious subjects;26 however, opioids at appropriate doses do appear to provide limited relief, and several nonpharmacologic approaches may be helpful.26–28 These are described by Harold Manning in the previous issue of Respiratory Care.29

Most patients with advanced lung disease also experience cough, and some are plagued by this symptom. Paroxysmal cough is particularly distressing to patients with limited respiratory reserve. In these patients, repeated coughing can cause a sensation of acute suffocation, often accompanied by panic. Like dyspnea, cough is poorly understood neurochemically; also like dyspnea, cough can be difficult to control. The management of cough and respiratory secretions was reviewed by Helen Sorenson in the previous issue of Respiratory Care.30

Except perhaps in the final days of life,31,32 advanced lung disease is not typically associated with major or sustained pain. However, some patients do experience a particularly distressing form of pain when corticosteroid therapy is complicated by rib or vertebral compression fractures. Both types of fractures can give rise to an immobilizing pain that is exacerbated by every cough. The pain persists for 6 weeks or longer and may be prolonged if multiple bones fracture in succession. Bed rest necessitated by vertebral compression fractures accelerates deconditioning and frequently contributes to depression, insomnia, and despair. Kyphosis resulting from multiple vertebral fractures may further impair respiratory function.

The best treatment of pathologic fractures is prevention. A trial of corticosteroid therapy for chronic lung disease should be discontinued if no convincing objective response is documented by pulmonary function or exercise testing, especially in post-menopausal women. For those who do respond, corticosteroid-sparing agents such as azathioprine or cyclophosphamide should be considered. Once fractures occur, treatment of pain is often complicated in patients with advanced lung disease by limited respiratory reserve. If tolerated, a long-acting opioid can be used alone or in combination with a nonsteroidal anti-inflammatory drug. Stool-soothing agents and/or laxatives should be administered early to avoid opioid-induced constipation, because straining at stools further exacerbates rib or vertebral pain. Back-bracing is often recommended for patients with vertebral compression fractures, but may be poorly tolerated by lung disease patients if diaphragmatic excursion is constrained.33 Vertebral body augmentation, a novel approach to control of pain and disability associated with vertebral compression fracture, is under active investigation currently.34 By this approach, polymethylmethacrylate or mineral bone cement is injected percutaneously into the compressed vertebral body to fortify the bone and prevent further deformity. Additional research will be needed to determine the role of this technique in palliative care.

Insomnia is a common complaint of patients with advanced lung disease. Retained respiratory secretions, nocturnal hypoxemia, obstructive apneas, dyspnea, anxiety, and depression can all contribute. Hypoxemia should be reversed by administration of adequate supplemental oxygen. If detected, symptomatic obstructive apneas can be prevented by nasal continuous positive airway pressure or bilevel positive airway pressure. Insomnia in dyspneic patients is sometimes treated with a nocturnal dose of an opioid, although no objective evidence supports this practice. Others advocate use of a sedating tricyclic antidepressant such as amitriptyline to treat insomnia in patients with advanced lung disease, particularly if depression is a contributing factor. Zolpidem is another option; this imidazopyridine has hypnotic activity similar to that of the benzodiazepines but no respiratory depressant effect. A short plasma half-life reduces residual daytime sleepiness. Using polysomnography, Girault et al found that 10 mg oral doses of zolpidem improve the subjective quality and the duration of Stage 2 sleep in patients with severe COPD without precipitating obstructive apneas or adversely affecting mood, vigilance, pulmonary function, oxygenation, or central control of breathing.35

Anxiety, dysphoria, and depression are other common complaints of patients with advanced lung disease, including the terminally ill.36 Anxiety and panic are closely associated with dyspnea in patients with advanced lung disease. Whether anxiety sometimes causes dyspnea in these patients is unknown, but is widely suspected by clinicians. Anxiety may be treated with an intermediate-acting benzodiazepine such as lorazepam (0.5–2 mg every 6–12 h) or Klonopin (0.5–2 mg 3 times a day) with or without a tricyclic antidepressant. A serotonin reuptake inhibitor such as paroxetine (20–50 mg per day) or a tricyclic drug such as desipramine (50–150 mg at bedtime) or doxepin (75–150 mg at bedtime) may be tried for depression. The highest recommended dose and 2–4 weeks of treatment may be required before benefit is observed. Methylphenidate (5–20 mg 2 or 3 times daily) is an alternative. This cortical stimulant may benefit some medically ill patients who are depressed and offers the advantage of a rapid onset of action.
Information on the response of terminally ill patients to pharmacotherapy for depression and other dysphoric emotional states including depression is limited and contradictory. Two studies suggest that patients with COPD or other chronic medical illnesses may be less responsive to antidepressant drugs and more susceptible to their adverse effects than physically healthy patients. However, two other studies did show short-term improvement of depression in patients with advanced COPD after pharmacotherapy. Thus, a drug trial may be warranted in patients with advanced lung disease who are severely affected by anxiety or depression.

Little is known about the prevalence of delirium in patients who die at home of advanced lung disease. However, inpatient experience with terminally ill respiratory disease patients suggests that delirium probably occurs commonly in the final days of life, regardless of the setting. Known risk factors for development of pre-terminal delirium include hypoxia, carbon dioxide retention, and the use of benzodiazepines and opioid analgesics. Indeed, the benefit of these medications for control of pain and dyspnea must be balanced against the common adverse effects of drowsiness, confusion, short-term memory loss, and agitated delirium. Delirium is treated in the setting of advanced lung disease by improving arterial blood gas tensions, if possible, and by reducing doses of psychotropic medications, if possible. Psychotic ideation and agitation respond modestly to haloperidol, administered orally, intramuscularly, or intravenously at an initial dose of 2 mg 2 or 3 times a day. The dose can be increased if necessary to 40 mg a day or more in divided doses.

**Dying at Home**

Although most patients with advanced lung disease express a desire to die at home, relatively few in North America actually do so. Unless a fatal complication supervenes, many spend an extended period of time confined to bed completely dependent on others for basic sustenance, hygiene, and comfort. Constant attendance and considerable skill are often required. Dyspnea at rest and accompanying anxiety and panic are distressing to onlookers and difficult to manage, even under the best of circumstances. Hospice programs can provide considerable support, including 24-hour-a-day bedside care for a few days. For others, the patient may best be served by terminal hospitalization. To avoid undesired, invasive emergency care, this possibility should be planned for in advance.

Funeral arrangements are also best planned in advance. Many older Americans appreciate the opportunity to discuss their own preferences for funeral arrangements. In the event that a person dies at home, by pre-arrangement, the funeral home can be summoned at the time of death. The presence of a physician is not required. The funeral home can arrange for the physician to complete the death certificate at a convenient time afterwards.

Physicians who learn palliative care recognize that death is not a failure, but an opportunity to practice a form of professional care that is as old as medicine and as gratifying as any other services we offer.

**REFERENCES**

Palliative Home Care for Advanced Lung Disease


Discussion

Benditt: Yesterday, Randy [Curtis] had used the words "terminal disease" for COPD [chronic obstructive pulmonary disease]. I was wondering if you could tell me what a terminal disease is, and is COPD a terminal disease?

Hansen-Flaschen: Good question. I come back to his thing: Is this likely to be the disease that will cause your decline and death? Of course we can never answer that with certainty. Someone can get hit by a car tomorrow. But is this highly likely to be your fatal disease? If the answer to that is "Yes," I would call that a terminal disease. Does COPD qualify? Only sometimes. I have this conversation routinely. I see a 68-year-old person who comes to me for shortness of breath. Their FEV₁ [forced expiratory volume in the first second] is 61%, and their CT [computed tomography] scan shows bullous emphysema. I'll tell them "You have chronic obstructive lung disease. You have emphysema. But given these pulmonary function tests and your age, I'm pretty confident that this disease is not going to totally disable you, and it won't be the major cause of your death." I think I can say that with reasonable confidence. At the age of 68, if you have only moderately severe emphysema, this isn't likely to be your fatal disease. So for that person, the answer is "No." Same person with an FEV₁ at 28% of predicted—that's likely to be the disease that causes that patient's decline and death, and I would call that a terminal illness. We could come up with rough criteria for other diseases—pulmonary vascular pressures and pulmonary hypertension, on down the list.

Curtis: I have a follow-up question to that. I like the way you presented the notion about end-stage and drawing the parallel to renal disease, but I have found that it's a helpful terminology to use in COPD, anyway, and I'd like to see what is your reaction to this. My sense is that for those patients who do have a terminal disease, we don't let them know that enough as physicians. The terminology "end-stage disease," both in communicating with other health care providers and with patients, is one way to do what you're saying, which is to say, "We are now in the end of life, and we don't know how long the end-stage will be." But it sets the frame-
work for thinking about the end-stage. The problem I have with advanced lung disease is that it doesn’t offer that same sort of framework. I wonder if you could comment on that.

Hansen-Flaschen: If you’re willing to restrict the term “end-stage” to people who have a median survival less than 6 to 12 months, then it may have some meaning. However, many people commonly use the term for all those patients who are disabled because of chronic progressive lung disease, including those who have median survivals of 6 to 8 years or longer. The other concern I have about it is I’d like to draw more attention to the population of people who live in institutions on mechanical ventilation—out of sight, out of mind—it’s an important population that’s rising in the United States. It’s a very expensive population—very analogous to chronic renal failure on hemodialysis. It has fundamentally changed the decision-making regarding terminal withdrawal of mechanical ventilation, because there is another alternative now that we didn’t have 20 years ago. So it also denies the opportunity to put a term onto those people specifically who are dependent on mechanical ventilation, and recognize them as a population that needs attention. In other words, “end-stage lung disease” could mean chronically ventilator-dependent, the same way “end-stage kidney disease” means dialysis-dependent.

Sorenson: I have a question regarding the prognosis, or, I guess maybe post-prognosis. We occasionally walk into a room to take care of the patient after the physician has been in there and given them the prognosis. Patients don’t necessarily want to believe what the doctor has told them, and they want another opinion. They’re asking us. I’m not comfortable with saying, “I don’t know,” because I do know. I’ve seen the chart. I don’t know what the physician has told them, and that’s OK.

Hansen-Flaschen: Well, that’s a great idea. What you’re describing must happen all the time. The next person into the room, often a therapist or nurse, picks up the pieces after that tough conversation. They really can’t think of anything else to talk to you about. That’s a wonderful response of a therapist. “What is your understanding of your prognosis or what was just said?” What to do if it’s way off target? I think I would be very forthright to say, “It may not be exactly as you understand; that’s a good reason to talk to your physician more to be sure you understand exactly what the message is.” If you were working with me, I’d very much appreciate your telling me about that conversation and explaining to me the patient’s understanding. More often than not, people don’t get the message right in the first conversation. It takes 2 or 3 conversations, a refinement of understanding over a period of time, where the physician is guided by feedback from the person directly or indirectly through a less threatening person, like a therapist. So I think you’re right on target with that approach.

Heffner: I think I was caught, too, by your preference for the word “advanced” in this era of advanced technology and advanced computer systems, and maybe the words we use are important for us in our communication with our colleagues. But when I discuss prognosis with patients, I tend to try to use the words that they’re most familiar with, such as “severe” or “bad,” and then try to frame it in terms of a story—what it means for them. I wonder, too, about your thoughts on severity of disease and need for hospice services—whether the disease also lives in the context of the resources in the family, and that some patients with similar disease but more family resources may be less of a candidate for hospice services, as opposed to another patient who doesn’t have that support structure.

Hansen-Flaschen: Two good points. In a conversation with the patient and family, I use “mild,” “moderate,” “severe,” and “very severe.” Those are my 4 words of conveying where they are with COPD. So I don’t routinely use the word “advanced” in the conversation with a patient. I don’t think that it means so much to that person.

The second issue is that a lot of people are not well suited for hospice care. I couldn’t agree more. Shortness of breath with absolutely minimal exertion (such as eating) or at rest is a terrible finale. It’s one of the worst things that any of us see. It’s frightening for onlookers. It is very difficult to take care of well. It’s very demanding. In this outpatient medical advance planning, the focus ought to be on realistic assessment of what can and cannot be done in the home for that individual. Very often, the spouse is old and disabled and the kids live half a country away. The honest truth is that it’s just not going to work out for them, and the physician steers realistically toward expectation of institutional care and identifying the most appropriate institution if and when it comes time. You could still say, “Let’s play this out at home as long as it works, but let’s be prepared to move into an institutional setting if that time arises and let’s go out and choose the provider.”

Levy: I want to go back to Helen’s [Sorenson] question for a second, because I think it’s really important, and
I think it also underscores Tudy's [Giordano] presentation yesterday, which is the need for palliative care education in the RT [respiratory therapy] educational process. I guess in my unit I would want to think that the respiratory therapist would actually have that conversation directly, with follow-up. I'm sure in most of our units, whether we like it or not, certainly the nursing staff does it. I think it speaks to this issue of moving end-of-life practices forward with or without physicians. As I've expressed here before, the frustrating question is, "How do we get clinicians, physicians in particular, to understand there's a problem?" My question for you, John, is, in your practice do you see the clinicians you work with, the physicians, beginning to understand that this can be improved—that what you're presenting as a practice in the clinic is a continual evolution of end-of-life skills? Or do they see you as, "Oh, yeah, John talks a lot about end of life?"

Hansen-Flaschen: The latter is more true. This is a very hard sell. There's a small group of people who incorporate this aggressively into their practice and a large group who stay away from it. I don't know if that will ever change. I have come to understand that many physicians play a pretty small role in end-of-life care overall. Even those who are most attentive and incorporate this into their practice, and put a lot of time and effort into it—we're small, albeit important, players in a saga that unfolds 24 hours a day for months or sometimes years. This is a family issue. People turn to whatever resources they have and very much to nurses and therapists and others in their community. If they tell the story afterwards, the physician may be a footnote or may be not a part of the story at all. So many people don't even do the small piece that physicians ought to do. Even those who do the piece we ought to do need to recognize we're often a small part of the story.

Benditt: In dealing with lung disease, one model that I've come to use is that the respiratory system is really two parts. One is the lung itself, and the other is the respiratory pump, which is what I deal with, mostly. Treating the pump failure is quite a bit easier. In fact, people ask me "Is ALS [amyotrophic lateral sclerosis] really a terminal disease?" That's a hard question to answer, because, in fact, by replacing the pump mechanically, people can stay alive for a long, long time. I focus on the quality of life for both the individual and the family, almost as opposed to, "Is this the terminal disease?" "What is this disease going to do to your life, your family?" We spend a lot of time focusing on that, particularly with ALS.

Hansen-Flaschen: You can ask whether the terminology is important or not. We're not saying "Yes" or "No" based on "end-stage" versus "advanced" versus "terminal." But I actually do think it is important. It would be worth while at some point for the appropriate people to get together and come to common understandings of some of these terms. I offered a very inclusive concept of terminal disease. It's the disease that's likely to cause your decline and death. If we were to use it in that way, it would have a different meaning than conveying the message, "You are dying." If we used terminal disease to mean, "You are dying," it would have a very different, meaning and encompass a very different group of people and circumstances. So we use these terms—it would be nice to come to a common understanding of what they mean.

Sam Giordano: I was reading the Medicare policy you distributed, and unless I misinterpret it, this is actually a local medical review policy for probably your area. Isn't it?

Hansen-Flaschen: It is a local medical review policy, but it's taken directly from the national policy. This is not something that's pre-approved. These are review criteria coming from Medicare to the intermediaries. If you're going to review a hospice, use these for the criteria. If their decision is appealed to an administrative law judge, the administrative law judge would be given this and be asked to consider the case against these guidelines.

Sam Giordano: The comment would be that the AARC [American Association for Respiratory Care] would gladly work with ACCP [American College of Chest Physicians] and ATS [American Thoracic Society], as it has and continues to do. Right now we're collaborating development of a national pulmonary rehabilitation reimbursement guideline. We'd love to participate in such an effort and will endeavor to follow up through our representatives on our Board of Medical Advisors, which, fortuitously, is meeting within the next 2 weeks.

I'd also like to add a personal comment about the term "hospice." My father passed away at home 5 years ago, having had cancer. Interestingly enough, he wanted me to promise not to bother him about going back to the hospital. That correlates very well with a piece I read in the Wall Street Journal in February that said that even though 70% of our population die in hospitals, their 2 biggest fears are, first of all, they don't want any more pain, and secondly, they don't want to die alone, which drives them to stay away from what they perceive to be a pain factory (hospital) and a place where you do die alone in some instances. But my father did not want to have hospice services. However, what he didn't like, I found out, was the term. I'd say "Dad, would you like a hospice?" "No, I'm not ready for that." "Well, how about if some people came and visited you at home and helped you out every day?" "Oh, yeah, I'd
like that.” Sometimes it’s what the term conjures that could either promote or discourage acceptance on the part of the patients.

REFERENCE


Hansen-Flaschen: My father too—same thing. “Hope and expect for the best but prepare for the worst” tries to get at that, but that word “hospice” is another message, another arrow in the chest. It conveys “You are dying now.” It’s the first of several hurdles to getting pulmonary patients involved in hospice. People understand that if they have metastatic lung cancer they’re going to die. They can’t escape. Almost everybody understands that metastatic lung cancer is a fatal disease. It’s not so easy to understand that amyotrophic lateral sclerosis or COPD or idiopathic pulmonary fibrosis or pulmonary hypertension may be fatal diseases. Going through that hospice portal is another waking up to it that many people avoid and hold off—the first of several obstacles to using the service.

Burt: Can I offer an observation about your modesty about the physician’s role in your exchange with Mitch [Levy]—the 15 minutes a day that physicians may spend with a dying patient. My observation is also coming from a patient perspective, my own experience in home deaths of several people close to me fairly recently. Though it is true that the doctors involved spent much, much less time than other caretakers—both hospice people and family—nonetheless, everyone waited for the doctor’s call. Occasionally, the doctor would visit, and then, even if it was a 10-minute call, it would be discussed for hours afterwards. “When he said this, what do you think it meant?” So the symbolic importance, and maybe the practical importance, is enormously larger than those 10 or 15 minutes, like it or not.

Hansen-Flaschen: Very fair statement. Until 50 years ago, doctors caught babies, we offered prognoses, and we presided over deaths, together with the clergy. Physicians made a living doing those 3 things. There was and still is enormous significance attached to those small periods of time physicians spent—and it’s a brutal responsibility, answering phone calls promptly, and being on time, and being there when people need you. One of the reasons my colleagues shy off is the fear they won’t be able to fulfill those expectations that you’re describing. Dying people and their families are very needy people. Understandably so. It’s a big responsibility to shoulder, and people shy away from it for that reason.

Tudy Giordano: I’d like to dovetail a little bit on what Mitch [Levy] said. You look around the room and it seems like everyone comes from a big university where knowledge is an asset. But I wonder about these palliative care education issues in community hospitals and rural areas. People are dying there too, in great numbers, but I wonder how to reach these people and how to motivate them to learn about palliative care.

Hansen-Flaschen: The things I described today I learned from my own experience and from listening to others—like this. They’re not out of reach of physicians, even in rural settings, who’ve learned from their patients and colleagues. We’d love to be able to reach them through things like this Respiratory Care Journal Conference. But the very best physicians, even in rural communities, turn out to have discovered, over a period of a career, many of the things we’ve talked about at this conference.

Curtis: My experience is that sometimes an intensive care nurse who really cares that families be informed can agitate to push forward palliative care in the case of an individual patient. I wonder whether a respiratory care practitioner who has learned about palliative care and can really challenge physicians to make sure they talk to patients about prognoses might not be able to do the same thing in rural as well as urban settings.
Palliation for the Dying Patient with Lung Cancer

Gerard A Silvestri MD

Introduction

Stage, Prognosis, and Treatment Options
Endobronchial Obstruction
Radiation Therapy
Lung Cancer Pain and Its Management
Pharmacologic Therapy for Pain
Adverse Effects of Opioids
Hospice Benefit
Communicating End-of-Life Issues
The Role of the Respiratory Therapist

Key words: palliation, radiation therapy, pain control, pain management, hospice benefit, end-of-life care, respiratory, stent. [Respir Care 2000;45(12):1490–1496]

Introduction

Lung cancer is the most common cause of cancer deaths in the United States. This year more than 160,000 patients will die of this disease,1 more deaths than can be expected from breast, colon, and prostate cancer combined. Lung cancer is largely preventable, as 90% of cases occur in patients who smoke cigarettes. The 5-year survival of lung cancer is dismal at 10–13% and has not changed over the past several decades.1 Research efforts aim to improve survival in these patients, but we must continue to care for the rest of the patients who will ultimately succumb to their diseases. These patients may benefit from the palliative care techniques described herein.

Palliative care treatment options for patients with terminal lung cancer include radiation therapy to ameliorate symptoms such as pain, cough, and hemoptysis, and pain management to relieve the suffering that can be associated with locally advanced or metastatic cancer. The hospice benefit is underutilized despite the positive effect this benefit has on patients and their families. We need to communicate carefully with patients about their wishes at the end of life so that we may respect their preferences regarding palliative versus life-extending care. The role that respiratory therapists (RTs) will play in the care of dying lung cancer patients is discussed herein.

Stage, Prognosis, and Treatment Options

We characterize lung cancer by the cell type (small cell vs nonsmall cell) and the extent, or stage, of disease, as this helps us understand the prognosis and consider treatment options. A more in-depth discussion of the diagnosis, staging, and treatment of lung cancer can be found elsewhere,2,3 but a brief description follows. Nonsmall cell lung cancer includes adenocarcinoma, squamous cell carcinoma, and large cell carcinoma and accounts for 80% of all lung cancer diagnoses. Small cell lung cancer accounts for the other 20%. Nonsmall cell lung cancer is staged progressively from Stage I, which is early stage lung cancer without involvement of lymph nodes, to Stage IV or metastatic disease. Survival decreases as the stage of disease increases. Stage IV lung cancer, which accounts for between 60,000 and 80,000 new patients per year, is incurable, with a median survival of 4 months with no treatment and approximately 7 months with treatment.1 Early stage lung cancer is treated with surgical resection alone. Locally advanced lung cancer—that is, cancer spread to the mediastinal lymph nodes—is generally treated with chemotherapy and radiation therapy. Metastatic lung can-

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A version of this paper was presented by Dr Silvestri during the RESPIRATORY CARE Journal Conference, Palliative Respiratory Care, held May 19–21, 2000 in Cancún, Mexico.

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cancer is treated with chemotherapy alone or with supportive care. Patients with earlier stage lung cancer may have recurrent disease; 75% will recur within 2 years. There is a 25% chance of distant metastatic disease (most commonly to the brain, bone, liver, and adrenal glands). The remaining 25% will have local recurrence within the chest.

 Patients frequently have symptoms related to their cancer, but not all symptoms are related to progression of the cancer itself. Table 1 illustrates the broad number of diagnoses that must be considered when evaluating lung cancer patients with dyspnea. In addition to therapy directed at treatment of the cancer, we treat the symptoms throughout the course of disease. Knowledge of the stage of disease is useful in deciding how aggressively one should pursue life-extending treatment options versus aggressive palliative care services. The complications of lung cancer and its treatment may have devastating effects in this patient population, but when recognized can usually be managed successfully.

**Endobronchial Obstruction**

Patients with bronchogenic carcinoma can develop endobronchial obstruction or extrinsic compression of the airway. Airway obstruction causes 3 main problems: dyspnoea, post-obstructive pneumonia, and hemoptysis. The more proximal the obstruction, the more profound the dyspnoea. Obstruction of either the right or left main bronchus can cause considerable shortness of breath. This problem is heightened in patients who have co-existing chronic obstructive pulmonary disease. Post-obstructive pneumonia occurs because the patient has difficulty clearing secretions, which form the nidus for infection. Until the obstruction is relieved the infection persists. Finally, endobronchial tumors tend to be vascular and hemoptysis can occur. The prevalence of endobronchial tumor obstruction is unknown. However, it is estimated that between 28% and 58% of lung cancer patients may have malignant airway obstruction.

The treatment modalities for malignant airway obstruction in patients who are not candidates for surgical resection include tracheobronchial stent placement, radiation therapy either by external beam or internal brachytherapy catheter placement, or some combination of these modalities. The use of radiation therapy is described below.

A number of airway stent designs, using various materials, have been developed over the past 30 years. In 1965, Montgomery introduced a silicone rubber T-tube for relief of subglottic stenosis. In 1990, Dumon published the results of a newly designed tracheal bronchial stent made of molded silicone, which was placed successfully in over 200 patients to relieve malignant airway obstruction. This stent is the most widely used tracheobronchial prosthesis in the world. Advantages of this stent include the fact that it is relatively well-tolerated by patients, has a low complication rate, and can be removed if there is difficulty with the stent. The disadvantages of the silicone stent are stent migration, reduction in the airway lumen because of the thickness of the stent wall, an increased incidence of obstruction due to secretions, and the need for expertise in rigid bronchoscopy, as these stents must be placed in the operating room under general anesthesia.

To overcome these difficulties and to allow for the use of flexible bronchoscopy to place stents in patients with malignant airway obstruction, metal stents were developed. The two stents available in the market are the Wallstent and the Ultraflex stent (Microvasive/Boston Scientific Corporation, Natick, Massachusetts). Both of these are self-expanding stents that can be placed via the bronchoscope combined with fluoroscopy. This type of stent can be placed in the bronchoscopy lab under conscious sedation. A guidewire is passed through the tumor obstruction. The bronchoscopist may use balloon dilation, laser resection, cryotherapy, or electrocautery to debulk the tumor if necessary. Once the lumen is re-established, the stent is passed over the guidewire and released from the catheter (Fig. 1). Many patients are discharged to home within several hours of the procedure. Increasing numbers of these stents are being placed for both benign and malignant indications. RTs caring for this patient population should be aware that it is important that patients have their cough suppressed for the first 24 hours so that the stent does not dislodge. In addition, chest percussive therapy should be avoided during the first 24 hours. After that, the use of nebulized saline or albuterol is sometimes employed to keep the stent moist and free of mucus inspissation. When these stents fail, it is generally because of mucus inspissation, stent migration, or granulation tissue formation, which results from irritation of the airway wall by the stent. Tumor ingrowth around the proximal or distal end of the stent can also occur.

Opening the airway can have a profound effect on a patient’s dyspnea and improve quality of life.
have also been documented improvements in pulmonary function.\textsuperscript{15,16,19–22} However, life expectancy is generally not improved with these interventions. Patients with malignant airway obstruction should be considered for stent if they have a reasonable performance status. Bed-bound patients will probably not benefit from stent placement. Patients who are ambulatory and have substantial dyspnea can have an excellent result from this procedure.

**Radiation Therapy**

Radiation therapy has been used for both "curative intent" and for palliation of symptoms. When the aim is cure, radiation therapy is given in small fractions over a 5–6 week course. Most patients have both the primary tumor and the mediastinal lymph nodes irradiated. Currently, radiation therapy for cure is utilized in combination with chemotherapy for patients with Stage III-A and, rarely, Stage III-B lung cancer. Occasionally, a patient who is not a surgical candidate for Stage I disease can have a solitary pulmonary nodule irradiated for cure. The 5-year survival in that group is approximately 25%.

Radiation therapy can provide excellent local control of tumor. In combination with chemotherapy for locally advanced (Stage III-A) lung cancer, cure can be achieved in some, but overall survival in this group is 17%.\textsuperscript{3} There are also situations where the patient is not eligible for treatment with curative intent because they have poor performance status or co-morbidities that preclude them from being treated with curative intent. If the goal of treatment is palliation, radiation therapy can be given over a much shorter time course, with excellent temporary results. A common regimen would include 10 treatments over a two-week period. The British have been able to provide excellent relief of the symptoms associated with lung cancer by providing two treatments, one week apart, directed at the primary tumor site.\textsuperscript{23} Treatment is usually very well tolerated. The main side effect of radiotherapy is radiation-induced esophagitis. A less common complication of radiotherapy is pneumonitis. Contraindications to radiation therapy include poor performance status and inability to capture the tumor within the radiation port. Table 2 shows the symptoms associated with lung cancer for which radiation therapy to the chest may be helpful.

Radiation therapy is an excellent adjunct to other therapies for the management of metastatic lung cancer, particularly patients with metastatic disease to the brain or bone. Both of these situations can be well palliated with a short course of radiotherapy.\textsuperscript{24}

**Lung Cancer Pain and Its Management**

In a recently published article, Steinhauser et al interviewed patients regarding the most important components
Palliation for the Dying Patient with Lung Cancer

Table 2. Palliating Intrathoracic Problems in Lung Cancer

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency (%)</th>
<th>Improved (%)</th>
<th>Complete Relief (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough</td>
<td>61–93</td>
<td>56–65</td>
<td>30–54</td>
</tr>
<tr>
<td>Hemoptysis</td>
<td>31–47</td>
<td>81–86</td>
<td>74–82</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>54</td>
<td>–</td>
<td>37</td>
</tr>
<tr>
<td>Pain</td>
<td>42–57</td>
<td>74</td>
<td>50–52</td>
</tr>
<tr>
<td>Atelectasis and Infection</td>
<td>26</td>
<td>–</td>
<td>62</td>
</tr>
<tr>
<td>Hoarseness</td>
<td>25</td>
<td>–</td>
<td>49</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>11</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
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Time, Dose, Fraction: United States: 30–35 gray in 10 fractions. Britain: 17 gray in 2 fractions one week apart. (Adapted from Reference 24.)

of a good death. They found that the most important component of a good death was pain and symptom management. Unfortunately, this goal is not always met satisfactorily. Cleeland et al reported on pain and its treatment in 1,300 outpatients with metastatic cancer. They found that 67% of the patients reported that they had pain or had taken analgesic medications during the week preceding the study. Thirty-six percent had pain severe enough to impair their ability to function. An additional 42% of those with pain stated that they were not given adequate analgesic therapy. Most patients felt their pain could be easily managed with proper medication. A disturbing finding in that study was that racial and ethnic minority patients were 3 times more likely to have inadequate pain management than nonminorities. Finally, the study revealed a discrepancy between the patient and physician in judging the severity of the patient's pain. This study illustrates the need for better pain management.

The symptoms associated with cancer pain vary depending on the location of the tumor and the tissues involved. Patients with locally advanced disease can have pain of the chest wall, vertebra, and brachial plexus. For patients with metastatic disease, the site of pain depends on the organ involved. Because metastatic lung cancer occurs predominantly in the brain, bone, liver, and adrenal glands, symptoms such as severe headaches, bone pain and tenderness, and upper abdominal pain are common.

Pharmacologic Therapy for Pain

Oral, transdermal, and parenteral analgesics are widely used in the management of cancer pain. The World Health Organization (WHO) has devised a three-step schema (Fig. 2) that serves as a widely-used guideline for pain management. The first step in the ladder is for mild to moderate pain and involves the use of nonopioid analgesics such as acetaminophen or nonsteroidal anti-inflammatory medications. A clinician proceeds to step 2 if the pain persists or is not adequately treated. In general, an opioid is used for moderate pain (eg, codeine, hydrocodone, oxycodone, propoxyphene). These medications are typically combined with the nonopioid analgesics. Finally, if the pain persists, or with uncontrolled severe pain, the patient proceeds to step 3 and should receive stronger opioids (morphine, fentanyl). These can also be used in combination with medications from step 1 and step 2. This approach has been shown to be effective in up to 88% of cancer patients and greater than 75% of those patients who have terminal disease. When initiating or titrating analgesics, it is not necessary to traverse each step of the WHO schema sequentially. Patients presenting with severe pain may require immediate initiation of a step 2 or 3 opioid as the first pain medication.

Opioid analgesics differ in their pharmacodynamics and pharmacokinetics. They are broadly classified as full agonist, partial agonist, or mixed agonist/antagonist. A more detailed description of these medications can be found elsewhere. There are some important guidelines with respect to how opioid analgesics should be administered. The oral route is the preferred route of administration of all pain medications. Opioids should be administered on a regular basis, with the interval between doses based on the duration of the analgesic effect. The regimen should be assessed frequently to ensure adequate pain management. In addition to the long-acting medications, patients should have immediate-release analgesics available for "breakthrough pain." As the frequency of breakthrough medication increases, the regimen should be re-examined, and it is likely that the long-acting medication will need to be increased.

Tolerance will eventually develop to these medications. There is no ceiling on the dose of opioids that can be given. Addiction potential is extremely low, and the goal of pain relief should outweigh any concerns about addiction. The only limitation to increasing the dose of these medications is the development of adverse effects. As previously mentioned, the oral route is the preferred mode of delivery of opioid analgesics. If patients are unable to take medications orally, the transdermal route can provide
excellent relief of pain. Transdermal administration using a fentanyl patch, which contains a 72-hour supply of medication, is an excellent alternative to oral opioids. The intravenous or subcutaneous route can also be used in those unable to take oral medications. Continuous infusion morphine, while inconvenient for the patient, has the additional advantage of providing continuous and constant analgesia. Rapid adjustment of the infusion rate can provide immediate relief of pain. It can be administered in the outpatient setting by the use of a portable pump. In addition to the constant infusion, small doses can be delivered at intervals for breakthrough pain. The use of patient-controlled analgesia (PCA pump) can allow patients to administer their own medication for relief of breakthrough pain.

**Adverse Effects of Opioids**

Respiratory depression from opioids can be managed by careful use of naloxone, an opioid antagonist. However, respiratory depression from opioids is usually preceded by drowsiness, and fear of respiratory depression should not be a reason to avoid treating a patient's pain.

One of the most bothersome adverse effects of the opioid class of medications is constipation, which should be anticipated and treated prophylactically at the time an opioid is instituted. The use of mild laxatives should be encouraged. Moderate to severe constipation can be treated with senna, bisacodyl, or lactulose. Patients should be encouraged to increase fluid intake. Exercise will also help alleviate constipation. Nausea and vomiting can also occur and frequently improve over time. Other adverse effects of this class of medication include dry mouth, urinary retention, pruritus, myoclonus, altered cognitive function, euphoria, lethargy, and increased sleep. The use of adjuvant medications can complement the opioid and nonopioid analgesics for specific types of pain. Such medications include corticosteroids, anticonvulsants, antidepressants, neuroleptics, antihistamines, bisphosphonates, and calcium. Corticosteroids have been used frequently in lung cancer patients. They are particularly useful to reduce edema in patients with central nervous system and spinal cord metastases. Anticonvulsants such as phenytoin and carbamazepine have been used to treat neuropathic pain associated with cancer. The antidepressants have been helpful both to improve neuropathic pain and to improve depression associated with end-stage cancer. Antihistamines such as hydroxyzine have an antiemetic, anxiolytic, and sedative effect. The bisphosphonates were recently found to be effective in reducing bone pain that accompanies bone metastases. Radiation therapy is the first line of treatment for bone pain. However, occasionally, patients can have widespread skeletal disease, and radiation therapy becomes impractical. Several recent studies have shown that use of bisphosphonates reduces both skeletal events (such as fracture) and pain in cancer patients.33-35 Coleman et al studied 86 patients with bone metastases and severe pain. Patients were given a single dose of pamidronate at 120 mg over two hours. Both patients had substantial reduction in symptoms as well as analgesic consumption. They also had improvement in performance status and in quality of life.35

Chemotherapy can be used to palliate the pain associated with cancer. However, while quality of life may improve, patients also experience adverse effects from the chemotherapy itself. More invasive treatments of cancer pain have been found to be effective. Neuroablative techniques such as neural blockade can sometimes control intractable pain when all other therapies fail. Temporary block with a local anesthetic agent is usually applied prior to planned neurolytic block using such medications as phenol or alcohol. Fifty to eighty percent of patients receiving such treatment may derive benefit.31 Other facets of pain management include physical modalities such as the use of heat or cold therapy, transcutaneous electrical nerve stimulation, acupuncture, and psychological interventions such as hypnosis, relaxation, and distraction techniques, which all serve to supplement and enhance the treatment methods already discussed.

**Hospice Benefit**

For the majority of lung cancer patients there is a point at which cure cannot be achieved and the patient is deemed terminal. These patients may benefit greatly from hospice services. Hospice was introduced to the United States in 1974. It has been a service provided widely throughout Europe, even many decades before the United States. Currently there are more than 3,000 licensed hospice programs serving nearly 500,000 patients per year. The goal of hospice is to provide palliative care, defined as treatment that enhances comfort and improves the quality of the patient's life.36 The WHO technical report on cancer pain relief defined palliative care as "the act of total care of patients whose disease is not responsive to curative treatment. Control of pain or other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families." Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anti-cancer treatment.37 The hospice benefit provides many of the above stated services. The hospice benefit has an advantage over traditional hospital-based care in that care can be delivered at home, allowing death to take place in a surrounding that is comforting to the patient. Because the training of the hospice staff is so specialized, they provide optimal relief of pain. There is very high patient satisfaction with the use of the hospice benefit, and hospice services may reduce the cost of end-of-life care. To be eligible for the hospice benefit
under the Medicare guidelines, a patient must be deemed terminally ill with expected survival of 6 months or less. When a patient accepts the hospice benefit, he or she waives all rights to curative treatment. In return, the patient receives noncurative medical and support services that otherwise would not be covered (eg, nursing care, physician services, medical appliances, medications, short-term hospitalization, homemakers, home health aids, physical, psychological, occupational, speech therapy, and social services).

While the physician must deem the patient terminally ill with an expected survival of 6 months or less, the patient is not denied the benefit if they live longer. In a study of over 6,000 patients entering hospice (21% of whom had lung cancer), the average survival is on the order of 30 days, and 14% of the lung cancer patients died within 7 days of being enrolled in hospice. There are many possible reasons for late enrollment in hospice. First, a patient may resist being told that his or her illness is terminal, and the physician may want to preserve hope. Second, it can be difficult to predict who will die. Third, the Medicare regulations, which state that physicians should be able to predict that the patient is terminal within 6 months, may make physicians less likely to enroll patients until they are “sure” that the patient is terminal. Finally, physicians may want to continue life-extending treatments and palliate the patient at the same time, which is not possible under the current hospice regulations. In the future, changes in the patterns of hospice enrollment may improve the quality of terminal care while reducing costs. For now, the use of hospice services, when appropriate, should be encouraged.

Communicating End-of-Life Issues

One of the most difficult aspects of caring for cancer patients is the decision to forego life-extending treatments and to concentrate on tending to the comfort needs of the patient. Physicians often feel uncomfortable discussing these issues with patients. More importantly, they feel that patients would give up hope if told that the disease is terminal. However, what physicians communicate to patients clearly makes a difference in how the patients decide which treatment option is best for them. Steinhauser et al found that patients identified clear decision-making as the second most important aspect of a good death, after pain and symptom control. In a study by Weeks et al, patients who believed that they would survive for more than 6 months were nearly 3 times as likely to favor life-extending therapy over comfort care as compared to patients who thought they had a 10% chance of dying in the next 6 months. In that study, physicians were much more accurate at estimating the patient’s survival than was the patient. Controlling for all known co-morbidities, patients who chose life-extending treatments had no better outcome than patients who chose supportive care. Why do patients overestimate their survival? In a recent survey of medical oncoLOGists, it was found that medical oncoLOGists overestimate patients’ survival for both untreated and treated metastatic lung cancer. This overestimate may be communicated to patients who, given a better perceived chance of survival, would then choose life-extending therapy (eg, chemotherapy). It is also possible that patients recall only the best survival estimates when given a range of survival probabilities by the physician. Either way, it leads to patients not receiving palliative therapy until very late in the course of disease.

Another aspect of patients deciding to choose chemotherapy or supportive care for metastatic lung cancer is that there is a large variability in what patients would demand in terms of survival benefit before agreeing to accept the potential adverse effects of chemotherapy. Pritchard, Welch, and I studied this phenomenon by presenting patients with metastatic lung cancer already treated with chemotherapy scenarios describing the risks and benefits of both chemotherapy and supportive care. Patients showed a large variability in willingness to accept chemotherapy. Some patients would agree to chemotherapy for as little as one extra week of life gained and others would not accept therapy for even two years of additional survival benefit. Patients held tightly to their preferences regarding life-extending chemotherapy versus supportive care. Currently, chemotherapy for metastatic lung cancer adds an additional 3-month survival benefit over supportive care alone. Many patients given that information would not choose chemotherapy and would prefer supportive care alone. Some, however, would choose chemotherapy and it should be offered to them. Clinicians must incorporate patient preferences into medical decision-making, particularly when there are trade-offs between quantity and quality of life.

The Role of the Respiratory Therapist

RTs have long been active in the terminal care phase of patients hospitalized with respiratory diseases. They are often called upon to provide oxygen therapy for hypoxic patients, chest physiotherapy for patients with post-obstructive pneumonia, nebulized bronchodilator therapy for patients with breathlessness, and ventilator therapy for patients with acute respiratory failure. In the intensive care unit setting, RTs are often an integral part of the team in deciding when and how to withdraw ventilator support. They spend much of their time with families and patients in that setting and may be the only health care provider at the bedside when the ventilator is withdrawn and the patient dies. Recently, RTs have moved out into the home care setting, and increasingly RTs will be providing home care for lung cancer patients who are in the terminal phases of illness. RTs are well prepared to provide care in that setting. Lung cancer patients will require assessment and
REFERENCES

Discussion

Curtis: That was a terrific summary. Let me start things off by making two observations and asking a question. The first observation is that if most physicians who put in these stents are cowboys, it strikes me that you might fall into the category of a “cowboy poet.” The second observation is that, with the treatments that you talked about, the difficulty we have in negotiating these treatments with oncologists comes in part from the fact that oncologists seem to have two meanings for the word “curative.” The one meaning is the one that we mean, which is that you cure the patient of the disease. The other meaning is that you shrink the tumor. I wonder if you have any advice for us on how to communicate with oncologists and radiation oncologists to try to steer between the two meanings of that word.

Silvestri: I work with a survey researcher and several medical oncologists, one of whom is very well trained in health services research. When we pilot these things, we pilot any of our surveys and decision-making tools among other medical oncologists in that practice. They insist that I do not use the word “terminal”—insist that I don’t use it in any of my questionnaires. In fact, you can see the ire. They want to use words like “not curative.” I think that pulmonologists don’t really see that much of a difference. Tumor response rates are something that they are trained in. If you look at any lung cancer paper—response, response, response—it’s the most important thing.

I don’t know how to get around it other than to tell you that I work with medical oncologists every day, one who’s incredibly aggressive, and he’s a great guy, but it’s been very difficult to work with him on that. But what I do say is that I really start pointing them toward the quality-of-life literature and say we really do have to start talking about quality of life.1–3 I do also make a strong argument for community-based clinical trials in medical oncology that look at quality of life and outcome in terms of survival. That’s the main thing. Fourteen percent 5-year survival—it’s unbelievable to me that we could still be arguing over platinum-based chemotherapy versus taxane-based chemotherapy when we’re looking at a 14% 5-year survival.

There’s no more horrifying event than being an intensivist and having a patient come into the unit with metastatic lung cancer who’s never had advance directives even discussed with him, and the family is looking at you now in your first half-hour conversation about the septic, neutropenic, ventilated patient and saying, “What do you mean their survival is so poor? Last week they told me the tumor shrunk 80% on the chest computed tomography!” It boggles your mind.

REFERENCES


Fins: Just a comment and a question on the issue of racial disparity, which came up a lot yesterday, and you alluded to it. Richard Payne, who is an African-American palliative care doctor at Memorial Sloan-Kettering Cancer Center, reflected, in an Op-Ed in the Washington Post several months ago, on his experience in Texas before he came to Memorial Sloan-Kettering. He wrote that African-Americans who were being encouraged to come into hospice felt that, “It wasn’t that long ago that we weren’t even allowed in these hospitals, and now you’re asking us to forego curative care?” He’s a huge proponent of palliative care, but I think there is an issue of trust (which is essential to the provision of good palliative care) in certain communities that have been marginalized over time. I think that’s an arena of greater need for study.

I also wanted to ask about hospice and hospice benefits. We were talking about hospice benefits, and I was very impressed with the stents and the opening up of the bronchus there, and you had a slide where you mentioned but you didn’t really discuss foregoing curative interventions under the hospice benefit, and we know it’s a capitlitated benefit. I was wondering if you’ve encountered problems getting coverage for people who are under the hospice benefit for those more aggressive palliative care interventions that seem to, perhaps, have a real quality of life benefit.

REFERENCE


Silvestri: No. I haven’t, but, really, for right or wrong, I got burned by for-profit hospice, and I exclusively use the nonprofit hospice and have worked very closely with educating the staff and volunteered lecture time. I’m not the medical director of the hospice (an oncologist is), but I have completely gone away from the for-profit hospice. One anecdote—and it probably isn’t a completely fair assessment, I must admit, but I have not had a problem with that, nor have I had a problem with palliative radiotherapy. Where I have had a problem is the medical oncology community trying to, I think, unfortunately, use the benefit to get both ends—to get a hospital bed in the home and other
things, and then say, "Oh, by the way, we’d like to give chemotherapy to palliate this patient’s symptoms." And hospitals have been very reluctant to do that. But I have not had that problem.

Heffner: If I understood one of your earlier slides correctly, you indicated that when patients are trying to predict their survival they overestimate survival but physicians are fairly accurate in their predictions. I wonder if that’s a good thing or a bad thing. When physicians are participating in the care of a patient, then a prediction or prognosis may be less of a prediction than it is a self-fulfilling prophecy. For instance, when physicians predict, do they change their approach to care? Do they switch patients from curative or supportive intent to palliative intent? And what does that mean for our predictive capabilities?

Silvestri: I’d never thought of it that way, but I must say I don’t think that’s what’s going on. In the SUPPORT study1 they went into the hospital and said “How long do you think you’re going to live?” And the patient said “Gee, I think I’m going to live 8 months.” And then they went to the doctor caring for the patient and asked the simple question, “How long do you think he’s going to live?” And the doctor said, “That guy’s going to live less than 6 months.” I don’t personally think it is a self-fulfilling prophecy. I think they truly know. And with lung cancer, as opposed to what John was talking about, it’s very simple. The curves are right there, even for locally advanced disease: 50% one-year survival, 28% two-year survival, 14% five-year survival. So the curves are there. With cancer, I think predicting is quite easy: more than 10% loss in body weight is a huge predictor of poor outcome. Malignant pleural effusion, even despite all those things, is a very poor prognostic. So I don’t think they convert. My problem has never been converting to palliative care. My problem with the communities taking care of patients with lung cancer are (A) patients want to continue aggressive care until very late in the disease, sometimes, and (B) oncologists continue aggressive care until very late into the disease. It’s not been the other way around where it becomes a self-fulfilling prophecy; they move to noncurative or nonaggressive treatment.

REFERENCE

Heffner: It seems like it suggests an interesting study wherein one could compare the predictive capabilities of a physician involved in a patient’s care at any point in time compared to the predictive capability of a physician equally trained who isn’t going to be involved in decision-making. If we were going to evaluate a new test, we wouldn’t let the test evaluator predict or have anything to do with knowledge of treatment. So it might be a dangerous area to have us conclude that physicians do have an inherent skill—the ability to predict the future of our patients. I know I often don’t when I talk to my individual patients.

Rubenfeld: If I’m not mistaken, the physicians in the SUPPORT study who were making the prognoses may not have been the outpatient attending. So it could have been the attending physician in the hospital. I’m not sure that it would have been the patient’s primary outpatient attending who would have been directing their outpatient chemotherapy.

Hansen-Flaschen: Good talk. A lot of good stuff. A comment and a question. I teach that pain more than 4 or 5 on a scale of 10 is a medical “urgency,” meaning, “Stop what you’re doing and take care of it.” This is another comment for respiratory therapists: If you ask that question, and you scale it, and you get back a number more than 4 or 5, I encourage you to stop what you’re doing, go get the nurse, and get the pain taken care of. Why that cut-off? It’s arbitrary, but this scale is not really linear in a conversation between a clinician and patient at the bedside. People say 8 out of 10 if they want you to go get some medicine. So you get a lot of 8 out of 10s, and that means stop what you’re doing and get the nurse, and take care of the person’s pain. If you do that, you’ll be a little bit of a pain for some of the nurses on the floor, but your patients will know your name and recognize and appreciate you and be very thankful. Step one is recognizing that pain more than 4 or 5 is a medical urgency. Stop what you’re doing and get help for the person.

My question is this: Our therapists don’t understand modern indications for airway clearance. Can you comment on airway clearance for people who have stents?

Silvestri: With the silicon stents it’s about 18% a mucus inspissation problem. So once the stent takes hold it won’t usually migrate, but we do want them—not in the first 24 hours—but we do want them to cough up, cough out, get rid of their secretions, because these stents can get inspissated with mucus, and then that’s another trip back into the hospital. With the metal stents, that’s much less of a problem. I think there are problems with metal stents, but the new technology, by the way, is moving toward biodegradable stents, biodegradable covered stents that will be less apt to cause granulation tissue, and for lung cancer patients, that’s great, because their survival, once they’re stented, is on the order of 3 to 6 months, but it can be a good quality of life. There are a couple articles out now1,2 and we’ve had the experience of getting patients off the ventilator, come in to
the intensive care unit with malignant airway obstruction, acute respiratory failure, stent them, and then go out, and I'm sure Dan Sterman's had that experience at your place.

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Benditt: That was a super talk. Thank you. I have one comment and a question for the group. You brought up a point about hospice that has been echoed each day of this conference. That is, even though we would like the medical system not to be a binary process—curative and palliative—in the eyes of the consumer, the patient, and I think even the doctors, oncologists particularly, it really is a binary system. You're either going for a cure or you're going for comfort measures. To me it's such a terrible thing, because it's really inhibiting the use of very valuable resources. It's causing more suffering.

The question I have for the group is: How do we change this? Do we change the names of all these organizations and say it's really "assistive home help" or something, as opposed to hospice? This is a major issue, certainly for a lot of my patients, and it sounds like for other people's, as well.

Silvestri: I wonder if Joe [Fins] might be the best to answer that question. But one thing I believe is that palliative care units are going to go a long way in the hospital to help that, because many patients are going to start at a much earlier stage in these palliative care units where they might be getting their chemotherapy, but they have pain problems, and the palliation team might start working with them and start bringing up these issues and moving them into that continuum a little more smoothly. My personal opinion is that if we could get those in every hospital—and our hospital is working on that right now, assigning some beds for palliation—my personal opinion is that that's the way to go. Joe probably has so much more experience.

Fins: I would add to that structural change in the institution—what John was talking about—and the hospice benefit—have to be completely revamped. We have to trust clinicians and families to make the decision, and it should be about functional status. There's a kind of depersonalization going on with the Inspector General for investigating doctors and institutions, notwithstanding the fact that in today's New York Times it said that Columbia HCA is paying $750 million in penalties. But I think that for the most part hospice provision is right on target, and we have to trust professionals to make the judgment. The benefit increases the dichotomization between acute and palliative care. End-stage disease is variable depending on the disease under consideration. So I think we really have to work hard, and it seems incredibly counter-intuitive and counter-productive that while the Institute of Medicine report was talking about improving access, the Inspector General is going absolutely counter to that mandate, that blue ribbon panel's mandate.¹

REFERENCE

Curtis: Let me just add a quick point about the terminology. To borrow a phrase from Gordon [Rubenfeld]—although I think this is an important issue, if we called hospice "Fred" then people would not want "Fred." A lot of it has to do with our society's attitudes toward death and dying.

Heffner: Yesterday, Josh taught us about the use of noninvasive positive-pressure ventilation as an approach for patients with neuromuscular disease at the end of life. What is the role of respiratory therapists in noninvasive positive-pressure ventilation at the end of life for patients with lung cancer?

Silvestri: That's a great question. I'm so fortunate to have a great respiratory therapy staff, and we use it. I use it in patients who are "do-not-resuscitate" and are breathless from progression of tumor, malignant airway obstruction, and other things where I say, "Let's ramp it in slowly and see if it can relieve their breathlessness." And we try to do that in a way that doesn't encumber their communication with their family because I try to trade those two things off. We've had great success, and our respiratory therapy staff has had great success. I have used it in the home setting for dying patients with lung cancer. I had no problem with the hospice getting coverage for that and have had respiratory therapists in the home to work that. I think it's a good try. I must say that technology for noninvasive ventilation is getting so much more comfortable, so much better, and that's not my field, but observationally I see my patients with sleep apnea tolerating it better. So we have this new technology that can work and I'd like to see it used more.

One of the things I believe physicians do is they avoid this end-of-life care because they think it's going to produce animosity, and the one comment I would make is that I think the richest experiences I've had with patients have been end-of-life care. Treating asthma, I give them the bronchodilator, they come back and say, "Yeah, I feel good" or "I don't feel good." Treating a patient in the dying process, helping their family through it, can really enrich a patient's life, and it certainly has enriched my life. The appreciation, even in the short amount of time you spend with
them—go to one wake or service afterwards—you will be in that patient’s heart forever. And make one home visit, as John did. It’s been such an enriching experience. Doctors who would get into that more would see that and not be so afraid of being involved.

Rubenfeld: The observation is as you know, after your time at Dartmouth, the things you pointed out about thinking about lung cancer are pervasive—these problems in decision-making and presenting people with alternatives. Although you said we’ve got a lot of prognostic accuracy in cancer, I still submit to you that even though those curves diverge a lot, and in any individual patient, everybody’s got their anecdote of the patient with the metastatic pleural effusion that went a year and such. There is always some variability. So prognostic uncertainty, communication among the team, that is we face this, whether it’s your trauma surgeons, or your transplant surgeons, or your oncologists, whoever the technologic person is that does it—the comments I made yesterday about iatrogenic diseases and the way you think differently from the person who “sells” (if you will) the oncologic treatment, so those communication issues come up in the intensive care unit, in cancer, and the last point (this is where the question is) is this issue of presenting the credible alternative. In other words, I think we all have problems presenting the alternative we actually wouldn’t want to give. For you that might be your ability to present the credible alternative of aggressive chemotherapy. For the oncologist it might be presenting the credible alternative of a palliative care option. So the two questions are: (1) How long does it take you to have this conversation? I realize it’s not just one conversation. But how much time are we talking about to do that? And (2) What’s your advice to people about presenting alternatives in a value-neutral way. John gave some terrific specific advice about—well, there’s this hand, this hand, and the other hand. Any thoughts about those two questions?

Silvestri: I have placed many patients in clinical trials for lung cancer, so I’m not adverse to chemotherapy. What I’m adverse to is that patients may have no choice in the matter. It’s OK even if they believe they only have one extra week of survival, that’s fine with me if they want it, and I’ve seen some great outcomes with chemotherapy. So I’m really not as adverse. We have worked out a system, though, that I think doesn’t work.

First of all, time constraints have made it almost impossible to have this conversation. I would submit to you that after you do the history and physical exam on a new patient with lung cancer, go through the stack of computed tomography scans they brought, look over biopsy results, and maybe schedule a few more tests, you have 15 minutes in a one-hour visit to get that done. So that decision-making process—and then I’m supposed to identify who wants me to make the decision versus them making the decision, versus sharing that process. I’m supposed to have the family members standing behind saying, “Don’t tell them they have a terminal disease.” All that is happening at the same time. That’s why I think decision-making is getting more complicated for me rather than that less.

What we have decided is this. I present them with exactly what John says: “Metastatic lung cancer: This is not good. It’s a very bad disease. You have about a 50% chance of living for 4 months. We can get a couple extra months.” But that hides the fact that some people live less and some live longer. What I tell them is, “Please don’t make any decisions today. Take this literature and read it. Meet with my medical oncologist.” Then I say, “Before you make any decision—because the oncologist might give you a little bit different information than me—call me up and let’s talk about it over the phone, or come back next week and decide.”

One of the problems with cancer, specifically, that’s different from COPD and IPF (interstitial pulmonary fibrosis) is that the most psychologically stressing portion of cancer care, any cancer care (and great studies have been shown here) is that despite the fact that the tumor has been there for years, the uncertainty between diagnosis and the day they either start treatment, or even supportive care, the decision is very stressful for a patient. They want the thing out, the treatment started: Why can’t we start today? What do you mean you need another test? So that all has to happen pretty rapidly. I’ve been able to start working with patients by saying, “Look, this thing has been here for a number of years; it started as one tiny cell.” They believe it’s going to start spreading that second to someplace else. It is difficult. We’ve done it. I call them back, and now a lot of patients are coming back. There was an article in Chest! this week about the number of patients accepting chemotherapy for metastatic lung cancer, and those numbers are going up. More people are getting treated. I have a large cadre of patients who do not choose chemotherapy.

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Fins: A quick comment about clinical trials for chemotherapy. I think we should expect IRBs [institutional review boards] when they approve enrollment in the informed consent process for clinical trials for chemotherapy to talk about the palliative care alternative or component. That should be part of the informed consent process.
Organizational Change and Delivery of Multidisciplinary Palliative Care

Barbara J Daly PhD RN

Introduction
The Problem
Environment
Environmental Change
Organizational and Structural Options
Assessing Strengths and Needs
Continuous Quality Improvement
Summary

Key words: organizational change, administration of intensive care unit, palliative care unit, palliative care consultation team, management of palliative care. [Respir Care 2000;45(12):1501–1510]

Introduction
The purpose of this paper is to address organizational features that affect the provision of palliative care, particularly in acute care settings. The premise of the discussion is that an important part of the explanation for the current inadequacies in care of the dying is failure to appreciate the extent to which the environment of practice influences care providers and processes. This is true in all settings, but particularly evident in critical care. Consequently, consideration of how we can understand environmental influences and design changes in critical care units can serve as an exemplar for approaches to improving care processes in any setting.

There is ample evidence that most practitioners, including physicians, nurses, and respiratory therapists (RTs), are not well prepared in the provision of specific components of palliative care. Previous reports have documented problems such as inadequate pain relief, rigid enforcement of restrictions in visiting, to the detriment of family support, and lack of knowledge and inconsistency in treatment withdrawal techniques.1–3 These data are particularly surprising in that, for many issues, it is not the case that we do not know what should be done or what outcomes we want to achieve—we simply seem unable to accomplish them. Despite the concerns of health professionals themselves about the use of inappropriate, aggressive, and futile interventions, there is ample evidence that these professionals often find themselves providing care that goes against their consciences.4

The two best examples of our seemingly institutionalized failure are pain management and decision-making. For example, Puntillo found that pain, its treatment, and communication about pain were important problems for a substantial portion of the intensive care unit (ICU) patients in her sample.5 Tittle and McMillan similarly found a pattern of undermedication, inadequate assessment, and underreporting of pain in both an ICU and a general surgical ward.6 The well-known Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) confirmed that, even with a well-planned intervention of specially trained ICU nurses and very precise, reliable prognostic data, investigators were unable to affect such outcomes as time in ICU, pain in the last days of life, adherence to instructions in advance directives, and use of complex technology in terminal states.7
The Problem

As with treatment of any problem, designing "curative" approaches to address these issues begins with an understanding of the etiology. Health care practitioners are subject to the same sociological forces as are American society and the health professions in general. Much has been written about the "death-denying" culture in our country, nowhere more in evidence than in acute care.8,9 In addition to this general and pervasive reluctance impinging on most of us, there are several other features or philosophical assumptions common to ICUs that act as barriers to establishing quality palliative care programs (Table 1).

Much of our modern health care system reflects the supremacy of the "technologic imperative." This imperative serves as a default principle that specifies that if a technology is available, it must be used.10 Thus the question “Can we?” always takes precedence over the question "Should we?”—to the point that evaluation of the rationale for intervention is often ignored. This norm continues to exist despite the recognition that an intervention is justified only if there is reason to believe that the intervention is likely to accomplish a defined goal and the burdens of the intervention are outweighed by the benefits, as evaluated by the patient or his or her proxy.

It is quite understandable that these two justification criteria were taken for granted in the early days of critical care. The range of options for saving lives was limited, the raison d'être for the existence of the ICU was precisely to provide specialized lifesaving treatment, and the burdens of attempting to save life were at least circumscribed in that they either worked or did not and the patient died fairly soon. Neither of these features is present today. Patients often do come to the ICU to have their lives saved at all costs, but sometimes they come only for trials of advanced technology and sometimes just because a particular support intervention, such as a ventilator, is not available on the general wards. Once in the unit, however, the range of options is almost limitless. And as our success in treating the most acute crises has improved, we have created a population of patients who are actively but slowly dying and unable to be cared for in the general divisions.

The original orientation of critical care units is perhaps most in evidence in the assumption that survival at all costs is the goal. This is sometimes evident in critical care staff's questioning the appropriateness of having a patient admitted to the unit after a do-not-resuscitate (DNR) decision has been made. Again, when attempts to resuscitate in the event of a sudden arrest were all that the ICU had to offer many patients, it was reasonable to equate DNR decisions in the ICU with inappropriate use of scarce critical care resources. Today, however, we know that treatment limitation decisions are much more complex than dichotomous all-or-nothing decisions. Rather, treatment limitation is best understood as existing on a continuum of aggressiveness, with the level or extent of limitation stemming from individual patient goals. In many cases patients may choose to receive all available interventions, although a cardiac arrest in this context will be understood as an indication that treatment is not being successful and resuscitation efforts will therefore be withheld. The use of standard treatment limitation levels, such as "DNR with all other treatments," "DNR and withholding of specific treatments," and "DNR with withdrawal of specific treatments" reflects the recognition of this continuum.11,12

Similarly, with the proliferation of treatment options, patients more often have the opportunity to express preferences to receive some interventions and to reject others. Mechanical ventilation and hemodialysis, for example, are interventions that some patients will refuse while still wishing to receive all other treatments in the hope that the need for ventilation can be forestalled.

The origins of these characteristics are quite apparent. The more important question is why problems in decision-making and symptom management with terminally ill patients persist despite the evolution of our understanding of treatment limitation, the existence of a body of research on the development of reliable prognostic systems that establish the futility of interventions in specific clinical situations, and decades of court cases formally establishing the right of competent persons to refuse any and all treatments.13 The recalitance of practice norms to overwhelming need for change demonstrates the power of the environment to influence practice.

Table 1. Typical Critical Care Assumptions that Present Barriers to Effective Palliative Care

<table>
<thead>
<tr>
<th>Assumption</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Technologic imperative: if we can, we should</td>
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<tr>
<td>2. All patients come to ICU to have their lives saved</td>
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<tr>
<td>3. Survival at all costs</td>
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<td>4. DNR = do nothing</td>
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<td>5. DNR patients should not be in the ICU</td>
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ICU = intensive care unit. DNR = do not resuscitate.

Environment

Reflection on the history of critical care in the United States suggests an interesting pattern. The opening of the first ICUs in the 1950s and 1960s was sparked by the recognition that greater efficiency and effectiveness could be achieved by creating a specialized environment that facilitated provision of quality care through concentrating people with unique expertise and specialized equipment in one place. As we know, this approach to organization of critical care units has been almost universally adopted.
with progressive degrees of specialization. Throughout this period of specialization, however, “environment” has primarily been understood as referring to the clinical specialization of providers along diagnostic or clinical service lines (eg, medicine, surgery, cardiovascular).

In comparison to the obvious benefits of being able to concentrate staff with special expertise in specialized procedures and use of high-tech interventions, there has been less recognition of the extent to which the environment itself contributes to or detracts from care processes. For the most part, “environment” has been understood simply as the physical structure. The importance of such features as lighting, noise, privacy, and provision for family visiting is clearly important, but represents only one aspect.

A number of studies have documented differences in practice that accompany the development of separate and specialized units. Seamark et al used review of medical records to compare the care provided to terminally ill patients in 12 regular community hospital wards with that provided by a designated hospice unit. Patients on the hospice unit were more likely to be admitted for pain and symptom control and less likely for terminal nursing care, and to have half the length of stay (8 d vs 16 d). Most importantly, community hospital patients had greater use of laboratory tests, radiation, and chemotherapy treatments. This study confirmed the earlier results of the National Hospice Study.

Several authors have reported similar findings after establishing separate units for patients requiring long-term mechanical ventilation. Elpern et al found positive clinical and financial outcomes when patients who required intensive pulmonary management were grouped together in a noninvasive respiratory care unit rather than in a traditional ICU. As found with palliative care units, Gracey et al also reported improved patient outcomes when ventilator-dependent patients were transferred out of the ICU to a long-term ventilator unit.

Why is it that placing patients in a different place changes the care processes? Physical features cannot be the entire explanation. Concentrating people who are expert explains some of the differences that occur, but it appears that the same people function better in a different environment. Explanation from the field of organizational theory suggests that the quality of work is a function of the whole environment, so that, for example, if we change only the people, or change their skill level, but leave the processes the same, we are unlikely to accomplish much real improvement. While there has been a persistent debate about how best to conceptualize organizational environment, sociotechnical theory offers a perspective that is particularly suited to redesign efforts intended to improve palliative care processes in both hospitals and extended care facilities.

Passmore has described organizational environments as encompassing both social systems and technical aspects. Social systems are comprised of the people who work in the organization and “all that is human,” including their attitudes and beliefs, their understanding of their responsibilities, traditions, group norms, hierarchies, and political forces. The technical system consists of the tools and techniques, as the term suggests, but also the methods, choices about how tasks are performed, and patterns and procedures by which work is accomplished. The function of technology is to enhance the quantity and quality of work performed and thus also includes features of the environment such as reward systems, supervisory techniques, role descriptions, flexibility, and variety of work.

Applying this theoretical framework to the ICU, for example, we can categorize the attitudes, knowledge, and preferences of staff, the communication patterns, and decision hierarchy as part of the social system. The methods of assigning nurses to patients, routines for daily rounds, presence or absence of interdisciplinary conferences, policies that direct how tasks are to be performed, and the numbers and types of equipment available represent some of the technical aspects.

Improving the efficiency and effectiveness of organization requires addressing both aspects. This means recognizing human needs and factors that enable people to perform better, such as the preference for autonomy, the need for new learning and growth, opportunity to see the long-range effects of work, to complete and identify with the whole task, maximize equality and minimize subordination, allow workers to set standards, creativity, and full development of human resources. Addressing the technical system factors requires analysis of the processes that foster or impede goals, how goals are set, how the tasks and responsibilities are understood, the criteria of success, and the presence or absence of systems to monitor effectiveness.

Environmental Change

Organizational and Structural Options

Consideration of how to improve palliative care services for patients often begins with the questions of where to care for such patients and who should care for them. These continue to be the subjects of considerable discussion in the literature. There are 3 general organizational and structural approaches: (1) create a physically separate unit, (2) designate a given number of beds and/or staff in an existing unit, or (3) establish a palliative care consultation service. Table 2 lists these options, the factors that must be taken into account in choosing a strategy, and some of the major decisions that are contingent on the choice. If organizational or structural changes are not possible or justified, then steps should be taken through edu-
organizational change and delivery of multidisciplinary palliative care

<table>
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<tr>
<th>Table 2. Practical Determinants of Organizational Structure</th>
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<tr>
<td><strong>Option</strong></td>
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<tr>
<td>Separate unit</td>
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<tr>
<td></td>
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<tr>
<td>Designated beds within unit</td>
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<td>Consultation team</td>
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cation and continuous quality improvement techniques to improve the overall standard of care. Strategies for this will also be addressed.

The well-documented success over time of palliative care units and hospice in general reflects the advantages of creating a new, separate environment.24–26 As with any critical care specialty, there are obvious benefits to having a separate unit where the goals of care are uniform and staff can be specially trained in appropriate techniques. However, in most instances, the ability to create such a unit is determined more by the many practical considerations, such as those listed, than by preference. A proposal to establish a palliative care unit must first establish feasibility. The average census of patients appropriate for such a unit must be documented, as well as the actual availability of space. The expense of supporting a small unit that averages only 4 or 5 patients at any one time will usually rule out this strategy. Given the fixed costs of overhead and the loss of some staffing flexibility, operating two small units will generally be more expensive than operating one large unit. In addition, support for admitting patients to this unit by the physician staff must be considered.

Equally important in evaluating feasibility are staffing considerations. In order to operate a palliative care unit, there must be sufficient staff (medical, nursing, and support services) who are interested in working in such a unit. Recruitment strategies can assist in identifying individuals who would find such a unit an attractive workplace, but opening any new unit needs to begin with the availability of at least a small core of staff committed to the project.

If it is either not possible or not justified to open a separate unit for palliative care patients, then patients with these needs must either be integrated among the unit’s population or segregated within the unit, such as by designating certain beds as hospice or palliative care beds or by creating a “palliative care team” among the regular staff. With the decision to open a distinct unit, the usefulness of designating certain specific beds or staff depends in large measure on feasibility issues.

Less concrete and perhaps more important than the relatively apparent practical constraints is the rationale for the decision of how to organize care. If, for example, the major roadblock to providing effective palliative care is lack of recognition of when it is appropriate to change the goal of care to palliation, then creating a separate unit will be of no use, and may even make it less likely that clinicians recognize the need. On the other hand, many ICUs are strongly developed around the provision of aggressive, life-prolonging therapies, are highly specialized, promote the use of very sophisticated technologies, and typically recruit staff who enjoy the fast pace and relatively short stay of patients. In some institutions it may simply be more efficient to designate a different environment for the provision of palliative care than to attempt to address all the features of this environment that would need to be changed. Asch et al, in a report of a survey of 468 critical care nurses’ views on end-of-life care noted that “the most compelling concept expressed by the nurses was that the environment of critical care is often insufficiently responsive” to patient suffering.27 The authors concluded that some ICUs might simply be unable to foster the compassion needed to support appropriate care of the dying.

One important disadvantage of creating a separate palliative care unit is that it supports the myth that palliative care—intensive symptom management, periodic reassessment of goals, and concentrated attention to the psychosocial needs of patients and families—is needed only by dying patients. The availability of special units for the dying then has the unintended effect of minimizing the importance of these elements of care for all patients. Fisher et al noted this danger of restricting care of the dying to just hospice personnel.25 Since hospice, or any specialized palliative care service, will never be able to assume care of all dying patients, this approach runs the risk that others will not have appropriate training and skill.

Managers sometimes are concerned that it is just too difficult to expect any critical care staff to be skillful in providing aggressive life-saving care for some patients and, at the same time, provide care oriented toward allowing a peaceful death. Although there are some differences with any specialty, it is not the case that segregating patients relieves staff of any need to be knowledgeable, nor
that some central skills, such as assessment and caring, do not cut across specialties. For example, Samarel, using ethnographic participative observation to study nurse-patient interaction in a hospital unit designated for both hospice care and acute care, found no differences in how nurses interacted with hospice versus acute patients. She postulated that highly developed caring attitudes resulted in gentle, appropriate models of caring strategies for both groups of patients. She concluded, contrary to Asch's findings, that it is possible for some nurses to deal with dichotomous populations effectively. Similarly, Mathew et al reported on the successful integration of hospice beds into an active medical teaching service; in fact, house staff in this study reported feeling more comfortable dealing with terminally ill patients as a result of their hospice experience.

A last alternative that has shown promise is the use of palliative care teams that serve as consultants to the primary team and in some instances assume responsibility for directing care. The model at Detroit Receiving Hospital is among the best known of the services designed specifically for critical care patients, although consultation teams have been used in acute care hospitals in the United States and other countries for some time. In extended care facilities this model is represented by referral of the patient to a freestanding hospice whose personnel then follow the patient and consult with the nursing home staff. Having such a service available has the advantage of providing ongoing assistance and education to staff and may obviate transfer out of the unit, as well as demonstrating the provision of improved symptom management. As with the other alternatives, the feasibility of this model is primarily determined by practical factors such as the availability of clinicians with specific expertise in palliative care and a sufficient workload to make such a service economically sound. In the case of patients in extended care facilities, the conversion to hospice status also may have important reimbursement implications for both the patient and the facility. Advantages and disadvantages of these models are summarized in Table 3.

Assessing Strengths and Needs

As can be seen regardless of which alternative is chosen, changing the environment begins with accurate assessment of both the social and technical aspects of the current environment. This is particularly important if organizational changes are not possible and efforts must be made to implement change within a given environment. Table 4 lists some of the most important aspects to investigate prior to planning changes. The purpose of the assessment is to identify those features that may act as barriers to changing the effectiveness of the care provided.

In some ways, the social aspects—characteristics of the staff—seem the most important and typically garner the most attention. Attitudes and beliefs of the nursing and medical staff are certainly important and can be readily assessed through use of surveys and tests. The Frommelt Attitude Toward Care of the Dying scale, for example, is a short 20-item Likert scale survey that can provide helpful information about general attitudes toward palliative care. There are also a number of tools available that can be used to assess knowledge and beliefs about pain management. It is often helpful to add several questions to any standardized assessment tool to seek information about staff preferences and perceptions about the environment, such as, “How well do you think we do in caring for the dying?” or “What is the most frustrating aspect of caring for a patient who is dying in the ICU?” Information such as this can be used in several ways. Summaries of responses are very powerful prompts for group discussions, and these can be helpful tools for general discussions as part of team-building exercises. Questions such as these also sometimes indicate hidden issues among staff members that have not previously been identified by managers. The data from such surveys are most helpful in identifying whether there are educational needs or attitudinal issues behind problems with standards of care. Last, questions such as these can be used to generate baseline data for demonstrating and measuring change, as part of evaluating the effectiveness of organizational initiatives.

There is a tendency in the health care professions, particularly in academic centers, to assume that the answer to changing behavior always lies with providing more education. While continuing education is often needed, attitudes and preferences play an equally strong role and must not be ignored. It is helpful, though, to review the education that has already been provided for the staff, to identify explanatory factors. For example, if the initial ICU orientation does not provide any content on palliative care or pain management and none of the staff development activities involve concepts of palliative care, it is understandable that many staff will be lacking current knowledge in this area. Certainly, content specific to the types of issues that arise in that particular environment is needed. For example, critical care units should have classes and discussions specifically covering techniques for discontinuing mechanical ventilation, whereas extended care facilities should routinely discuss withholding and withdrawing of artificial nutrition and hydration in their orientation programs.

Our tendency to focus on the knowledge base of personnel sometimes contributes to a lack of attention to the technical aspects of the environment. These features are critically important in influencing behavior and must be carefully addressed. As indicated in Table 4, a good place to begin this is with a statement of philosophy. Most critical care units do not have a statement of philosophy because it is assumed that the mission of the unit is clear—to save lives. A very helpful activity when initiating a change...
Table 3. Advantages and Disadvantages of Palliative Care Units and Teams

<table>
<thead>
<tr>
<th>Type of Organization</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>Separate unit</td>
<td>Facilitates specialization and acquisition of high level of skill among staff</td>
<td>May reduce general skill level among other staff</td>
</tr>
<tr>
<td></td>
<td>Centralizes staff who prefer this specialty</td>
<td>May increase costs and decreases efficiency if volume is low or inconsistent</td>
</tr>
<tr>
<td></td>
<td>Enables development of policies and procedures designed just for this population</td>
<td>Highest requirement for adequate numbers of staff</td>
</tr>
<tr>
<td>Designated beds and staff within a unit</td>
<td>Facilitates specialization and acquisition of high level of skill among some staff</td>
<td>May reduce general skill level among other staff</td>
</tr>
<tr>
<td></td>
<td>Allows some ability for staff who prefer this population to specialize</td>
<td>Supporting different philosophies and procedures within one unit may create conflict and competition for resources</td>
</tr>
<tr>
<td></td>
<td>Allows for staff and bed use to be adjusted daily as patient census and needs fluctuate, thus maintaining efficiency</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enables development of policies and procedures designed just for this population</td>
<td></td>
</tr>
<tr>
<td>Consultation team</td>
<td>Provides patients with access to experts</td>
<td>Financial security for consultation team depends on constant and adequate referrals unless the team has other sources of income</td>
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<tr>
<td></td>
<td>Avoids need to transfer patient to other area as goals of care change</td>
<td>May convey the message that other staff do not need the skills of palliative care</td>
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<tr>
<td></td>
<td>Consult team can be effective teachers and role models for other staff</td>
<td>Effectiveness of consultant is determined by willingness of staff to follow recommendations</td>
</tr>
<tr>
<td></td>
<td>Minimizes need for changes in staffing or physical environment</td>
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Table 4. Organizational Assessment

<table>
<thead>
<tr>
<th>Component</th>
<th>Element</th>
<th>Method</th>
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<tbody>
<tr>
<td>Social components</td>
<td>Attitudes of staff</td>
<td>Survey</td>
</tr>
<tr>
<td></td>
<td>Knowledge of staff</td>
<td>Tests</td>
</tr>
<tr>
<td></td>
<td>Orientation program</td>
<td>Content review</td>
</tr>
<tr>
<td></td>
<td>CE offerings</td>
<td>Review offerings</td>
</tr>
<tr>
<td></td>
<td>Preferences of staff</td>
<td>Survey, team meeting</td>
</tr>
<tr>
<td>Technical components</td>
<td>Statement of philosophy</td>
<td>Content, theme analysis</td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
<td>Role descriptions</td>
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<td></td>
<td></td>
<td>Evaluation tool</td>
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<tr>
<td></td>
<td></td>
<td>Reward system</td>
</tr>
<tr>
<td></td>
<td>Documentation system</td>
<td>Review forms, standards</td>
</tr>
<tr>
<td></td>
<td>Assignment pattern</td>
<td>Review patterns</td>
</tr>
</tbody>
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CE = continuing education.

All environments are replete with features that communicate the expectations for behavior to staff. These are sometimes subtle and sometimes overt, but always require modification if we are to accomplish change. Role descriptions and evaluation tools should be examined for any explicit statements describing the desired behaviors. This might include such things as “coordinates multidisciplinary plans of care for dying patients” or “individualizes plan of care to meet the unique needs of dying patients and their families.” Recognition that expert palliative care requires a set of particular skills, just as any other specific dimension of health care, such as patient education, hemodynamic monitoring, or caring for mechanically ventilated patients, rests on the ability to define and enumerate these skills, which can then be used in the evaluation process. McClement and Degner have summarized the most common “expert nursing behaviors” identified in the nursing literature, and many of these are equally usable by any discipline.36

As managers, we know that expectations directly influence behavior, but we sometimes apply this principle only to our verbal expressions and neglect the many ways expectations are communicated. Another way in which expectations are conveyed is through reward systems. For nurses, these rewards might include such formal steps as promotion on a career ladder or informal signs such as positive anecdotal notes in a personnel folder or being provided with some paid time in which to work on writing care plans or using work time to attend a conference on palliative care. Meir et al argue for the importance of
financial support for physicians, clinical and programmatic research, professorships, and the availability of teaching mentors in creating a positive climate for palliative care.\(^7\)

Sociotechnical theory also directs us to pay attention to the routines and procedures in the environment that can act as barriers or facilitators to the desired work processes. Typically, there are many features in a critical care unit’s operations that have strong effects on how work is accomplished, but two of the most important for nurses are the assignment pattern and documentation system. It is another obvious but frequently ignored principle that consistency in care providers is an essential feature of quality. Because the majority of patients in an ICU are there for only short periods of time, systems to assure consistency, such as primary nursing, have not been well developed. For most patients this does not have important effects on their care. However, for the dying patient and family, establishing personal, intimate relationships with caregivers and having confidence that the caregiver knows the plan of care and understands what is important in the last few days is absolutely critical. Clearly, there are multiple factors that have to be taken into account in making patient assignments on any one day, such as skill level, learning needs, and preferences of the staff, but consistency of care must be at least added to the list. Some units have adopted a pattern of forming “primary teams” to deal with the problems inherent in the use of 12-hour shifts, which tend to increase inconsistency over time.

The documentation system can also be either a barrier or facilitator. Documentation is a central work process in any health care environment. As such, it can have important effects on both the social and technical aspects of work.\(^8\) Quite simply, if we want staff to pay attention to certain aspects of care, requiring that these be documented is a straightforward way to reinforce this behavior and also to provide a tool for monitoring. However, it is not a simple matter to alter documentation systems and habits without adding unrealistic expectations for cumbersome, redundant charting. It is possible, though, to make some minor modifications that help guide staff in the desired direction. For example, if pain management is an issue, adding a column on the ICU flow sheet or vital sign record for regular recording of the pain level, using a 1–10 scale, reminds the staff to assess pain hourly. Voigt et al confirmed the effectiveness of this in their program to improve pain management in patients undergoing cardiac surgery.\(^9\) Using a pre-post design, the researchers found a significant decrease in the average pain levels experienced by patients after the addition of a pain flow sheet to the standard documentation system.

Using preprinted forms to document the discussions and decisions at a multidisciplinary team conference makes it easier to ensure that all staff are aware of plans. Computer screens can be designed to have places to record the name of a primary nurse and automatic 7-day reminders to update care plans, with designated areas for documenting level of treatment limitation, pain, and dyspnea management approaches.

It is particularly useful to have preprinted forms that require specification of the goal of treatment for all treatment limitation decisions. This prompts staff to evaluate the decision to withdraw or withhold specific interventions, such as mechanical ventilation or vasopressors, in light of the goal of care. The aim of this is to decrease the likelihood that such decisions will be arbitrary and more related to professional biases than part of a coherent plan. For example, if the goal is to facilitate a peaceful and inevitable death, withdrawal of all life-prolonging interventions may be indicated. If, on the other hand, the goal is to maximize the chance of returning the patient to his home once more without adding to the current burdens of treatment, withholding additional interventions might be indicated whereas withdrawing treatment and monitoring would not.

Consideration of documentation systems also involves evaluating the place of standardized care plans or care paths. These can be very helpful in guiding staff to attend to common areas such as pain and other symptom management. Unfortunately, because dying patients do not fit neatly into single diagnostic categories, use of such standardized tools may result in more variance than compliance. If care paths are to be used, they must be written broadly enough to encompass the many different kinds of issues that come up.

A slightly different approach, which borrows its rationale from the care path literature, is to add standards to existing care paths. For example, we know that in the ICU there are some specific common trajectories and syndromes experienced by dying patients. Long-term mechanical ventilation, end-stage congestive heart failure, multi-organ system failure, and liver failure are among the frequently-seen patterns. It is therefore reasonable to add palliative care elements to any care paths used for these populations. The elements can be written with some flexibility, using such standards as treatment limitation discussion held by the fifth day in the ICU and repeated at least every 3 days, involvement of the patient’s clergy if desired by the patient/family by the third day, social work consult by the third day, provision of appropriate support resources to family (eg, grief counseling, support group name and number) by the day of patient death. This serves multiple purposes: it guides staff in knowing what behaviors are expected; it sets a standard for use in monitoring; and, perhaps most importantly, it works against the tendency to avoid thoughts of death.
Continuous Quality Improvement

Regardless of whether the issue of palliative care is addressed through major changes in the environment or minor modifications in procedure, attention to effectiveness must be ongoing, or the strong technologist and interventionist biases of the critical care environment are likely to overcome positive changes. The principles of continuous quality improvement (CQI) can be very useful in assuring that we monitor and address ongoing needs.

Much has been written about this management technique. Briefly, CQI is best understood as a framework for assuring that there are continual improvements in the work of an organization. The assumptions underlying the framework include, first and foremost, recognition that work production occurs within a system of interdependent parts and that improvements are a function of the application of values, professional knowledge, and knowledge of how to make improvements. Analysis of opportunities for improvement requires a thorough understanding of the processes of work that occur between the parts, as well as the identification of what constitutes quality, both from the consumer and professional standpoint.

Continuous quality improvement departs from traditional management approaches in assuming, as does sociotechnical theory, that workers are creative and invested in their work, that identifying and removing barriers will enable them to achieve, and that learning and mastery are fundamental needs of all humans. Thus, motivating individuals to perform better does not require more rigid structures and rules, but may instead require providing opportunities for employees to take part in the analysis of barriers and redesign of more effective processes. Variations are not assumed to reflect merely poor performance of individuals, but are instead analyzed to determine if the variation is assignable to system problems or if it is merely common, random variation that cannot be reduced without altering the input or characteristics of the task.

This process can be illustrated with a very simplified analysis of a common problem in critical care units. Because of the complexity of illness of most patients, consultants are used quite routinely. Ideally, input from the consultants is transmitted through the primary team. That is, decision-making remains with the primary team, and communication with patients and families should be made with the agreement of the team, through the team, or in the presence of someone from the primary team. In all cases, the consultant must be aware of the goals already established between patient and providers and the plan of care. Suppose, however, that several of the consultants frequently talk directly to patients’ families without talking first with the primary team and that this has resulted in inconsistent messages to family members, confusion, and the need to reassess and regroup.

One approach to addressing the problem might be to assume that the individual consultants are at fault. This might be followed either by ceasing to use these experts or by establishing a policy that no consultant may talk with the patient’s family without first talking with the patient’s primary physician. Note that this approach assumes that the source of variance in question (inconsistent communication) can be traced to individuals not performing appropriately, without further analysis of any system factors that might generate this behavior.

Continuous quality improvement analysis would instead first analyze the processes surrounding this aspect of work. Figure 1 is a simplified example of the processes of communication regarding patient condition. The lines represent processes occurring between parts of the system, in this case, communication between people. The nodes represent points of analysis, indicating that every process surrounding the identified variance must be understood and assessed as an opportunity for improvement. In our hypothetical situation, a discussion among all involved might reveal that, first, there is some common variance in their behavior simply because of unique, uncontrollable features of the clinical situation. Patients and their families, for example, may ask the consultant to explain his findings as he is examining the patient; thus it is not reasonable to expect that no communication take place. In addition, there is often no one from the primary team available when the consultant examines the patient. Given this, it is imperative that the consultant have at least a basic understanding of the plan of care, current goals, knowledge of what further decisions are contingent on his recommendations, and a clear agreement with the primary team about communication with the patient and family. Thus, the process to target for improvement is not communication between consultant and family, but rather communication between the primary team and the consultant prior to the consultation.

As can be seen, CQI differs from isolated quality assurance projects in that it requires a philosophical commitment both to principles of improvement and human relations. It is founded on a deep appreciation of organizations as systems of interconnected and interdependent processes. A considerable body of literature has been de-
veloped on this topic and the reader is referred to these references for a more complete discussion.4,0,2-44

Summary

This discussion has been intended to complement the more specific discussions in the conference of discrete areas for improving the care provided to dying patients by respiratory professionals, such as pain management, communication techniques, and treatment withdrawal methods. I have argued that in order to facilitate changes in one area and incorporate these changes into stable components, attention must be paid to the overall environment in which care takes place.

Features of the organizational environment that are most readily addressed are the physical location and the knowledge and skills of personnel. These are always appropriate to target for improvement. However, a comprehensive understanding of the environment as a system of both interacting structures and processes is required if we are to design and redesign facilities that encourage us to collaborate and continuously improve the care we provide, rather than facilities that are overwhelmingly characterized by the rule of rescue.

REFERENCES


Discussion

Editor’s note: Barbara Daly was unable to attend the conference, so her presentation was made by and the discussion lead by the Conference Co-Chairs, Gordon Rubenfeld and Randall Curtis.

Rubenfeld: It’s a superb manuscript. These structural issues are probably the key to trying to do a lot of this, and she really did a great job.

Curtis: It’s something that Gordon and I believe strongly, and yet we sort of give short shrift to, because it’s so difficult to make structural changes. With that, let’s throw it open and get comments from people.

Benditt: I hate to keep haranguing on this, but the terminology and this binary thing [dichotomy between curative and palliative care] is really becoming a major theme in my head. I looked at the Oxford Textbook of Palliative Medicine,1 and the introductory chapter gave a nice new diagram of what they think palliative care should be, and that is that even at the time of diagnosis there’s a little bit of palliative care there, and as a terminal disease progresses it becomes more and more palliation—a continuum rather than a binary process. How can we get away from this binary perspective?

REFERENCE


thing we educate physicians very well about. I think that will probably be their most important legacy.

Hansen-Flaschen: Several years ago, we decided that our 24-bed medical intensive care unit has 3 goals: to restore health when possible, to initiate comprehensive rehabilitation, and to care for the dying. We’ve incorporated the third goal into our concept of medical intensive care on the idea that this unit is very richly endowed with staff, 1-on-2 nurses, 1-on-4 house staff, students, pharmacists, 2 attendings for 24 beds who pretty much live there for the duration. We have a staff that we can bring to the bedside of someone who was dying much more comfortably than somewhere else in the hospital.

It had two practical implications. We started accepting critically ill patients from other ICUs in the hospital and elsewhere in the region who were dying. And we started holding onto people who were dying for a few days in our ICU. As a result, we started drawing patients from a helicopter transport radius, as people realized that we would take their very sick patients. Our mortality rate went way up—way way up. There is a down side. We found it’s very hard to fully staff a medical intensive care unit in an ICU-nurse-shortage area where we have such high morbidity and mortality. Today 6 of our 24 beds are closed for lack of capable ICU nurses while we establish some strategy to bring people back into this environment.

In summary, what we found is that it is possible to incorporate hospice into the core purpose and value of an intensive care unit. You can turn an ICU bed into a bedroom for a dying patient. However, it’s very hard to staff such a unit, particularly in a cost-containment era.

Rubenfeld: Let me just read what Barbara [Daly] wrote about that:

Most critical care units do not have a statement of philosophy because it is assumed that the mission of the unit is clear—to save lives. A very helpful activity when initiating a change process is to ask staff to write a brief statement, 4 or 5 sentences, of the philosophy of that unit, specifying the mission and values. This is an unusual activity for most critical care personnel but it can be very effective as an initial assessment tool.

Obviously that can be effective as a change tool.

Curts: I want to make a point about what both Joe [Fins] and John [Hansen-Flaschen] said. These models that Barbara presents are obviously one way of viewing it. Joe has actually presented something that I would argue is a combination of the first and third models. So it’s a separate unit, but the team functions as a consultation team. John very nicely made the point that different models may work best in different institutions. This isn’t going to be a one-model-fixes-all approach. That’s going to be most apparent, obviously, in the rural hospital with a 4-bed ICU, where they are not going to create a 2-bed palliative care unit.

Heffner: The comments are really right in terms of organizational change, and I think that Gordon [Rubenfeld] highlights that this is part of our performance improvement theory; it’s not the individuals but the process of care. If I can review a personal vignette, too: we were very interested during my last position in Arizona to have organizational change around enhancing the awareness and perceptiveness of all caregivers for ethical issues and ethical dilemmas. We attempted to do what Gordon suggested in teaching people how to recognize the problems so we could initiate a solution. We found that administrators were extremely resistant because they were interested in cost reduction. So we worked at the grass roots through nursing and respiratory therapists, and we found a very receptive audience. Their value structure was more oriented toward a patient-centered approach. We trained nurses and respiratory therapists to be perceptive about ethical dilemmas or palliative care issues the same way we trained them to identify skin breakdown. They became our alert system for ethical problems. We also informed them of the legal liability for caregivers of not noticing problems. We helped the nurses to become empowered and use their chain of command that may or may not always include the physician. If they were thwarted in their identification of an ethical dilemma and notification of the primary physician (in terms of getting a reasonable response), they had alternative routes that were not competitive but contributive to the mission of the unit in which they worked.

Rubenfeld: It’s unusual in my experience that physicians initiate ethics consults. They come from the groups of people you’re talking about.

Tudy Giordano: My father was diagnosed with neuroendocrine pancreatic cancer in January. Following a chemotherapy treatment he experienced a transient ischemic attack and was admitted to the oncology floor for observation. The physical layout of this floor was conducive to supporting the patient and family. Families can live there, essentially: there’s a refrigerator in the room, the couch makes out into a bed, there’s a VCR in every room, and the unit has a huge family area complete with a full-service kitchen. The unit is phenominal; it had just been remodeled, yet it excluded every patient but oncology patients.

To me, as a respiratory care practitioner, I thought “What a perfect place for COPD patients.” We can learn so much from oncology models and extrapolate them to the COPD patients, but we don’t. It’s unfortunate that palliative care is often limited to those
with cancer diagnoses. Clearly, people are dying of other diseases who could benefit from the progress in oncology care.

Curtis: Really good point. You could argue that what we’re learning there is oncology nursing, not necessarily oncologists. It’s really a structure of the unit and the nursing approach to oncology that could be so useful in so many ways.

Tudy Giordano: It’s a supportive care, and I think if we get into names, “support care” isn’t threatening to a patient, or wasn’t to my dad, when they told him, “You’re going to the oncology floor.” He said “But, I’m dizzy, that’s all I am.” I said, “You have a cancer diagnosis, but it’s a supportive unit.” And, he went, “Oh, OK.” As long as he didn’t think he was going to the oncology floor, because people do associate that with the death walk.

Levy: I want to reinforce what I think I heard Joe [Fins] and Randy [Curtis] say, which is that not only are different models appropriate for different places, but different combinations of the models may be used as a means to get rid of the model altogether. We wouldn’t want to put forth a model that led us to not train all caregivers to deliver palliative care in a critical care unit. So one view of these models is as a vehicle for getting to the point where you don’t need the model anymore. I think that’s really important, because we’re talking about how to improve end-of-life behavior. We don’t want to create a model where we, in fact, do the exact opposite.

When I worked at a small local hospital in Massachusetts during some performance improvement work, I really became the pulmonary critical care doctor who was consulted by other pulmonary critical care doctors when they couldn’t withdraw life support, because they didn’t want to do it, and unfortunately there was no opportunity for learning involved in that situation.

Rubenfeld: I wouldn’t be the least bit surprised if a number of people around this table have that reputation locally.

Heffner: I think the theme of this meeting is that we’ve got a number of hindrances to improving palliative care in terms of knowledge and acculturation, and our success is going to be a long road toward organizational change. But a common theme addressed during this conference is that this change takes a long time to build but only a short time to tear down. The fiscal restraint we live under threaten the movement to improve end-of-life care. We may have to challenge ourselves with clearly articulating our arguments in support of palliative care so that we can address those threats in a consistent and organizational way.

Rubenfeld: As usual, John, you’ve made one of the key points. We’ve talked about this around postgraduate course at ATS [American Thoracic Society] that some of us were involved with, and the big change-in-education challenge to the people at this table is how to get the people who aren’t at this table to this table. We have no problem preaching to the choir. We have no problem getting the choir to attend. We have no problem getting the choir to sing. The problem is how to get people who are outside the church, if I can beat the metaphor to death. That’s a problem: I don’t know what the solution is. I loved your idea of empowering, because I think you were right. When I talk about this, the people who come to the talk are nurses and respiratory therapists. So maybe the answer is you go through them and empower them.

Fins: I would just be shameless in talking to administrators and asking them about the death of their parents or their kids, or their spouses, or their siblings, and ask them how their loved ones died. After they start tearing up, say, “You really want us to do it better, don’t you agree?” Because I think we tend to distance ourselves from that reality and that these people are deeply concerned. They want to do the right thing. They want to set priorities. They too are operating under fiscal constraints and have to create a budget every year. But you need to make it a personal plea and tap into something deeper within them. Then you have an opportunity to promote change, because allies of palliative care have to be throughout the organization.

Levy: Guilt!

Fins: Guilt is good. My mother taught me that.

Rubenfeld: One of the points that Barbara [Daly] makes in her manuscript is the value of paper prompts and forms. This is a form I just put up that you can’t read, which is something Randy and I have been working on with a group at Harborview [Hospital, Seattle], and I’m sure many of you have similar types of protocols—perhaps even for comfort care in the ICU. This is our “comfort care orders” in the ICU that goes through some of the steps I talked about yesterday.

The point here isn’t to have you critique our midazolam dosing, but rather to take note of the fact that it’s on a form that begins with the fact that a do-not-attempt-resuscitation order has been written, and that there’s been a formal documentation in the chart. Also it makes the point that on the back of this form is a set of principles, sort of an educational opportunity. Do we have any idea that this is effective? We don’t—not yet. But the point here is that you take the opportunity to educate and to provide people with a paper order form at the same time. Barbara makes this point in her manuscript about documentation of the discussion. So I think it’s very important.
Death and the Practitioner

Louisa Viles MSW

Introduction

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Organizational Responses to Clinician Distress
Improving Clinician Coping in the Intensive Care Unit

Risks and Costs of Coping Strategies

Key words: palliative care, end-of-life care, stress, burnout, coping, death.

Introduction

Many health care providers find caring for dying patients difficult. What can providers do to cope with their own feelings, discomfort, and distress regarding dying patients? How can these skills and techniques improve the care that providers give?

Scope of the Problem: The Difficulty of Dealing with Death in the Health Care Setting

Stress is recognized as one of the major “occupational hazards” faced by health care practitioners. Health care professionals in various settings who are both responsible for the care of and repeatedly exposed to the distress of dying patients and their families face additional challenges. With few exceptions in our society, dealing with death is uncomfortable at best, and wholly avoided at worst. While proximity to dying people may provide a feeling of honor or enlightenment, for the most part death remains taboo. Clinicians who work with death and dying risk “contamination” and may attempt to hide or minimize this aspect of their work. Those who face death daily spend their working lives on the fringe of our cultural comfort zone.

Stress and Burnout in Dealing with Death

Expanding the definition of what is “stressful” from a purely biological “stimulus and response” state to a relational concept helps to explain why one clinician may characterize aspects of working with dying patients as “stressful” while another may not. Expanding research efforts to quantify the stress of working with dying patients, Lazarus and Folkman suggest that “there is no objective way to predict psychological stress as a reaction without reference to properties of the person. Psychological stress, therefore, is a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.”

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A version of this paper was presented by Ms Viles during the RESPIRATORY CARE Journal Conference, Palliative Respiratory Care, held May 19-21, 2000 in Cancún, Mexico.

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Hospice professionals have been shown to rank issues relating to death and dying lower than symptom management as occupational stressors and may have lower death anxiety than other providers. However, health care practitioners in hospital or home care occupations repeatedly include dealing with death among the most distressing aspects of their work. The reasons for these differences are enlightening. While there may still be uncertainty surrounding the circumstances of death for patients in hospice care, this care is more explicitly located within the context of palliative care: the “shift from cure to comfort” has been formalized in eligibility criteria. Workplace stress in hospice may also have been adequately addressed earlier in the development of the hospice model.

While the literature reports various signs of distress and dissatisfaction among physicians, contributing factors often include myriad factors, such as increased paperwork, changing reimbursement mechanisms, increased patient access to information, the threat of litigation, and increasing medical technology. Few studies outside of the palliative care literature have focused on the effects of working with dying patients on the physician, and even less is known about the strategies used by physicians who cope successfully and find satisfaction in the challenges of working in the intensive care unit (ICU) and other nonhospice settings with terminally ill patients. To reduce clinician distress—the perception of the negative effects of stress—strengthens clinician coping skills, and improve end-of-life care, the focus must shift from whether caring for dying patients and their families is difficult to how this stress, both negative and positive, manifests and impacts both the caregiver and the quality of care given.

Stress in the context of providing care to critically ill or dying patients may not always be experienced as a negative factor by clinicians. Clinicians may find fulfillment in opportunities to apply their professional skills. Discussions of stress on health care practitioners may be hasty in pointing to clinicians as “burned out.” Effective coping strategies include defense mechanisms that may be justifiable responses to the stress of ongoing work with dying patients. Adaptation to the sounds and smells of an ICU and desensitization to or “denial” of patient suffering may allow clinicians who face death daily to maintain composure where others would be in crisis. Yet when the cumulative effects of sustained exposure to the negative effects of dealing with death outweigh a clinician’s satisfaction, stress feels like distress. In the helping professions, the concept of “burnout” has been developed to help identify and understand the detrimental constellation of signs and symptoms associated with the unmitigated stress of caring for others.

A pioneer in occupational stress research, Christina Maslach offered that “burnout is a syndrome of exhaustion, depersonalization, and reduced personal accomplishment.” Often characterized as a process, the “phases” of burnout may be loss of motivation and idealism, loss of concern, distancing, or outright contempt for one’s patients or one’s job, increased frustration and somatic symptoms, and, finally, a desire to leave the field. It is likely that a clinician need not reach the level of “burnout” before inadequate or insensitive coping strategies negatively impact those in their care.

**Impact of Clinician Distress on Patient Care**

Research on stress and dissatisfaction among health care workers, especially in nursing, may have its roots in institutional attempts to reduce the financial impact of staff turnover, especially during critical care occupational shortages, and only recently has focused on employee health and well-being. While the literature on patient and family needs in critical care settings has grown, little is known about the impact of clinician stress and coping behaviors in the quality of care of dying patients and the satisfaction of their family members with this care.

Left unexamined, the attitudes and behaviors of health care workers will impact end-of-life care, including discussions and decisions regarding withholding or withdrawing life-sustaining treatments. Despite moves toward shared decision-making and incorporating patients’ preferences in end-of-life care, research suggests that physicians’ preferences supersede those of patients or other members of the health care team, resulting in inconsistent approaches to the care of dying patients, which may negatively affect the family’s experience of care and the confidence of members of the health care team in individual and team actions.

Clinician tolerance of uncertainty plays an important role in attitudes toward dying patients. Physicians with unexamined discomfort with the uncertainty of disease process and treatment, the certainty of death when treatments are withdrawn, or with the very processes of withdrawing care may favor methods of withdrawing life-sustaining technological that shield them emotionally from a patient’s death. Feelings of failure or hopelessness that continuous exposure to death engenders may lead to wishes that the patient would die. In the critical care setting, a physician’s ambivalence or ambiguity about withdrawing life-sustaining treatments may serve as a buffer to his or her emotional reaction by avoiding discussions of the patient’s prognosis with family or other members of the health care team. The physician’s coping mechanisms, while decreasing his or her stress, may actually exacerbate the distress of the nurse or respiratory therapist (RT) charged with carrying out these measures. Conflict within the health care team is transparent to many families that observe interclinician tension and may per-
ceive that the best care is not being given. Their mistrust of the health care team’s motives can become a barrier to family willingness or ability to forgo life-sustaining treatments.9

Whether because of inadequate training in end-of-life communication, personal discomfort, or a combination of the two, some physicians have been shown to avoid discussion of advance care planning with patients or discussions of withdrawal of life-sustaining treatments with families. When discussions do occur, some clinicians use euphemisms for death or minimize poor prognosis to minimize negative emotions in such a way that patients and families may not realize that a discussion about futility or treatment preferences has taken place.10 Younger medical residents who report higher death anxiety and are uncomfortable caring for dying patients may be more likely to use avoidance or denial coping strategies.11

Humor in health care is often used to decrease anxiety, create breaks in tension, and create the perception of social support. As a short-term strategy, use of “gallows” humor, especially among ICU staff, may serve this end, but the sense of solidarity gained can be fleeting. Gallows humor may leave individual clinicians pressured to react to workplace antics, while the real benefit of a shared laugh with colleagues is no longer enough to offset compound unresolved grief and frustration. The incongruity and perceived irreverence of laughter around a dying loved one may engender negative emotional reactions by family members toward practitioners. Palliative care reduces the pain and discomfort of disease and dying when treatments aimed at restoring health are no longer helpful. Palliative coping relieves the immediate discomfort of dealing with death, but may not allow clinicians to acknowledge when they feel hopeless.

Sources of Stress and Distress

Stress in health care is caused and manifested on multiple levels, including that of the individual clinician, between clinicians, between patients and family members, and on an organizational level.

Sources of stress on the organizational level include inadequate staffing and increasing workloads with a resulting inability to use sick or vacation time, to rotate into other positions, or even to take allotted daily breaks. Ambiguous work expectations and lack of institutional supports such as supervision, combined with poor orientation and education in palliative care and lack of emotional support can leave clinicians emotionally and physically exhausted and breed conflict among caregivers.

Dealing with Death in the Intensive Care Unit

ICU staff face the challenge to provide aggressive and highly technical care for the most acutely ill patients in the health care setting, with the goal of preserving life, while acknowledging that a substantial portion of the time these efforts will end in the patient’s death. The technologic monitoring and treatment devices and the clinical skills that form the basis for professional competency in the ICU may become barriers to personal communication and care between the provider and patient. ICU clinicians juggle the provision of highly technical medical interventions while making psychosocial assessments and developing and sustaining relationships with other clinicians, patients, and families. This is done in a context where emotions are high, sense of time is distorted, and outcomes are uncertain.12,13 Death in the ICU increasingly involves “managing”—withholding or withdrawing—life-sustaining therapies.14 Clinicians are expected to maintain control over their own emotional responses and these added burdens, and are afforded little opportunity to process their own grief.

To avoid identification and uncomfortable emotional attachments with particular families, clinicians may respond by dehumanizing patients and avoiding the unit when these families are present.

While there is a growing body of research on the impacts of working in the intensive care environment on physicians and nurses, little is known about the experience of RTs. RTs may not have primary assignment to the ICU, creating a barrier to their developing membership in the ICU “team.” Family members may come to see the RT as the cause for having to leave their loved one’s room and may develop distrust of the services provided by the RT. Liberalization of visiting policies after decisions to withdraw life-sustaining treatments may be an added stressor for the RT who, denied the opportunity to develop a relationship with the family, must provide palliative treatments that are aimed at increasing patient comfort but that may continue to be perceived by the family as “invasive.” Ultimately, the therapist who must turn off a ventilator or remove an artificial airway, often in front of grieving family members, may feel disproportionate responsibility for the death, perhaps most acute in the withdrawal of life-support from a pediatric patient.

In more autonomous settings such as home care, clinicians lack the perception of social support found in working as part of a team, including shared responsibility and decision-making. Little is known about the stressors of working with dying patients in this environment but without the support of a hospice program.

Clinicians working with dying patients may experience responses to stress on a personal or interpersonal level. Somatic manifestations may include headaches, digestive
disorders, nausea, musculoskeletal pain, reduced immunity, and lowered sexual response. Behavioral responses include alcohol or drug use or abuse, compulsive behaviors, overwork, underwork, absenteeism, irritability, acute impatience, risk-taking behaviors, phobias, and social isolation. Affectively, clinicians under stress may experience fear and anxiety, especially surrounding their own or a loved one’s death, or guilt or anger manifested in hostility toward patients, coworkers, and personal family members. Feelings of helplessness, professional ineffectiveness, incompetence, and loss of control combine with negative cognitions or cognitive distortions and may erode the clinician’s self-image and lead to ineffective coping behaviors. Thoughts and images of dying patients or personal experiences with death may intrude into a clinician’s day, adding to the coping task.

Interpersonally, clinicians may be unable to communicate or sustain intimacy necessary to form and sustain personal relationships. They may become withdrawn or overly assertive, and may be unable to handle conflict at home or at work. Ironically, clinicians working with dying patients may fail to allow themselves to fully grieve their own personal losses.

Personal attributes of those who choose to work in the helping professions may be the same factors that make them vulnerable to the effects of “compassion fatigue.” Coping strategies learned early in medical residency and other clinical education programs, often in conditions of overwork and sleep deprivation, combined with inadequate educational preparation for caring for dying patients, may impede efforts to encourage clinicians to understand and change negative patterns. The same personality traits that make one suited for medical school may not encourage the development of coping strategies that contribute to resiliency in working with dying patients and can be detrimental to personal and professional relationships.

Characteristics and responsibilities of the traditional roles practitioners play may also be felt as stressors by individuals within each profession working in various settings with dying patients.

Nursing research suggests nurses may be distressed by the care given to ICU patients and by exposure to death and dying in the ICU. A study by Gray-Toft and Anderson in 1981 found 3 common sources of stress across 5 different units: death, excessive work load, and dealing with the emotional needs of patients and families. Stressors included lack of opportunity to share experiences and feelings with coworkers, the death of a patient, little opportunity to offer emotional support to patients, inadequate training to help with the emotional needs of patients, and uncertainty about equipment. No significant difference in stress level was shown for ICU versus non-ICU nurses. High trait anxiety was found to be correlated with high stress levels, and was lower in the ICU nurse cohort, also pointing to personality traits as possible moderators of stress.

Inconsistent and contradictory findings from nursing studies comparing stress reactions in ICU and non-ICU nurses support the need to look for “moderator variables” such as social support, personality traits, past experience, and coping strategies to describe the ICU and other work environments in order to better prepare clinicians.

Sources of stress for RTs include working in intensive care or pediatric units, heavy patient load, frenetic work pace, competing orders, interpersonal conflict with other staff members, role conflict (especially with nursing staff), and lack of respect for or confidence in professional judgment by physicians. Citing the expansion of respiratory therapy following the rise of technologic advances in health care, Prewitt found the potential for role conflict to become an increasing source of stress for RTs as their skills are increasingly in demand, yet nurses and physicians are reluctant to acknowledge their contributions in patient evaluation and monitoring. Other studies have shown the importance of task performance in job satisfaction for RTs, and that comfort in performing familiar tasks is central to decisions of RTs to remain in the field.

These sources of stress suggest that providing care for dying patients may be an important additive stressor not previously examined.

Just as the critical care team manages patients with various illness trajectories, clinicians in the home, pulmonary rehab, or ambulatory clinic setting are responsible for patients with various stages of lung disease. Like the balance between goals of “cure” and “comfort” for the ICU clinician, the rehab team simultaneously attempts to help patients achieve and maintain maximum function and quality of life while alleviating symptoms of advancing lung disease. The “success” of the ICU patient who is able to get off mechanical ventilation becomes the challenge of the pulmonary rehab therapist, where unrealistic hopes of returning to pre-admission baseline may have to be negotiated and transformed into attainable goals. Patients who are discharged from ICU care settings may pose an added challenge to a therapist lacking in palliative care training. Ventilator-dependent patients may meet guidelines for “clinical stability” for discharge to acute, intermediate, long-term care facilities or to home, yet mortality among this group remains high.

While trends in home care staffing may be changing dramatically, the nurse or RT employed by a nursing facility or durable medical equipment company serving these patients will probably find him- or herself the sole health care professional in the home or nursing setting, responsible for ongoing clinical assessment of both the patient and family caregiver, and may become the sole target for a patient’s or family’s grief or anger.
While the autonomy of the home care clinician may be a source of satisfaction, few pulmonary rehab programs offer education about end-of-life issues and communication skills, perhaps assuming that this responsibility falls to other members of the health care team.

In the critical care setting, family members may be asked to leave the patient’s room during respiratory care procedures. In the home setting, the RT may have to perform patient care under the watchful eyes of anxious family members, creating a level of performance anxiety that the critical care therapist may not face.

Maintaining a professional distance that allows the therapist to perform procedures perceived by the family to be uncomfortable for their loved one may at the same time prevent therapists from establishing empathic relationships with those they treat.

There is evidence from the pulmonary rehab setting that patients are interested in discussing end-of-life decisions with their physicians and would prefer to have these discussions in an outpatient setting before they experience an acute exacerbation. While attention has been paid to improving physician skills in communication about end-of-life care with patients, patients also indicated that they would prefer to get information from nonphysicians.27 For the therapist who feels repeatedly inadequately prepared to address end-of-life issues in the rehab or critical care setting, feelings of professional inadequacy may lead to resentment, dissatisfaction, or job changes.

Coping with Death

Calls to incorporate palliative care education into clinical preparation stress the provision and modeling of palliative clinical skills over explorations of the nature of grief, bereavement, and individual stress and coping. Providing skills without establishing the rationale for self-reflection, and experience without ongoing self-evaluation may only increase the perception of mastery and may not lead to improvements in care when the same mistakes are repeated. For example, RTs who help alleviate dyspnea and other symptoms for dying patients may do more to improve the experience of an anxious family than any amount of empathic communication could provide; educating RTs in the concept of palliative respiratory care may enhance individual confidence and competence, but may not increase the sense of organizational or personal support needed to address and decrease death anxiety and other distressful individual reactions.

Improving Individual Coping

In their chapter in Burton’s textbook, Susan Rickey-Hatfield and Timothy Hatfield end their overview of effective interpersonal communication skills and applications with the caveat that responsible patient care requires a continuous balance between technical knowledge and interpersonal skills.28 They cite 3 necessary components:

1. Self-assessment: Having a clear idea if working in an environment where uncertainty will be a daily challenge to your clinical skill “fits” you.

2. The concept that perceptions of situations can initiate stress responses.

3. Borrowing from Kobasa’s work on stress in business, the belief that “a person’s commitment to a particular line of work and the felt sense of doing something that matters contributes to a harder, more stress-resistant personality.”29

Bond suggests 4 possible approaches to stress management: mental and physical distraction, self-nurturance, rational problem-solving, and emotional expression.30 Every death is a unique event. Clinicians who develop the flexibility to use multiple coping strategies will be better prepared to provide high-quality care regardless of the circumstances surrounding the death of a patient. “Distraction” may come in the form of regular physical exercise or enjoyment of hobbies. Care must be taken to balance these activities with seeking time with family, friends, and other sources of emotional support. Self-nurturance on a daily basis includes taking breaks and getting adequate nutrition and sleep, but also encompasses attention to meeting personal spiritual needs.

Strategies for increasing self-awareness include skill in self-disclosure and learning to effectively offer and receive feedback to and from others, and may be especially important for home care clinicians who may not have the benefit of working with a peer group.31

Under the direction of traumatologist Charles R Figley at the University of Florida, Eric Gentry and Anna Baronowsky have developed an “accelerated recovery” program to combat “compassion fatigue.”32 This program has been used in hospital settings with oncology staff, in which clinicians are guided through a process of strategies, including narrative, anxiety management, progressive relaxation, and video-dialogue, aimed at gaining awareness of cognitive distortions and memories that produce clinician anxiety and impact caregiving. Offering individuals access to psychiatric or social work counseling in the workplace may offer clinicians another perspective to turn cognitive distortions and negative thinking into more accurate ideas about themselves and their environment. Services offered to surgeons whose treatment efforts were unsuccessful have been shown to bring about changes similar to changes in people undergoing psychotherapy.33

Identification and awareness of the nature of stress in working with the dying is not sufficient to reduce its somatic effects, and may actually increase psychological strain, adding to the “work” of coping, especially in clinicians working autonomously. Clinicians may have difficulty observing their own reactions and behaviors as signs.
of distress. Simultaneously, the tendency to "pathologize" the coping reactions of patients and families to the stress of illness and death creates a culture where care staff experiencing identical emotions fear acknowledging or having their reactions "exposed." The focus on the "angry" or "obessive" family or patient inhibits the clinician's ability to remain sensitized to the reality of the stressors in the environment. Just as clinicians communicating with patients and families in crisis should acknowledge and reflect strong emotions and behavioral reactions, they should be encouraged to use their own reactions as clinical tools to aid in the assessment of families, and as gauges to identify situations that cause them personal distress and may become a barrier to their professional ability.

**Organizational Responses to Clinician Distress**

Employee well-being is both a necessary resource for and arguably an outcome of the provision of good quality end-of-life care. Health care organizations have a responsibility for disseminating information on stress and coping strategies to their professional caregivers. A proactive rather than a preventive approach conveys the institutional expectation that providing care to dying patients and their families in the midst of efforts to save lives will be a personal and professional challenge. Explicit information on ways for caregivers to identify the symptoms and signs of stress and distress in themselves and in coworkers should be made part of employee orientation and ongoing supervision. Managers who include nonpunitive assessments of employee well-being in regular evaluations may help address negative coping responses before they negatively impact patient care.

Researchers in the field of stress management advocate increasing job satisfaction by encouraging employees to "control" their environments and to reduce aspects of the workplace that "produce affective reactions." For clinicians working with dying patients, this may not only be an impossible feat but may also diminish the clinician's ability to provide humanistic care. There are interventions that can improve the clinical work environment: the provision of role models in palliative care can help clinicians develop clinical skill that can enhance their confidence in their ability to care for and cope with dying patients. Creating well-defined interdisciplinary care teams and providing regular forums for discussion of patient care can help decrease overlap in tasks and increase recognition of each discipline's contribution. Conflict in this forum may help clarify and align team goals and prevent tension from creeping into the provision of care. Including a psychiatric or social work liaison in the team may help keep the focus on the experience and needs of the patient and family as well as provide a model for assessing clinician reactions to dying patients and the care environment to encourage clinician well-being.

**Improving Clinician Coping in the Intensive Care Unit**

Clinicians who work in the ICU setting need to develop and maintain coping and adaptive mechanisms that will, over time, change their sense of self and their world views. Increasingly, the principles of palliative care are being incorporated into the goals of ICU care. While this cultural shift may alleviate the apparent professional contradiction of providing rescue from and comfort in death, the effect is to increase the responsibility of ICU clinicians to "manage" and provide "good deaths" in the ICU. Incorporating support forums into the physical and organizational structure of the ICU is more likely to promote effective coping than group sessions that require clinicians to forego lunch breaks or stay overtime. Effective models exist, such as the incorporation of autognosis rounds at the Massachusetts General Hospital. Goals of the weekly rounds include identifying personal reactions to clinical care situations and learning strategies to minimize their effects.

Organizations and individuals need to better understand and define a "good death." Realizing her own guilt and inadequate educational preparation for the care of dying patients and their families, intensivist Judith Nelson now visualizes her work as a continuum of curative and palliative medicine that promotes the concept of "saving lives and saving deaths." She attributes this shift to the inception of a comprehensive palliative care curriculum for faculty in her institution. Adding clinicians with a combination of critical care and palliative care experience to intensive care teams may help create educational experiences for unit staff to avoid distancing and pessimism, and can help younger clinicians incorporate emotions once undermined by medical training.

Routinely holding family meetings early in care can encourage clinicians to build relationships based on the goals of providing the best possible care in each situation, and may be helpful in improving clinician understanding of family and group process, including conflict management and de-escalation. Providing opportunities for all staff who are involved in the care of a given patient to attend the conference is a helpful way to minimize staff stress.

Staff need both formal and informal opportunities to discuss or individually examine their feelings about patient deaths. Some staff may find rituals helpful to mark deaths in their unit.

**Risks and Costs of Coping Strategies**

In the interest of maintaining a balance between work and home life, clinicians may develop strict boundaries
between work and home. This separation is offered as a positive coping strategy, often cited by those who profess mastery over the demands of clinical care. However, for the clinician whose work routinely involves death and dying, this compartmentalization may result in increased tension with significant others. Either in an effort to shield loved ones from the intimate and graphic details of death or as the result of feeling that those “outside” the care environment could not “truly” understand these realities of caring for the dying, the effect may be communication conflicts, difficulty maintaining trust and openness necessary for sustaining personal relationships, and limitation of one’s social circle to those from similar professions.

With individual and institutional efforts it is possible to create a clinician and team “personality” that is harder and more resilient to the negative effects of working with dying patients. Providing an individual and institutional perspective that what is routine in working in health care settings (where facing dying and death often occurs) is not a routine event anywhere else may be the key to helping clinicians understand, cope with, and improve their role in the care of dying patients and their families.

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Discussion

Levy: That was great. I really appreciate your willingness to share your thoughts on this topic. One of the things that struck me (and about which I feel very strongly) is the issue of ongoing nonpunitive supervision. One thing that I always mention in the orientation to the house staff and fellows, especially with the house staff, is that they would never think in the beginning of their month to put in a PA [pulmonary artery] catheter in the middle of the night and then in the morning say, “Oh, by the way, I threw in a PA catheter last night. I didn’t bother to call you because it was fine.” But on the other hand, they have no problem having a major end-of-life discussion at a difficult time without asking for help. I think in part that’s because we as teachers have abandoned the training process, so they have learned that if they don’t do it, it doesn’t get done, and no one is going to teach them how to do it anyway. It’s really important, that I hear you, especially as a nonphysician voice, saying to clinicians “It’s good to be trained. It’s OK. We need training for this.” I think that’s a really important message.

Curtis: Louisa, that was excellent. I had several epiphanies during your talk. One of them is that I don’t allow gallows humor near patients or families when I’m the ICU attending, and Gordon [Rubenfeld] rants at the nurses about turning off the monitors—and I realize that those are both coping mechanisms, and if we’re going to ask people not to use those coping mechanisms, we need to offer something in their place if we’re going to effectively change behavior. I wonder if you have specific advice for us about some ways of offering, in one or two of those circumstances, a replacement coping mechanism.

Viles: That brings up the work I’ve done on addiction, I hate to say, but, again, the idea of replacing a negative coping strategy with a positive—I don’t have an answer to that. I think that gallows humor is going to happen. Whether it happens in the ICU in your presence or not, it’s happening. So I think at some point, look at the desire to control that, and where that comes from. I think there is a measure of our own values that enters into that. There may actually be patients and families who use humor as a way of coping. The content of the humor may be very different. That can be pointed out as a clinical tool to really assess a team. Our end-of-life care research team routinely meets in a library outside the pulmonary function lab. If you think that there’s no stress in research on death and dying, once we were engaged in a pretty loud and fairly graphic discussion about a patient care instance with the door open. I realized that there was a patient waiting for the pulmonary function lab outside in the hallway, and I almost wanted to go and apologize to the RT because I knew the lab values would be all wrong because of the content of our discussion. And yet I think humor is valid. I think there’s a place for it, and I think it can be used.

I found the idea of the autognosis rounds very helpful, because it gives (outside of the sort of open intensive care setting) an opportunity for people to do that. One of the things they use is “likeability” scales. You can talk about a specific family or patient in terms of their “likeability,” and I think that really brings to the fore—especially in dealing with some of the patients that we have who are either from very different backgrounds than us or from very similar backgrounds—some of the discomfort that comes from that. So I think that provides another opportunity.

Rubenfeld: First of all, thank you for a great talk. It’s a challenging area to present. I want to revisit the issue of gallows humor too: I don’t prohibit it. I prohibit it anywhere at the bedside or within reach of patients or anything like that. I don’t prohibit it in the doctor’s area or in discussions, and I sometimes even participate in it. Sometimes I feel guilty about it and sometimes I feel that the house staff feel guilty about it when they do it. And yet I value it as a form of camaraderie and as a coping skill. I’m glad to hear you present a very correctly ambivalent approach to it.

Over time I’ve evolved an approach to handling house staff guilt and handling their “I made a mistake. I did something wrong,” and I developed an approach to that, but I’m not sure I know what the right approach is to private gallows humor. Is it something I should encourage? I’d be curious about your response as an outside observer both on my behavior and also of Harborview [Hospital, Seattle] house staff behavior and also how other people deal with this, practically, in the ICU.

Viles: I’m going to open it up to other people, first, to offer their observations, if anyone has anything to offer.

Heffner: I think it’s a very important topic, and I’m concerned that the term “gallows humor” is overly pejorative. It wells up in every situation through millennia when we face death and dying issues. It arises both when one is the victim and the observer of a death and dying event. When I attended the Respiratory Care journal conference a year and a half ago about airways and tracheotomy, there was very little humor in the conference. This week we’re talking about palliative care and death and dying, and I think our interactions have been marked by a very healthy sense of humor and laughter.

Humor may serve many purposes in this setting that we don’t understand. I think there’s something very celebratory about watching M*A*S*H on television. Those who were the best physicians, who were coping the best,
were those who used gallows humor. In Shakespeare and Chaucer death and dying are often merged with comedy. Comedy and humor can be used for hostile purposes or human devaluing intent, but they can also help us to stand back and reflect on some of the strains of human existence.

Levy: I’m a very strong proponent of humor. I think there’s a deep spiritual aspect to humor and the point is—and you said it well, John—it’s understanding whether the humor is being used to hurt or if it’s coming out of an attempt to take a bigger view. In my training I’ve learned that if you develop a deep base of spiritual compassion, then humor and irreverence is completely fine. It’s almost a natural outgrowth of that. And so, what I do in the ICU, in particular with the new residents, the first or second day when I do my talk on end of life, is that I get them to visualize their own funeral and to think about loss and who would miss them and what they would miss most in their own lives. Some of the house staff, obviously, do or don’t have kids, and I get them to really experience some of the grief of loss and get them to a pretty sad space, but a space which I then suggest they could use for the rest of the month as a way of truly being empathetic and allowing the compassion to come out. With that foundation of compassion, it’s not gallows humor anymore. It’s just appreciating the natural irreverence of existence.

Viles: I agree. I would add that what I do in my own practice and with the teams at Harborview is that when I observe the use of humor in a group setting, especially in the ICU, I look for the person who’s not laughing. That tends to be where I focus my efforts.

Silvestri: First, I want to say something about the somatic complaints. I counted five that I had last week. (I think we need to talk later on.) And Bo [Burt] turned to me and said, “I’m sorry, I missed some of that; I was daydreaming about my anxiety level.” I want to add something about humor. With cancer patients I use humor. There’s one thing no one’s mentioned. You’ve got to be funny. If you’re not funny, it just doesn’t work. So for people who are funny, it works. And, in fact, a couple of weeks ago I was sick, and the next time I went to visit one of my cancer patients who was in the hospital, and I wasn’t cracking jokes with the guy, and he said, “Man, what’s wrong? You’re just not yourself today.” And he was sad for me. This guy was a Marine general, had a few days to live, and was asking me what was wrong with me, why wasn’t I giving him the business that day? I think humor at the bedside is inappropriate, but out on rounds I definitely think it’s a way to relieve stress and have a lot of fun.

My question for the senior leadership here is this: We know that rates of disability among physicians have skyrocketed and physicians are getting out early. They’re having difficulty coping. Job satisfaction is at an all-time low. Among nurses we’re seeing about a 5-year shelf life with ICU nurses before they get disgusted and go do something else like home care. Respiratory therapists, the same thing. I think all 3 groups are exactly the same, under the same constrained resources, and one thing I’ve noticed is that we really don’t take care of each other very well. Particularly for physicians, there’s no empathy for other people’s stresses in their lives. I wonder if the senior people are watching clinicians go through this, and what recommendations they have.

Pierson:* I think it’s a very important thing that you raise. Think about what happens when you do get sick and how reluctant you are to take any time off because of the burden you’ll place on your colleagues, and how we walk around at death’s door, probably doing more harm than good by being at work sick, whereas in many other job categories around us we don’t see that kind of behavior. I think that’s a kind of pathologic manifestation of our inadequate coping, at perhaps a different level than we’ve been talking about, but I think it’s also symptomatic of our need for better coping skills.

Hansen-Flaschen: Humor is the best coping skill that I know of. Gerard, I’m confident that your humor is affectionate and never contemptuous or derisive of patients. You can be affectionately humorous with a patient, but I draw the line on derision and I’m sure you do too.

Silvestri: Let me introduce John [Heffner]. He is now the Dean of Faculty Development at my university and ask him, “When I come to see you with my ulcer, headaches, etc., what will you do to help me. John? Impotence—can we put that on there, too?”

Heffner: We are interested in what happens to organizations, medical cultures, and our traditions, values, and missions that are millennia old, when cost-cutters take control. We hope to institute programs that preserve our core institutional values. How can we use reimbursement pressures to refortify us as to why we went into medicine? What values in health care will always persist, such as the rewards of talking to patients and families? Many medical centers are putting new innovation, time, and commitment into faculty development to preserve our mission. Some senior physicians recollect, “You know, when I went into medicine, we were excited to see an interesting patient or a patient who could benefit from our care; we weren’t excited to see our bonus at the end of the month.” Maybe we have to recapture

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some of that part of our career that will continue to sustain us.

Benditt: Your talk really resonated with me. All the talks have been terrific, but this was a really important one for me. Let me relate how I’ve dealt with that.

I will never forget the day when I had 4 new patients in my clinic and some follow-ups, and each one of the consults said, “Please discuss end-of-life issues with this patient” whom I had not met before. I’d gotten very quick at getting into the discussion. I don’t leave it for the last 15 minutes. I felt like the guy at the bottom of a mountain watching an avalanche come down.

So I had to figure how to get out of that, and I think it’s very appropriate for this conference, because one mechanism I’ve used is that I never go in alone, anymore, for that discussion. I now have a terrific respiratory care practitioner who comes in with me every time, and then in the last two months, actually, I’ve had a nurse practitioner too, and we go in as a group. That helps me as a clinician, for whatever psychological mechanism, because I no longer see myself as the focus of these intense emotions from the patient. It also has very practical implications in that when they call in, they don’t always call and ask for Dr. Benditt. We have a group of us who handle this, and everybody brings a little different perspective to it, but can share in that. And so it has relieved me of this intense personal pressure. So that’s one thing I would share.

The second thing I would ask the group as a whole (as the medical director of respiratory care services at my hospital) is this: One thing I’ve really tried to do is get the RTs to round with the ICU team—not a senior RT, but each one who cares for that patient—to get the input into general issues about respiratory care but also about the end of life and how we would do such. But it’s been very hard because the time constraints and patient loads have been incredible for these people. I’m wondering if anybody has any techniques where they can free up their RTs to come to the rounds to be in this team.

*Sam Giordano:* A lot of people are finding success using protocols or a consult service to manage down demand. The result is that they’re not forced to provide a higher number of unnecessary procedures, yet they haven’t compromised clinical outcomes. It’s the most clinically effective and cost-effective way to use respiratory therapists and organize respiratory therapy services. This approach frees up, without additional stress on salary budgets, respiratory therapists to participate in some of these other activities.

Benditt: So to make it a consultative service? Is that what you mean?

Sam Giordano: They use protocols. They do assessments. There’s a high percentage of misallocation of respiratory therapy treatments,¹ so they eliminate the ones that are not indicated by the patient’s condition, and end up doing fewer treatments. They therefore have more time on a per-patient basis. AARC [American Association for Respiratory Care] developed an extensive bibliography on that, which I’ll be happy to send along to you.

REFERENCE


Sam Giordano MBA RRT FAARC, Executive Director, American Association for Respiratory Care, Dallas, Texas.

Tudy Giordano: Respiratory therapists across the nation have been experiencing decentralization of their departments, and their leaders are no longer comrades. Department heads could be pharmacists, they could be from nursing, they could be whomever they choose, so it’s not necessarily a respiratory therapist who’s running these departments now. Not to put more stress on a physician, but the RT looks to physicians, pulmonologists, for leadership. If you think of a symphony, they’re the conductor. We can’t do a thing—we can’t dance, we can’t make the music without them. In some facilities the only time a respiratory care practitioner gets recognition from physicians and colleagues is during Respiratory Care Week. And often it’s only because the respiratory therapy department head said, “Guess what? It’s Respiratory Care Week!” It means so much to be recognized. It just takes a pat on the back to say, “You’re doing a good job.” In today’s health care climate, many RTs don’t have the leadership and the cohesiveness that others are afforded. So unfortunately, to add to your stress, we need your support too.

Sorenson: I just wanted to corroborate what Tudy and Mitch [Levy] said. This concept of cost containment and decentralization has really left a lot of respiratory therapists without a home. I like the idea of nonpunitive, ongoing supervision. Whoever is out there who can pick up the ball and help some of these people who are wandering without a home, be they pulmonologists, or whomever they’re looking to, I think that’s something that really is needed. The other comment I would make to Sam is that I agree that protocols have helped. Unfortunately, when therapists do protocols effectively, and do less therapy, they cut back the number of therapists in the hospital.
The Limitations of Protocols for End-of-Life Care

Robert A Burt JD

The basic goal of practice protocols for end-of-life care is to guide clinicians toward individualized care of dying patients. The contemporary impetus for such protocols arises from the well-documented past clinical practices of direct infliction of harm on dying patients, typically through pointless pursuit of aggressive curative therapies, or abandonment of patients, typically through inattention to physical and psychological suffering. Remedial efforts protocols cannot be effective, however, unless powerful irrational impulses that accompany imminent death are acknowledged and addressed. These impulses cloud rational judgment, inspire a sense of “wrongfulness” and “wrongdoing” about death and can readily lead clinicians to new, though disguised, versions of past harmful inflections on patients. Typical practice protocols enunciate rationally-based directives for patient care; but insofar as these protocols restrict their attention to rational considerations, they will miss (and contribute to the perpetuation) of the irrational impulses that have obstructed prior professional efforts to serve patients’ welfare. Key words: protocols, end-of-life care, death, dying, palliative care. [Respir Care 2000;45(12):1523–1529]

Medicine can save lives, but the very strength and intensity of this life-saving ethos sometimes carries unfortunate consequences by clouding accurate assessment of the possibility that a particular patient’s life can be saved or that he or she can be restored to some reasonable state of health. This critique of the rescue imperative in medical practice — of clinicians’ relentless battle against death that becomes transformed in too many cases to an aggressive assault against an inevitably dying patient — has by now become widely accepted. This contemporary critique stands in the background of this conference and frames the careful and humane prescriptions for palliative respiratory care that have been put forward in the previous presentations.

The goal of all of those presentations has been quite practical: to translate the general critique of overly aggressive “rescue efforts” into concrete, specific measures for assessment and palliative treatment of dying patients. The goal has been not simply to speak in generalities but to set out practice protocols that can guide clinicians in shifting their attention from the battle against death, where appropriate, in order to provide optimal care for those who are dying.

I believe, however, that there is an inherent tension, a tendency toward self-contradiction, in this prescriptive effort that must be openly acknowledged. The tension has two components. The first, I would say, is on the face of the effort to draft useful practice protocols. The avowed ultimate goal of these practice protocols is to ensure carefully individualized assessment and individually tailored treatment for each unique patient. The very structure of the protocols, however, rests on the premise that clinicians do not, and must not, confront each patient as if this encounter were a unique experience. The protocols are based on the premise that there are recurrent problems common to large groups of patients and that standardized techniques of assessment and treatment must be followed in order to arrive at appropriately individualized responses to individual patients. This is a sensible and, indeed, essential premise for all medical practice. Nonetheless, there is a tension in this premise. The inherent tension, the tendency toward self-contradiction, in this enterprise is that routine protocols intended to guide practitioners toward individualized response can become routinized practice — rote applications of the “cookbook” — in which the individual needs and perspective of the patient become lost.

The existence of this tension does not mean that the effort to design routine protocols should be abandoned. It means that the protocols should be designed to provide specific safeguards against the transmutation of “routine

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A version of this paper was presented by Prof Burt during the Respiratory Care Journal Conference, Palliative Respiratory Care, held May 19–21, 2000 in Cancun, Mexico.

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practice” into “routinized practice”—to identify crucial points at which, metaphorically speaking, some kind of “mnemonic jolt” should be administered to the clinician to jar them away from the inclination toward rote practice, to remind them or even rouse them back toward an alert awareness of the individuality of the specific patient at hand.

This is not a problem unique to medical practice. It is common to other professions, especially those that regularly encounter and offer promises of assistance to intensely needy people. The imperative to distinguish between appropriately routine and mindlessly routinized rules of practice is critical for the legal profession—both for attorneys and for judges—as it is for health care practitioners. Thus, I do not see myself here today lecturing at you from a safe and successful distance. I am talking about a problem that my profession shares with yours, a problem that gives my profession at least as much difficulty as it gives yours.

As difficult as this problem is across the entire range of medical as well as legal practice, I believe that this problem takes on a special intensity in direct confrontations with the prospect of death. In the legal context, we can see this in the convulsive impact of capital punishment in our jurisprudence, especially during the past 30 years, and the powerful tendency in the administration of the death penalty for courts to fall back on routinized procedural dodges and away from direct confrontation with the individual claims of prisoners about to be executed. This “death row” pressure is unusual, however, in legal practice; it is much more commonplace in the ordinary practice of medicine. Issues of death and dying arise only rarely in legal practice, but they are at the core of the practice of medicine. Most patients are not dying, of course; most patient visits to doctors’ offices do not involve confrontations with the prospect of death. But to some degree at least, death and anxiety about death hover over all encounters between clinicians and patients, and this hovering presence of death is palpable in many contexts of respiratory medicine, and especially in intensive care settings.

The palpable and at least implicitly disturbing specter of death is at the core of the second component of the inherent tension, the tendency toward self-contradiction, in the formulation of protocols for end-of-life care. The first component in this tension that I have identified—the tension between sensible routine and mindless routinization of practice—affects all manner of generalized practice protocols. This second component—the special problems engendered by the looming presence of death—affects protocols for end-of-life care with particular force and with potentially disastrous implications for patients’ welfare.

There is a long and distressing history of medical mistreatment of dying patients—a history that has only recently been acknowledged and that the practice protocols that have been advanced in this conference are intended to correct. The medical mistreatment can be summarized characterized in two charges: that many clinicians have responded to patients who were clearly and inevitably dying either by abandoning them or by actively inflicting harm on them. Abandonment has occurred not only in clinicians’ unwillingness to interact with patients once it is apparent that life-saving treatment efforts have failed, but also in the failure of the medical system to acknowledge the physical and psychological pain suffered by dying people and to implement even simple, well-proven palliative interventions. The characteristic sign of active infliction of harm has been the relentless pursuit by clinicians of aggressive therapies notwithstanding their patent ineffectuality, accompanied by devastating side effects that rob the patient of a potentially peaceful ending to his or her life. This aversion to death, this refusal to “say die” is of course often shared by both clinician and patient, but in this folie à deux, this refusal to accept the rationally foreseeable end, clinicians presumably should have greater access to rational bases for evaluating probable outcomes than their patients. This failure of clinicians to forego rationally unjustifiable and brutally aggressive therapies can ultimately be understood as unacknowledged but barely disguised warfare against death and the aversive embodiment of this enemy in dying patients.

Notwithstanding the current widespread criticism of this medical mistreatment—both in professional and lay circles—these twin evils of abandonment and active harm inflicted on dying patients have not magically disappeared from contemporary medical practice. An article just recently published in the New England Journal of Medicine documents the persistence of these evils by some practitioners of respiratory medicine in the use of pharmacologically paralytic agents in withdrawing mechanical ventilation at the end of life. I want to focus on this specific practice in order to explore the limitations of practice protocols in rectifying the medical mistreatment of dying patients.

In the New England Journal article evaluating the use of paralytic agents in withdrawing ventilation, the authors state that “neuromuscular blocking agents have no analgesic or sedative properties” and observe, in a somewhat understated manner, that this fact “may be overlooked by clinicians.” The consequence of this oversight can, of course, be quite horrendous for patients; as the authors note, “the neuromuscular blocking agents may mask the signs of acute air hunger associated with the withdrawal of the ventilator, leaving the patient to endure the agony of suffocation in silence and isolation.” In other words, the paralyzed patient stands as the very paradigm of the historically documented medical mistreatment of dying people: the dying patient paralyzed for the withdrawal of me-
mechanical ventilation is both abandoned and actively harmed by the physician.

This horrendous use of blocking agents may not be prevalent respiratory practice; the authors report only anecdotal clinical episodes. And, of course, the authors propose practice guidelines to assure that this practice will not occur again. But a question nonetheless hovers over these guidelines. The question is: How could any physician believe for a moment that the use of blocking agents without sedation might be appropriate medical practice in the withdrawal of ventilator support? How could any physician fail to understand that paralysis of the patient dying of oxygen deprivation would produce anything but helplessness and terror?

It is not plausible that the physicians engaged in this practice were viciously motivated—that we have anything here approaching the conscious sadism that we associate with the concentration camp experiments in Nazi Germany. The authors of this article identify a very plausible beneficent motive in one documented case regarding a dying infant: the clinician wanted to “guarantee . . . that the patient would not have seizures or make any gasping respiratory efforts after the withdrawal of ventilation” and thereby was “seeking to relieve the family’s suffering” as they stood by their dying child’s bedside. But the plausibility of this motive points to the difficulty in assuring that generalized practice protocols will effectively guard against similar kinds of abuse inflicted on dying patients. The clinician in this instance had benevolent motives, and those motives served as a self-deception, spread a falsely comforting cloud over the infliction of terrible and terrifying suffering on a helplessly paralyzed dying person.

The proposed practice guidelines say “never do this” based on irrefutable rational logic. But the guidelines are addressed to rational intellect—and it was not rational intellect that produced the wrongful conduct in the first place. This is the basic and most troubling limitation of typical practice protocols (that they speak to rationality but they are entirely ineffective—they might as well be speaking into the wind) when the problems they address arise from irrational forces that are deep-rooted, difficult to identify, and unlikely to be consciously acknowledged. This does not mean that practice protocols are inevitably doomed to be ineffective. It does mean that practice protocols will be ineffective and, indeed, will provide a misleading patina of order and propriety unless the irrational forces engendered by the imminent prospect of death are acknowledged and somehow accounted for in the design of the protocols.

My goal in this presentation is to sketch some of the irrational forces and to speculate about them on the basis of some documented evidence of their power and their salience for undermining practice protocols intended to safeguard the welfare of dying patients. In my view, we can identify 3 steps in the psychological dynamic that can lead well-intended physicians to the kind of abuse represented by the use of blocking agents for ventilator withdrawal. The first step occurs when anxiety about the prospect of death clouds the capacity for rational judgment of both physicians and patients.

A classic experiment in social psychology, published in the New England Journal of Medicine in 1982,2 powerfully demonstrates the pervasive power of death anxiety in medical practice. The researchers included Harvard radiologist Barbara McNeil and Stanford psychologist Amos Tversky. In the experiment, the same information about therapeutic alternatives for lung cancer was presented to separate groups of patients, physicians, and business school graduate students. Half of each group was told that surgery for lung cancer carried a 90% likelihood of survival for more than one year; the other half was told that the therapy carried a 10% likelihood of death within one year. Where the information was presented as a probability of survival, 75% of the subjects opted for the surgery; where the information was presented in terms of probability of death, only 58% chose surgery.

In formulating their initial hypothesis for the experiment, the researchers anticipated that lay patients would be much more influenced by the differential framing of the information than the physicians or the graduate students. “Much to our surprise,” they reported, the differential effect was virtually the same for the physicians, notwithstanding “their considerable experience in evaluating medical data,” and for the graduate students, all of whom “had received statistical training.” As the researchers observed, “this effect of using different terminology to describe outcome represents a cognitive illusion” that clouded the rational decision-making capacity of physicians as much as laymen.2 A powerful and irrational aversion arose among physicians as well as laymen from the simple mention of the word “death.”

That experiment was conducted 20 years ago, but I doubt that the psychological capacity of American physicians for rational deliberation about the prospect of death has dramatically altered since then. There have been some important changes, notably represented by the convening of this conference about palliative respiratory care. The underlying premise of virtually all of the presentations at this conference is a virtually irrefutable rational proposition—that many respiratory patients die and that the possibility of death must be acknowledged and planned for with the same attentive care that has previously been focused on the possibilities for survival. As the research I have cited indicates, however, it is easier to say this than to do it.

The first downward step from the practical application ofrationally devised protocols to protect the welfare of dying patients comes from that cognitive clouding. The second step comes from a common, specific feature of the
cognitive clouding provoked by the specter of death—that is, the sense that is widely shared among physicians and layman alike that an aura of wrongfulness or wrongdoing surrounds the imminence of death. I use the word “aura” quite purposefully: it is a vague word, a cloudy word. Like many vague, hard-to-pin-down emotions, this aura of wrongfulness surrounding imminent death does not have the crispness or apparent clarity of rationally cognizable propositions. As a matter of rational discourse it is easy to refute the claim that all death is wrongful. For some people, continued life involves such pointless suffering that death can clearly be a preferred state, both as a rational and as a moral conclusion. As a simple empirical proposition, moreover, it might seem senseless to assert that death is wrongful, since—with the possible exception of a few recorded instances of miraculous resurrections—death is a universal human experience. If “wrongfulness” means the deviation from some moral norm, the claim that death is wrongful necessarily means that we are all sinners.

But that very proposition begins to illuminate the vague and cloudy point I want to make about the common understanding of death, at least in our Western culture. The proposition that “we are all sinners” has distinct religious connotations, and when we look to the explanation for death in the Western religious tradition specifically, we find that death made its first appearance as a punishment for wrongdoing. If Eve and Adam had not eaten the fruit of the tree of knowledge, if they had obeyed God’s specific commandment, they would have lived forever, but they disobeyed, were expelled from the Garden of Eden, and lost eternal life.\(^3\) This deeply rooted cultural explanation for the universal human experience of death—as a punishment for wrongdoing—reaches a climactic expression in the final book of the Christian Bible, the Book of Revelation, when “a new heaven and a new earth” will appear entirely cleansed of sinfulness and “death shall be no more, neither shall there be mourning nor crying nor pain any more.”\(^4\)

This tradition speaks directly, of course, only to believers. I believe, however, that this cultural conviction about the inherent wrongfulness of death did not vanish at the same time that formal adherence to religious belief retreated in response to the Enlightenment progression of secular rationality. In Western culture, and in the United States specifically, it is only during the last hundred years that medical science has taken complete custody of death. Physicians have had a specially sanctioned cultural role in forestalling death since Hippocrates’s time and before, but until the late 19th century, physicians’ role regarding death as such was limited to prognostication. When it was clear that death was approaching, the accepted past cultural practice was that physicians would withdraw from the case and that clergy would take command. Over the last hundred years, this practice has been dramatically altered: the presence of clergy to preside over death is now optional and, in any event, does not displace the physician’s primary role. As a matter of state law, a person is not “officially” dead until a physician has declared death, and this legal requirement, which itself became formalized beginning in the late 19th century, reflects the shift to the medical profession in our culture’s conception of the primary custodian of death.

It is conceivable, at least as a logical proposition, that this cultural turn to medical custody would have been accompanied by a newly secularized, empirically-based, and morally neutral attitude toward death—a rational attitude that sometimes death is wrong, is an evil, but sometimes it is not, and that sometimes the costs of combating death outweigh the possible benefits. This kind of rationalized cost-benefit analysis is, of course, not just logically conceivable. It is the preferred course for many physicians and laymen today, and this kind of analysis is the underlying premise of all of the practice guidelines that have been advanced by speakers at this conference.

We know, however—indeed, it is the organizing principle of this conference—that wholehearted embrace by the medical profession of a rationalized, morally neutral attitude toward death would be an innovation in medical treatment of dying patients. For virtually the entire past century, since the medical profession took primary custody of death and dying in our culture, the dominant publicly-avowed ethos of the profession has been to wage a relentless battle against death. Medicine’s explicit embrace of this ethos was visible from the very first moment of its self-presentation as an organized profession. When the American medical profession was established just before the Civil War, its first public campaign was to press for the adoption of new, highly restrictive abortion laws based on a so-called “scientific finding” that life begins at conception and that the prior social and legal practice of permitting first-term abortions (before “quickening” or the discernible movement of the fetus) was murder. This social history has been lost from public view today, when this adamant pro-life stance has become associated with religious proselytizing. But it is a striking social fact that religious groups played virtually no role in persuading state legislatures in the 20 years following the Civil War to adopt new abortion restrictions; the virtually exclusive role in this advocacy was played by the newly organized medical profession, staking its avowedly “scientific” claim as the relentless champion of the sanctity of life and, therefore, the implacable opponent of death.\(^5\)

Abortion as such no longer has the same moralistic valence for the medical profession as such, but the social history of the medical profession’s original role in this “pro-life” battle, this warfare against death, illuminates the relentlessly combative medical ethos that quickly spread through the entire medical professional enterprise. The
underlying premise persists to this day that death is the enemy and that medical science is locked in implacable gladiatorial combat against this enemy—so much so that any patient’s death is still widely understood as a medical failure. Even if no individual physician is considered at fault for a given death, each death is nonetheless viewed as a challenge and an implicit rebuke to medical science. It has been, moreover, part of the ethos of medical practice that no physician is expected or entitled to entirely acquit himself of blame for any death. Dr David Hilfiker has pungently characterized this ethos, in describing his own reaction to his patients’ deaths:

Seriously ill, hospitalized patients... require of doctors almost continuous decision-making. Although in most cases no single mistake is obvious, there always seem to be things that could have been done differently or better: administering more of this medication, starting that treatment a little sooner. . . . The fact is that when a patient dies, the physician is left wondering whether the care he provided was adequate. There is no way to be certain, for it is impossible to determine what would have happened if things had been done differently. . . . In the end, the physician has to suppress the guilt and move on to the next patient.6

This kind of self-flagellation is not fun, and this relentlessly combative attitude toward death and its self-punitive corollary of obsessive “medical perfectionism” have been subjected to a thoroughgoing contemporary critique both inside and outside the medical profession. It is important to acknowledge, however, that this critique has not (at least not yet) taken firm hold in the medical profession generally, and that, beyond the rational arguments about the values for patient welfare of this medical perfectionism, there are strong irrational or nonrational convictions supporting this stance—both among physicians and in lay public expectations of physicians—that are not easily dislodged by rational argumentation.

We can see evidence for the stubborn persistence of these irrational or nonrational convictions, and their relative impermeability to rational contradiction, in recent surveys that have examined physician attitudes toward withdrawing life-sustaining treatment for dying patients. A 1993 national survey of physician attitudes found that 87%, an overwhelming proportion, agreed that “all competent patients... have the right to refuse life support, even if that refusal may lead to death” and that thus allowing patients to die “by foregoing or stopping treatment is ethically different from assisting in their suicide.”7 At the same time, however, two thirds of the physicians saw an “ethical difference between foregoing (not starting) a life support measure and stopping it once it has been started” and three quarters found it “helpful” to distinguish “between extraordinary (or heroic) measures and ordinary treatments... in making termination-of-treatment decisions.”

These distinctions have been uniformly rejected by courts, government commissions, and working ethicists as essentially irrational—as distinctions without a difference. But these authoritatively-issued practice protocols were obviously ineffective in reaching a large majority of practicing physicians. The survey researchers suggested that the wide variance they had documented between these practice protocols and the predominant views of medical practitioners may have a simple and rational explanation: that the medical practitioners were “unaware of... pertinent national recommendations.” If this were the basic cause of the variance, the solution would also be clear: more education for practitioners, more information provided in a rationalistic cognitive framework; and this, indeed, is a principal recommendation put forward by the survey researchers. The survey data raise serious questions, however, about the probable efficacy of this rationalist recommendation. In their open-ended interview data with a sample of practitioners, the researchers identified other reasons for practitioner misperceptions that are not readily amenable to rational refutation: the researchers cited “psychological discomfort with actively stopping a life-sustaining intervention, discomfort with the public nature of the act, which might occasion a lawsuit from disapproving witnesses even if the decision were legally correct, and fear of sanction by peer review boards.” But even these stated reasons conveyed the sense of a rationalizing structure erected over vague but powerful misgivings; as the authors noted regarding one of the seemingly erroneous distinctions, “for many practitioners it does feel worse to withdraw than it does never to have initiated a course of treatment.”

These survey data provide some documentation for the proposition that I have put forward as the second step on the way to medical abuse of dying patients—the proposition that some aura of wrongfulness, and even of physician wrongdoing, accompanies the imminent prospect of death. This aura of wrongfulness can co-exist with a rationally justified conviction that nothing wrongful has occurred—that in specific cases, the patient’s death was inevitable, was morally neutral, even that death was morally desirable because the patient wanted it, because continued life involved only pointless suffering. In response to these conflicting rational and irrational beliefs, it is tempting to take the path that Dr Hilfiker recommended, “to suppress the guilt and move on to the next patient,” and this, indeed, is the path of typical practice guidelines that speak only to rationality and ignore any underlying resistance, any aura of guilt or wrongdoing.

But there is a cost—a potentially heavy cost—in that suppressive pathway. That pathway invites the third step in the downward psychological spiral that culminates in
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the abuse of dying patients—the abuse paradigmatically represented by physicians’ use of neuromuscular blocking agents for withdrawing ventilator support. This third step does not inevitably follow for everyone from the first two steps—that is, from the clouding of rational judgment and the underlying aura of wrongfulness provoked by the imminence of death. The third step, as I see it, arises from the fact that many clinicians are intensely uncomfortable with this aura of wrongfulness and are not willing to accept blame for any wrongdoing. This unwillingness typically has strong rational support, because there is in fact no rational basis for any such blame. But if, notwithstanding this rational conviction, the irrational sense of wrongfulness about imminent death stubbornly and inexplicably persists and the clinician’s intense wish to avoid any blame also persists, then a third step will follow—though there are some variations in this downward step toward patient abuse.

One variation, one easy way to avoid blame, is to blame someone else—and crude as it may seem, I believe this is the underlying impetus, the internal logic of irrationality, that leads many clinicians to view their dying patients as somehow guilty of wrongdoing, to blame patients for their own deaths, and to punish them for it. This impulse, it seems to me, is at the core of obvious abusive and rationally inexplicable inflictions such as paralyzing dying patients before removing mechanical ventilators. Another way to avoid blame for the wrongfulness of death is, in effect, to flee the scene of the crime—to run away from dying patients as if their condition were contagious. This impulse to abandon dying patients is perhaps more common among clinicians than direct infliction of abuse, but it is harmful to patients nonetheless. In any event, this aversion toward dying patients can often work in ways that are indistinguishable from punitive inflictions. In our paradigmatic example of the paralyzed ventilator-withdrawn patient, the clinician may be understood as looking away from the individual suffering of the patient—as treating the patient not as an individual but as a fearful specter of death.

Some clinicians of course do not take the third step but remain transfixed by their own sense of blameworthiness in failing to conquer death. Though this position may seem preferable to shifting the blame and directly or indirectly inflicting abuse on the patient, this irrational self-flagellation by clinicians does not reliably serve patients’ interests. This position also treats patients as fearful symbols of clinicians’ failures rather than as individuals suffering in their own terms. And the pursuit of the patient’s individual welfare becomes clouded accordingly.

There are, however, some clinicians who can put these irrational impulses and fears into a manageable perspective, who are able to free themselves from the distortions provoked by the imminence of death and clearly to see the individuality of their patients—and, in particular, to see and compassionately respond to their patients’ death-provoked impulses and fears. How are these clinicians able to accomplish this when others are not? Whatever the explanation for this achievement—this considerable achievement in the face of the powerfully irrational forces unleashed for everyone by the imminence of death—I think it is fair to say that these clinicians do not develop the capacity to tame these forces because professional practice guidelines tell them that they are obliged to do so. Practice guidelines do not—in their nature, they cannot—speak directly to the irrational forces that afflict all of us, medical clinicians and laymen alike. Practice guidelines speak to rationality, and in this mode of address they have as much chance of arresting the downward spiral toward abuse and abandonment of dying patients as the proverbial King Canute was able to command the ocean waves to recede.

It may be that some practice guidelines could be drafted with sufficient specificity (for example, “don’t use the following specific neuromuscular blocking agents in the following specific circumstances”) so that they might break through and effectively arrest clinicians’ irrationally punitive impulses. But this highly specific prohibition wouldn’t touch the more basic problem. There are many ways to inflict suffering on dying patients in the course of withdrawing their ventilator support, and there are many ways for clinicians to deny to themselves that they are in fact inflicting suffering—particularly if they can cite a cookbook-type practice protocol that lists specific obligatory steps but nonetheless leaves some discretionary space, however small, for interventions that cannot be specified in advance. Every imaginable practice protocol must provide this discretionary space, at the least, for making judgments about individual patient characteristics and special needs. Every practice protocol regarding ventilator withdrawal, for example, must provide open-ended instructions to require monitoring of each individual patient for unexpected signs of discomfort, since different patients have different thresholds of pain or have subtly different physiologic reactions to the experience of oxygen deprivation. Especially in these open-ended instructions, irrational, punitive, and self-punitive motives can insinuate themselves, notwithstanding the conscious determination of the clinician to be a “good caretaker.” Unhappily, moreover, this conscious wish to be “good” can itself have the paradoxical impact that I have sketched: precisely because the clinician wants to be “good,” he blames himself and his dying patient for being “bad” because his judgment is clouded by the imminence and the felt “wrongfulness” of death.

The basic challenge for practice protocols is to counteract these paradoxical, irrational, and consciously unwanted influences. But they are not amenable to frontal assault. Who would dispute an explicit prohibition against inflicting suffering on patients? What physician would say, even to himself, that he wants to inflict suffering on his
patients? It does seem to me, however, that practice protocols might make some headway against the subterranean influence of these irrational forces—not by focusing on the substance of the rules that should be followed, on specific “dos” and “don’ts” for the provision of medical treatment, but by setting out the range of considerations that should influence choice of treatment in various patient circumstances and by specifying processes of collaboration that should take place in deliberating about those choices and in subsequently reflecting in individual cases on the consequences of the choices that were made.

Collaborative decision-making holds the best potential, I believe, for countering the irrational forces provoked by the imminence of death. As difficult as it is for any individual even to discern the influence of these forces on his thinking and his actions, it can be easier for these forces to come into visibility when different people with different perspectives and experience deliberate together. Collaboration is not, however, a panacea. Rather than enhancing individual self-reflection and accountability, collaborative decision-making can readily descend into diffusion and denial of individual responsibility. And this, of course, is another way for physicians to abandon dying patients. Moreover, genuine collaboration based on open admission of uncertainties and vulnerabilities is at least somewhat alien—and many people would say, entirely alien—to the traditional practices of physician dominance over other health care providers and, among physicians, the rigid hierarchy of deference to senior attendings. The contemporary emphasis on health care teamwork, and shared decision-making with patients and their families is intended to counteract this authoritarian tradition, but old habits die hard.

Discussion

Curtis: I think you have nicely challenged what some of us are recommending in terms of these guidelines and protocols. I wonder whether guidelines and protocols have been the kinds of things that one person can take and look at and follow. I wonder whether the way to build into guidelines and protocols is to include collaborative decision-making, and whether that is a step in the right direction.

Burt: Well, that was the shred of hope that I could bring myself to offer. But it seems to me it could be done. To think of protocols not as lists of, “Here’s what you as an isolated individual should and should not do,” but—just as Louisa [Viles] was saying—to see isolation as the problem. In that sense, if you see the audience of the protocol as the individual who might take this and follow it all by himself, the protocol should say to that individual, “Don’t do this by yourself.” It’s as you were saying, Josh [Benditt], about taking someone with you—not necessarily to the bedside, but to do this together so you can refrain and enlighten one another and bring all these forces up into awareness. But, of course, to do that in the busy professional settings is very difficult—and we’re back to Louisa’s very apt observations about the barriers to that. But it seems to me that guidelines can clearly be specified to say, for example, in these following circumstances you have to have at least 3 people involved in decision-making.

Viles: In speaking of the protocol that Gordon [Rubenfeld] showed, my understanding of that protocol in our institution is that it not only came from a group of physicians who were interested in protocolizing this care, but more importantly is the result of 10 years of interdisciplinary involvement on a bereavement care committee who had pushed and pushed for some change across disciplines in the hos-
pital because they noticed differentials in care. So, I think that it's important to note the genesis of these documents, and also the difference between a palliative care order and a palliative care philosophy.

Rubenfeld: Bo [Burt], it's a challenging area, and certainly you brought up a lot of these issues about the culture of death and the death-defying culture. I think those go into your points 2 and 3. I actually wanted to challenge you on the veracity of your first point. I think you're wrong in saying that death clouds rational judgment. In fact, I think Amos Tversky would say that being human clouds rational judgment. In fact, the study you cite is one of many that show what's called "the framing bias," which means that if you frame 90% chance of success in anything, not necessarily death—and I just wanted to add to that, not because I think that makes your first point wrong, I just think it just makes it a subset of a variety of problems that Gerard [Sils-vestri], for example, is studying in these approaches that we have the decision-making. In fact, Tversky was quite pessimistic about our abilities to make these judgments completely rational. They are, as you say, resistant to our approaches to either education or any of these other cultural approaches, as a matter of fact. So I guess my comment is that it isn't, in fact, death that makes our judgments irrational; it is just the nature of human decision-making.

Levy: That's stimulating. I think the point you made, with which I so fundamentally agree, is that the challenge we face is a spiritual one. What we really need to do if we're going to impact this process is to change the cultural approach. It's almost asking for more spiritual reflection on the process of dying. And that's why it's so difficult to get clinicians to hear what we're saying, as you mentioned, with protocols—because you can't protocolize a spiritual view. It is very difficult to ask someone to take a more spiritual look at the way they're relating to the clouding of rational judgment and death.

The thing I have to add (because my tradition is an Eastern spiritual tradition) is that you brought up the reaction to death being clouding of rational judgment and in part being tied to a sense of blame or guilt. From an Eastern contemplative perspective, it would be a fear of uncertainty. So, from that view, it would be that the fear of nonexistence itself leads to that clouding of rational judgment—rather than a sense of wrongfulness or guilt, it's the fear of nonexistence. The recognition of the transparent nature of ego makes us by nature afraid of dying, of nonexistence. That does transcend any kind of decision-making process, death or otherwise. The fundamental fear of nonexistence makes us physically uncomfortable, and we create a lot of strategies to work against it.

Again, it comes back to asking people to change that. It's such a fundamental change and cultural paradigm that I have to say I share in your pessimism about it.

Burt: I agree. I was very careful to say that I'm just talking about the Western tradition. I've started to delve (ever so lightly) in the Eastern tradition—learning a bit about meditative processes, and trying to imbibe this teaching. But I still find that my Western mind is trying to process these thoughts. It's seductively easy to say that the East has it better—and that we should all move to the Zen perspective. There's a lot of contemporary literature that invites Americans to do this. But we come with our history and our already-shaped cultural patterns, as you say. We can't just suddenly erase them and start again—even if it were true that they actually do all this better than we do, which I'm not sure of.

Levy: I don't mean to suggest in any way that one tradition does it any better, because that fear of uncertainty is the fear of death, and it's all the same; we all react to it the same way. The only thing I would say in terms of optimism is that I agree with you and with what Randy [Curtis] said, which is that the nature of collaboration is the optimistic view; that by opening up our reaction as clinicians, as physicians, to other people we get a better view and a fresher view—which can only enhance the process.

Burt: There is another Eastern thought that does occur to me at the moment. That is the sense that, at least as I understand the teachings that have been offered to me, you start with each individual and from that, enlightenment can come. That, it seems to me, validates this process among ourselves at this meeting. Perhaps this should turn around some of the darkness of my conclusion. Perhaps I shouldn't be saying, "What's the use of practice guidelines to influence everyone's behavior out there? By God, we're going to stumble and it won't work." It

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Burt: Well, that could be. Whether this is a subset of a more general problem or not, this is particularly nagging, it's still the same bottom line. I had an anthropology professor in college whose specialty was the Nuer tribe in Africa. He told us how he reached an important decision when he had to decide between staying at one college or going to another. He went out into his back yard and threw chicken entrails, which is what he learned from the tribe he was studying. The entrails told him he should go to the other university, and he did. That seems pretty irrational.
may be that the best thing is for us here to support one another in bringing this forward so we can tame these forces, and then go out in our settings and model it and offer the same kind of freedom and enlightenment to those who are around us and that they will see it as attractive. So it grows and it grows.

I should say that one of the great joys of my life has been my involvement in the Project on Death in America of the Open Society Institute, and in particular, the Faculty Scholars Program, of which we have two splendid examples here. That's the philosophy of this program—to start within the profession, individual by individual, and to offer mutual support. That's the really quite extraordinary and beautiful thing that I have found in the meetings and interaction of that group. When the program first got started—and it's only 6 years old now—the first cohort were already imbued with the notion that things had to change in the care of the dying, and they were changing things in their immediate clinical practice. But they all said, "You know, we feel so isolated here. We feel so alone. We're scorned in our institutions. We are "Doctor Death." In saying that, the faculty scholars discovered suddenly that they were not alone. This is spreading now. In this meeting, too, those who have this perspective can. I think, go away from today saying 'I'm not as alone as I felt when dealing with this death tinged crazy stuff as I was before." So maybe the Eastern person-by-person approach has some hopeful possibilities.

**Burt:** I would say most of all hold your ground. Don't be scared off by the threats that are actually mounting out there. One of these threats is the Hyde-Nickles bill now pending in Congress that would terrorize physicians against using appropriate pain medication, in the supposed service of arresting physician-assisted suicide. This is part of Joe's [Fins] observation about physician-assisted suicide—the subject of Kevoian comes up, and the legislators' response is, "This is so wrongful that we have to throw away baby, bathwater, everything." That's what the Hyde-Nickles bill itself does. But the best thing the clinician community can do is not to be scared off and to mutually support one another.

In very specific practical terms, let me recommend a lawyer to you. The Project on Death in America has made a grant to establish a palliative care litigation project, which is based in Washington DC. Mary Baluss is the attorney who is now heading this up. Her goal is to establish an effective presence to protect physicians and other health care providers who are working in the palliative care field, who are doing the right thing and are being harassed, particularly on pain issues. This is a new consultative and litigative resource that has just been established and is really an important thing that every physician should know about. Mary can be reached at the Bazelon Center for Mental Health Law, 1101 Fifteenth Street NW, Suite 1212, Washington DC 20005. Telephone: 202-467-5730.

**Hansen-Flaschen:** Your comment that death clouds rational thought and behavior is useful to me in accepting, or at least tolerating, irrational decisions that are otherwise very anger provoking, to no benefit. I want to ask a question, for Gerard's [Silvestri] sake here. I want to ask the lawyer and the philosopher in you. He makes a diagnosis of a fatal disease. Should he take the viewpoint that the patient needs to know the prognosis or is entitled to know? Should he be sure within the first visit, or first 2 or 3 visits, that the person fully understands what mesothelioma means, or should he invite questions and wait to be asked?

**Burt:** The lawyer in me has an easier answer than the philosopher. The lawyer answer is that there is still in our law the so-called therapeutic exception to the obligation to fully inform a patient. The therapeutic exception, which has been around a long time, means that if the physician has reasonable grounds to believe that informing the patient will harm the patient in some way, then the physician is not obliged to harm—in fact, quite the contrary. Now, to responsibly carry that out, you just can't have a vague suspicion. You have to have some good reason. And I think that requires, actually, exactly the iterative process that you described in your talk today.

And then the philosopher, the moralist, in me says that is the only decent way to proceed. To begin with, the presumption of dumping this information on the patient (given the clouding of rational judgment and all of the difficult forces unleashed by the prospect of death) is unpredictable in its impact. So, you have to proceed delicately and with close attention to whom you're addressing—to start a back and forth conversation and get a feel for how much the patient is prepared to know and to absorb. I think it was you, John [Hansen-Flaschen], who said that in your experience patients never understand in the first conversation anyway, and that you must have a second and a third. That's exactly right. That's the way to do no
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harm. But not to do what the tradition of medical authoritarianism has been, which is to say, "Virtually every patient will be harmed by it, so I'm not going to explore the issue at all." This is the old way of doing it, and also the way to run away from death itself. This kind of conversation is very hard to do well. It requires time and support, which typical clinicians don't have.

Silvestri: I just wanted to follow up on that. In that study that we've just completed, patients uniformly want this information—99% want this information. Family members (statistically significantly) don't want them to have this information at about 75% of those. Clinicians—in terms of do they believe the patient should have the information, particularly about the terminality of the illness or noncurative nature of their illness—also fall off. Patients want this information. And so I leave it up to the patient. I think it is a back-and-forth process.

I will tell you that we have an expert in palliative care research at our place who happens to be a nurse who was recently diagnosed with breast cancer, and I gave this talk at our place. She was still going through chemotherapy, and at the end of the conversation, she said to me (and she's a nurse who had been involved in this type of thing), "The second the doctor told me I had cancer, the rest of the conversation was over; I don't remember anything. It took me 4 hours to recover, and that night I went on the Internet and got every bit of information I needed about cancer."

So I agree with John. This has got to be an iterative process, but clinicians can't just give away this responsibility. Patients want to know, and they need to know in order to make decent decisions. I think that process should start almost immediately—whether you get a sense that they can handle it or not. Some part of that has to start right up front.

Fins: I was listening to your discussion. I want to focus on the successful doctors who were able to overcome all this and engage in the care of the dying in a successful way. It struck me that there may be a kind of parallel to a successful bereavement, and it reminded me of what we were talking about previously about jokes. Freud wrote about jokes and their relationship to the unconscious. He analogizes to dream work, in which the dream is a kind of repetition, the recurrent nightmare (as it were) as a way of gaining mastery over an unsettling experience. It seems to link that up to what you said, that there are legitimate and successful types of mastery—that is working through and talking with colleagues and sublimating interests. And then there are destructive ones that are kind of false masteries, like perhaps a neuromuscular blockade in certain kinds of situations. I don't know the answer to how to do this, but we have to promote the successful working through, and maybe there are lessons to be learned from a productive bereavement experience. You never get over the loss, but you move on, and you master your new environment and your reality in a new and, perhaps, uplifting way.

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Rubenfeld: I'm concerned about having a specific follow-up to Josh's [Benditt] question. People are going to look at the speaker list and see that you're a lawyer and go right to the discussion section, and I'm concerned about leaving the last comments about malpractice liability be that phone number. So I wanted to give you a chance to speak to what specifically concerns many of our readers is this particular kind of case in the intensive care unit. I wonder if you would care to comment specifically about the issue of legal liabilities. This is the sort of case you're asking about—legal liabilities, and withdrawing life-sustaining treatment in the ICU.

Burt: In specific kinds of circumstances, where there's conflict with the family, you mean?

Rubenfeld: Correct.

Burt: And the patient himself is noncommunicative? Well, legally, that is a complex circumstance. There is a Fourth Circuit Federal Court of Appeals decision interpreting the Americans with Disabilities Act to say that withholding care is discrimination against disabled people, and that you can't do that.

You may know about this case of an anencephalic baby who clearly had no long-term survival capacity, and the physicians wanted to withhold treatment based on their evidence-based practice of medicine, and the mother, for her reasons (indeed they were not religious reasons, so it wasn't even a church/state kind of issue) resisted and brought suit and won the suit. In that case, the treatment was not terminated. Had they terminated treatment in the face of her objection, I think there was also the possibility for a huge malpractice liability. But that issue is not over yet, and there's lots of dispute about the soundness of that decision in legal circles and in professional circles.

I think it is very appropriate and quite important that that particular resource—the new palliative care litigation project—be in the journal, along with the phone number, because what we're trying to do is establish a consultative resource, so that when someone is faced with a problem they don't simply have to go to the hospital counsel. I could talk an entire hour more about the role of hospital counsel in these areas. Some are good, but they're a minority. Most just don't want to get sued. They don't care what you're
doing—you just take the path that will mean you won’t get sued. So that means, for example, that if you think care should be withdrawn, but there’s some unhappy family member, a third cousin twice removed, who opposes withdrawal, counsel will say don’t do it because we might get sued. This is a terrible way to give advice to clients. It’s destructive of good practice, and it’s not the only way.

There’s a Milbank Memorial Fund report about the role of hospital counsel in end-of-life care decisions, for those of you interested in pursuing it. I recommend it. In that report we talk about two different models. One is the supportive hospital attorney who understands clinical reality and the other attorney just doesn’t want to get sued. If you were in a hospital with legal counsel who is of that latter ilk, I would just urge you to call Mary Baluss and talk to her as a consultation. Obviously, she can’t overrule your hospital counsel, but she can start helping you and giving you information to feed to the hospital counsel. Or, if you should find yourself in trouble with your state Medical Review Board—if the Board pursues you for your opiate prescriptions—you should contact Mary.

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Curtis: I think one of the things Gordon [Rubenfeld] and I really like about this chapter that Marshall Kapp wrote is that we see a lot of physicians who say that they feel they have to continue life-sustaining treatments in situations where none of us feel it’s good medical practice because of the fear of a lawsuit. One of the things that Marshall does well is to make the point that that’s not a reason to continue life-sustaining treatment. There have not been situations where physicians have practiced good medicine, within the scope of practice, withdrawn life support, and then been successfully sued. Would you agree with that?

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Burt: Yes. But let me say one other thing going back to the desirability of collaborative decision-making. The best protection against getting sued is to share widely what you’re doing before you do it—to collaborate within your institution and elsewhere, and if it looks like you’re involved in a really heated issue, call some nationally recognized experts for a consultation. If you are subsequently sued—and you may well be sued, because anyone can be sued about anything—you can then say, “Hey, I wasn’t off on a frolic on my own. I wasn’t just doing this because it occurred to me on a Saturday afternoon. I consulted widely and all these people signed on with me. And they’re ready to be expert witnesses on my behalf.” That case will be won. What some hospital counsel keep doing is shutting off this process and the possibility of successfully making this point in litigation. Collaboration is the key. Nothing done in secret.
Palliative Care in Respiratory Care: Conference Summary

Mitchell M Levy MD

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Key words: end-of-life care, palliative care, respiratory care practitioner, hospice, lung cancer, pulmonary rehabilitation, dyspnea, withdrawal of life support. [Respir Care 2000;45(12):1534–1540]

Introduction

The topic of this conference is very timely for respiratory care clinicians. There is increasing recognition that palliative care concepts are integral to the care of all patients, not only those with end-stage disease. It is often the respiratory therapist (RT) who is at the bedside of a patient dying in a critical care unit, or, for that matter, on a medical ward with a patient suffering from lung disease. Therefore, as was emphasized by each of the conference participants, it’s important for these caregivers to cultivate the necessary skills to serve these patients and their loved ones. Unfortunately, training and support for the clinicians involved with end-of-life care for these patients, although improving, still remains less than adequate, despite 20 years of conversations among caregivers and educators. As per tradition, as conference summarizer, I will review each of the presentations from the conference and end with some of my thoughts on the important themes that surfaced during the meeting.

Palliative Care: An Overview

Joseph Fins presented an overview of palliative care and discussed the goals and the achievement of patient-desired quality of life. Enhancing communication skills, both among caregivers in the team and within the patient/caregiver relationship, was an important theme of Joe’s presentation, and one that was consistently mentioned by conference participants. As Joe presented, the roots of the hospice movement began in Europe as a religious model,
as opposed to the American model, which was much more community-based.\textsuperscript{1-3} The American hospice movement evolved outside of the mainstream and took root in spite of rather than because of the American medical establishment. In part, this is because of how difficult it is for many clinicians to suspend the curative mentality. Several important questions came out of the discussion after this presentation, among them: How do we incorporate palliative care skills into critical care and respiratory care practice? How can we teach clinicians when they need to ask for help? And how do we know when we’re not doing a good job with palliative care? Joe suggested in his presentation—and the consensus among all of us—was that better observation and listening skills will play an important role in improving palliative respiratory care.

Dyspnea Assessment

Helen Sorenson’s presentation on dyspnea assessment was particularly important. As she discussed, many different descriptors for dyspnea, such as the traditional diagnostic evaluations like laboratory tests and pulmonary function tests, don’t correlate well with symptoms.\textsuperscript{4,5} This observation, shared by many end-of-life caregivers, underscores the need for objective tools for assessment, not simply to measure and assess dyspnea, but more importantly as a means to establish and enhance communication with patients and treatment of dyspnea. Scales can seem very daunting and in many ways unnecessary. However, when considered a means to enhance communication rather than simply to assess dyspnea, these scales may be viewed differently by clinicians.

Treatment of Dyspnea

In Harold Manning’s presentation on the treatment of dyspnea, the multiple mechanisms of dyspnea were discussed. He emphasized the disease-specific mechanisms of dyspnea, leading to the conclusion that treatment should be targeted to these specific mechanisms. This presentation included a review of specific agents, in which it was clear from an evidence-based review that only opiates and supplemental oxygen have been demonstrated to have a significant beneficial impact on dyspnea.\textsuperscript{6} Trials with nebulized opiates have not yet demonstrated a beneficial impact.\textsuperscript{7,8} Furthermore, benzodiazepines, phenothiazines, and alternative medicines have also failed to demonstrate any significant beneficial impact on dyspnea.\textsuperscript{9} Further studies are needed to find improved ways to treat dyspnea at the end of life.

Managing Secretions

In her second presentation, on management of secretions, Helen Sorenson discussed the importance of secretion clearance for palliation and the need to adjust the means of secretion clearance to specific patients. As was mentioned by several members of the group, many patient surveys of post-intensive care unit (ICU) care identify suctioning as one of the most anxiety-provoking and painful ICU procedures.\textsuperscript{9} Critical care clinicians tend to underestimate the distress caused by suctioning. The question is, do we need to suction patients, especially when they are imminently terminal? Are we suctioning patients for their comfort or because of the caregivers’ discomfort with the gurgling sound (death rattle)? Perhaps this is an example of the need for ongoing education of patients, families, and staff about the process of dying and what to expect when people die. So rather than suctioning patients constantly because the staff and family appear to be uncomfortable and thus subjecting terminal patients to unnecessary suctioning procedures, we might all be prepared for the types of sounds made by patients during the dying process, which may not necessarily reflect discomfort.

Palliative Care in Pulmonary Rehabilitation

As I have already stated, one of my goals as conference summarizer is to emphasize the points that were common to all presenters, and John Heffner raised an issue that is certainly one of them. That is, in spite of what some clinicians seem to believe, most of the surveys in end-of-life care indicate that, for the most part, the majority of patients really do wish to participate in end-of-life decisions. The question that critical care clinicians face is, how well do we facilitate this decision-making process? This becomes even more difficult when dealing with an illness such as end-stage pulmonary disease, where we are unable to predict the time course or overall prognosis all that well. Therefore, uncertainty plays a large role in our discomfort with end-of-life discussions. This dilemma is made worse by the limited time available for discussion with patients, whether it’s in the outpatient clinic or in the critical care unit. As a result, we often ignore or fail to ask about advance directives. As a potential solution to this clinical problem, John suggested that the rehabilitation environment might be an appropriate setting for facilitating end-of-life discussions. Because pulmonary and cardiac patients have life-limiting disease, these patients are often enrolled in rehabilitation programs. Two important factors make the rehabilitation setting attractive for these discussions: first, there is often more time available during rehabilitation visits, and, second, patients are less acutely ill. Given that the majority of patients want to have their end-of-life discussions when they’re feeling well rather than when intubated or acutely dyspeic, it may be that the rehabilitation setting, where patients tend to be in better health than in the hospital, may provide a more favorable environment in which to have end-of-life discussions.
habilitation programs may also be a more favorable setting in which to provide education for patients about advance planning and end-of-life decisions. In truth, it is during rehabilitation where education, especially for patients with chronic obstructive pulmonary disease (COPD), is already happening. Recognizing that it is often difficult for physicians to initiate these discussions and empowering a caregiver in the rehabilitation environment with the responsibility for initiating and continuing these discussions may be beneficial.

**Palliative Noninvasive Ventilation**

Josh Benditt discussed palliative noninvasive mechanical ventilation. He described a reverse double effect of noninvasive ventilation: that is, both the relief of dyspnea and the prolongation of life, and presented evidence that noninvasive ventilation reduced dyspnea in acute respiratory failure, in addition to improving survival and quality of life in amyotrophic lateral sclerosis patients. As Josh described, the advantages of noninvasive ventilation are that the patient is able to speak and eat and requires less sedation. When noninvasive ventilation is applied to patients who have do-not-intubate orders, about 50% of those patients (in certain diseases) actually survive. Those are very important data for critical care practitioners to understand. In my mind, two major questions came out of Josh’s presentation. First, is noninvasive ventilation comfortable? Although patients are under do-not-intubate orders because they don’t want to be intubated, and we can offer them noninvasive ventilation and prolong their lives, the question is how much more comfortable is long-term noninvasive ventilation than endotracheal intubation? However, if noninvasive ventilation increases the quality and quantity of a patient’s life and if these are goals desired by the patient, then clearly it’s an appropriate intervention.

The second question raised by this presentation is much more profound. That is, these data challenge us to alter our approach to end-of-life discussions and raise a new question that we must ask our patients, which is, “Are you unwilling to undergo intubation, or are you ready to die?” I don’t think we’ve really presented the question to our patients in this way. We often say, “Do you want to go through intubation and a breathing machine again?” Now we have to be much more careful with that question, and communication is, again, the key here. Caregivers must discern patients’ wishes much more precisely—whether the wish is to not be intubated or to refuse life-prolonging care. Given the success of noninvasive ventilation in improving survival of patients to discharge, it is clear that these are now two very different questions. I think that is a very very important message from this presentation that needs to be contemplated by clinicians and incorporated into end-of-life discussions. We now have the ability to prolong life of some patients with respiratory failure without using endotracheal intubation, and we must be certain that, in our communication with patients, we find out which they want, or more to the point, which they don’t want.

**Communication with Patients and Families**

Randall Curtis discussed communication with patients and families. A harsh reality of end-of-life research is that controlled trials have thus far failed to show any significant impact of education and other interventions on the incidence of advance directives. In the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), no effect was found on either decision-making, aggressiveness of care, or cost of care by improving end-of-life discussion skills. However, as Randy made clear, patients do want to discuss end-of-life care, and, in fact, the earlier the better. As was shown by some of the surveys presented by Randy, many patients believe that it is the physician’s responsibility to initiate these discussions. This is another consistent theme throughout the conference: families rank communication as more important than clinical skill, and family satisfaction is often tied to the consistency of communication with caregivers.

Randy also presented excellent suggestions on the “how to” of end-of-life discussions and I would refer the reader to Randy’s paper for details. In summary, Randy mentioned that most research on end-of-life care communication provides evidence of the problems, but not clear solutions. He offered clear advice on how to enter into end-of-life discussions with patients and families, which included an important suggestion to have an internalized protocol of where you’re going to have the discussion, how is the patient doing, and what are the family’s concerns, so that, essentially, a caregiver has a checklist about the various aspects of communication.

**Principles and Practice of Withdrawal of Life-Support**

Gordon Rubenfeld’s presentation included a discussion on principles and practice of withdrawal of life support. Gordon made some important points that are worthy to pass along. First, withholding is morally and legally equivalent to withdrawal of life-support. Although well known to some clinicians, it is not uncommon to find clinicians who do not either feel that’s true or know that legally it’s true. Any treatment can be withdrawn, including antibiotics, nutrition, and intravenous fluids. Furthermore, Gordon made the point that withdrawal of life-support should be considered a medical procedure, and in the same way that physicians are at the bedside when a pulmonary artery catheter is inserted, they should be at the bedside when
life-support is withdrawn—a very important point. Gordon also introduced a challenge to clinicians: When a family or patient indicate a wish to have some form of life-support withdrawn, a caregiver must consider whether this, in fact, means all forms of life-support and that, possibly, with a little more support and education on the spot during that first conversation, a caregiver might facilitate a more rapid and clear resolution. This could be a more compassionate approach for many families, rather than forcing them to make repeated decisions during prolonged end-of-life care. He followed with a suggestion that we remember to consider the setting and presence of monitoring when we withdraw care, as well as the importance of appropriate sedation. As Gordon emphasized, removal of the endotracheal tube after withdrawal of mechanical ventilation, despite all of the debate in the literature, ultimately is a matter of style rather than a matter of morals.13-15 Gordon also reminded us to prepare families for the possibility of patient survival. We’ve all witnessed the anguish families experience when unprepared for the continued survival of a loved one after withdrawal of life-support. Gordon concluded with a suggestion to view end-of-life care as a quality indicator, which could then be reviewed as any other quality indicator by the institutional critical care committee.

Treating Dyspnea with a Ventilator

This was a very stimulating presentation by John Hansen-Flaschen. It does appear to be possible both to measure dyspnea in patients undergoing mechanical ventilation and to affect dyspnea through adjustment of one or more ventilator settings. So, as John so nicely suggested, one of the first questions clinicians must address at the bedside is, “Is it dyspnea?” We often assume a patient to be short of breath either because of their underlying disease or because they are receiving mechanical ventilation, and yet how much of the discomfort is from confounding factors such as lying in bed, tape on the patient’s face, turning, temperature or humidity of inhaled air, suctioning, intermittent sedation, anxiety, or panic? Understanding this leads to another important question raised by John: How do we talk to patients who are intubated? As he so eloquently phrased it, “What is the etiquette of talking with patients who are undergoing mechanical ventilation?” Unfortunately, as every clinician knows, our communication often devolves to the “nod your head” request, which doesn’t really do the trick. We all fall prey to that—when we’re in a rush our communication with a ventilated patient becomes something like: “How are you doing? Are you in pain? Just nod your head Yes or No.” John introduced the term “patient-centered mechanical ventilation,” which is a great reminder that comfort becomes the primary goal. We need to take the time to communicate with patients receiving mechanical ventilation, especially if the patient is awake during end-of-life care. Is the patient comfortable? Does he prefer one mode to another? We all have the experience of asking patients if they’re ready to have the tube out during the weaning process. Many clinicians accept the fact that patients with COPD know best when they’re ready to be extubated, and yet we fail to extend that to patients during end-of-life care. How rare it is for us to ask, “Are you more comfortable on this, or this?” It is a logical extension of what we already know yet rarely apply.

What is the Role of the Respiratory Therapist in Providing Palliative Care?

Tudy Giordano discussed the role of the RT in providing palliative care and asked an interesting question: How much of palliative care is really simply good quality chronic care? If care for the chronically ill patient is equivalent to palliative care, then there is certainly a real need for RTs to be trained in and to understand the principles of palliative care. This is a very seminal question. There is, in fact, very little active training for RTs in palliative care. Yet, the RT is often at the bedside during end-of-life care. We were also reminded that in many institutions RTs are not included properly in the critical care team and are asked to be technicians but not full players. Tudy made the important point that as the population ages and more limitation of care occurs, RTs will play an expanding role in end-of-life care—another reason why proper palliative care skills training for RTs is essential.

Palliative Care of Patients with End-Stage Lung Disease

John Hansen-Flaschen’s second talk, on palliation in patients with end-stage lung disease, focused on the difficulty clinicians have conveying or framing a prognosis, because of the uncertain progression of end-stage lung disease. Because prognosis in COPD has such wide confidence intervals, the ability to articulate a clear prognosis becomes very difficult. Unfortunately, clinicians often use this as a reason to avoid the discussion or emphasize the positive or negative, depending on their personal views. John had some good suggestions for working with this obstacle:

First, determine the patient’s preference for where to hold the discussion.

Second, identify who will be involved in the discussion.

Third, have the actual discussion about life support preferences.

Finally, discuss the “what ifs” with patients and families. John described this aspect as dealing with the practical concerns of patients and their families.
Above all, John reminded us to simply be “human beings” and find out what the patient thinks you said. As John so nicely put it, “This is the beginning of the forthright relationship between a physician and a patient in the face of a chronic or terminal disease.” As conference summarizer, I think the most consistent point raised throughout the conference was the importance of open communication between caregivers and patients. Everybody had a different way of describing it, but without question this was the most consistent and determined message throughout all presentations and discussions.

**Palliative Care of Patients with Lung Cancer**

Gerard Silvestri shared some sobering statistics about lung cancer. Despite years of research, the overall 5-year survival from lung cancer remains 14%. These poor survival statistics underscore the importance of understanding palliation in lung cancer, and make much more remarkable the lack of proper funding for palliation in lung cancer. Gerard emphasized the importance for clinicians of being aware of the various palliative approaches available in lung cancer, including stents, management of malignant effusions, radiation therapy, and skillful therapy of bone metastases.

**Organizational Change and the Delivery of Multidisciplinary Palliative Care**

Barbara Daly began her presentation with a statement on a frequently expressed theme: “Inadequacies in the care of the dying are often related to failure to appreciate the extent to which the environment of practice influences care providers and care processes.” Given the fast pace and time constraints in both the critical care unit and the clinic, we may overlook the importance of environment. Barbara discussed various organizational models for palliative care, including a dedicated unit, designated beds and staff within an existing unit, and, finally, a consultation team. This led to an interesting discussion on the challenge of providing adequate consultative services without undermining the process of teaching clinicians how to improve their personal end-of-life skills. The point is, no matter how well we develop a good organizational model, whether it’s a dedicated unit, designated beds, or a consultation team, sooner or later most clinicians in this field are going to be at the bedside of a dying patient. We will have ultimately failed in our goal to provide the highest quality of care to patients at the end of life, if through these organizational processes, we encourage some clinicians to abandon their practice and training in end-of-life skills to a consultation team. These practitioners may still be at the bedside at those crucial periods with a dying patient, and we must remember that our goal is to enhance end-of-life skills for all critical care clinicians, not just simply provide a way for clinicians to get help from someone else when they are uncomfortable with the process.

**Death and the Practitioner**

Louisa Viles made some very important points about caregivers and death anxiety, which clearly is inadequately explored or discussed by clinicians in the field. As clinicians, we rarely deal with our personal sense of loss or grief that arises from our interactions with patients. Inevitably, failure to address this deep emotional process can only serve to increase burnout and distress among caregivers. Louisa pointed out that this may be heightened by the conflict that often exists between the traditional role of the clinician and the role required during the dying process—that not only are we being asked to provide optimal care and make an accurate diagnosis, but we also now have to manage and provide a good death. Louisa offered some useful suggestions about being proactive in regard to stress and burnout in the workplace, including programs that offer ongoing, nonpunitive supervision, establish multidisciplinary care teams, offer forums for discussion and support, and provide role models in palliative care for practitioners. This is helpful information about working with stress and distress, which reminds clinicians of the importance not to go it alone—that collaborative care is not an accident. Collaborative care works, in part, because it unloads the stress of all the caregivers by bringing other team members into end-of-life discussions from the beginning and providing support for caregivers during this difficult process.

**The Limitations of Protocols for End-of-Life Care**

The final presentation, by Robert Burt, was very thought-provoking. He made a challenging effort to identify some of the obstacles and pitfalls that can arise when we attempt to improve end-of-life care. Be wary of the reformer and the self-righteous, he reminded, because if our goal is compassionate care and we recognize that nurturing and caring for ourselves is the first important step in providing good end-of-life care, then it’s important that we convey that same message to all clinicians and not become fanatical about the message to the point where it becomes counterproductive. Professor Burt suggested that the very character of death leads to inevitable obstacles for meaningful communication with dying patients and their families. He postulates from the Western tradition that there are 3 irrational forces that undermine practice protocols intended to safeguard the welfare of dying patients. The first is the clouding of rational judgement, which leads to the second, the aura of wrongfulness provoked by the imminence of
death that, in part, certainly seems to be related to a sense of guilt or shame, and leads to the sense of failure on our part as caregivers—that we’ve done something wrong or there’s something we could have done to make this patient better, which then leads to further reactions such as blame, transfer avoidance behavior, or self-flagellation.

The third step, patient abuse, such as physicians’ use of neuromuscular blocking agents for withdrawing ventilator support, does not inevitably follow from the first two steps. Professor Burt suggested that it is the caregiver’s ability to put fear into rational perspective that provides the foundation for good end-of-life skills. I think it is difficult to say whether we put fear into rational perspective or just become comfortable with the uncertainty about the dying process. Regardless of how we describe the process, there are some caregivers who seem to be able to work with the uncertainty of the dying process and communicate a sense of ease and comfort that fundamentally nurtures patients and allows them to feel more comfortable.

The question is: How does this happen? How does the caregiver transcend the discomfort that arises when working with the dying patient and learn to manifest a truly genuine, nurturing presence? Bo’s point was that it’s certainly not from protocols and guidelines. In fact, we all agreed that a much more fundamental change is required—that affects one clinician at a time and that leads to understanding the importance of collaboration and mutual support as well as fostering self-examination.16.17 Perhaps then we may see clinicians move away from the traditional reaction to uncertainty and to develop natural, intuitive end-of-life skills.

Summary

In the end, I would like to emphasize some of the consistent themes of the conference.

1. Communication. Almost every presenter talked about the importance of communication in good end-of-life skills.

2. The need for training and support. Can we identify core competencies in end-of-life care? Can we train clinicians in these skills? And can we encourage clinicians to desire this training?

3. The need for all critical care clinicians to routinely incorporate palliative care principles into daily practice—not waiting until we are convinced that a patient is dying, but once a patient is identified as having a life-limiting disease we can begin to incorporate fundamental palliative care principles.

4. Learn how to better assess our patients’ needs, both during acute illness, while on mechanical ventilation, and in the clinic. This, perhaps, may be the first step in establishing genuine communication. If, as clinicians, we appreciate both the importance of identifying patients’ needs and the fact that we often fail to live up to this goal, then the logical next step is to improve our communication skills, perhaps through some form of training and support.

5. Finding the right environment for end-of-life discussions: the where and when of it. Being sensitive to the impact of the environment—whether a hallway or noisy, crowded room—on end-of-life discussions.

6. Valuing the impact of just being present with patients. This concept was referred to by several participants as open communication and by others as therapeutic intervention. The point is, that being truly genuine with our patients and manifesting a compassionate presence is a very powerful tool, one that is often undervalued by caregivers.

I would end the summary of the conference with some personal reflections. First, solutions may be much more simple than we suspect. Improving our communication skills may be a matter of really learning how to listen, which is not always simple, but doesn’t necessarily have to be all that complicated. We can overcome the impulse to always provide answers and solutions. We can avoid making the solution to our struggle with end-of-life care more complicated than the problem. We don’t have to have a long-winded explanation for what to do for our patients and their families when they face the anguish of dying. In fact, we can view as healthy our reactions and those of our patients and families to the prospect of dying. Panic in the face of uncertainty and the threat of loss is a very healthy reaction, and we can learn to react with, not to, our patients and their families in the dying process. This is the true nature of empathy.

Finally, we might appreciate the power of simply nurturing our patients and ourselves. This was a consistent message from every conference participant. If I were to characterize the picture of an outstanding end-of-life clinician that emerged from the conference, it seems to boil down to being a genuine, decent human being who reacts honestly to patients and is willing to share a personal sense of sincerity and tenderness. Not very technologic, perhaps, but nonetheless a very powerful therapeutic tool.

What are our challenges for the future? Several unanswered questions remain. How can we encourage caregivers to view end-of-life skills as a lifelong educational process? Can we develop a formal training process for end-of-life care? How can we impact government and public opinion to improve understanding of the issues in palliative and end-of-life care? How can we educate patients and families to demand appropriate end-of-life care? How can we bring all caregivers into the palliative care process? The quality of care our patients receive at the end of life will depend on our ability to slowly evolve answers to these difficult questions.
REFERENCES


Occupational asthma has become the most commonly recognized occupational lung disease in most developed countries. This second revised and expanded edition of Asthma in the Workplace provides clinicians and investigators with a comprehensive, thorough, and up-to-date resource on occupational asthma, and reflects the rapid growth in interest, research, and knowledge concerning occupational asthma. The intended audience is broad, including primary care physicians, pulmonologists, occupational health specialists, immunologists, allergists, epidemiologists, laboratory investigators, and industrial hygienists. Despite the expansive nature of the book, it will also be an important resource for primary care providers; those most likely to first evaluate patients with work-related asthma. Several topics covered, such as physiologic testing, latex allergy, and prevention, are particularly relevant for therapists and nurses.

The book is divided into 4 major sections that address the many facets and aspects of asthma in the workplace. Part I, "General Considerations," covers topics such as the definition and classification of asthma, pathophysiology, animal models, and epidemiologic approaches. The chapter on animal models of occupational asthma has been extensively updated and expanded, reflecting recent advances in the field. An important new addition is the chapter on genetics and occupational asthma. It provides an excellent overview of the genetic basis of atopic asthma, as well as a thorough summary of the potential genetic markers for occupational sensitizers.

The recognition and diagnosis of occupational asthma is particularly difficult and challenging for practitioners. The second section of the book, "Assessment and Management," provides several thorough chapters that delineate the optimal approach to clinical evaluation of patients with possible occupational asthma. An excellent overview chapter is followed by more detailed chapters covering topics such as the physiologic assessment, specific and nonspecific challenge tests, the immunologic evaluation, and environmental monitoring. Additional chapters cover medico-legal considerations, impairment and disability, and surveillance. The book does an outstanding job of delineating the optimal approach to evaluating patients with possible occupational asthma.

Unfortunately, physicians are frequently forced to make diagnostic decisions using a more limited armamentarium of available tests and data. Nevertheless, this practical, clearly written section is valuable for therapists, nurses, and primary care providers involved in the evaluation of patients with possible occupational asthma.

The third section of the book, "Specific Disease Entities," has greatly expanded on the prior edition, and covers major specific causes and types of occupational asthma, such as high-molecular-weight agents, isocyanates, metals, wood dusts, and reactive airways dysfunction syndrome. These chapters provide detailed and well-synthesized information on these key topics. The chapter "Reactive Airways Dysfunction Syndrome or Irritant-Induced Asthma" has been expanded and does justice to a complex and controversial problem: irritant exposures. Several new chapters have been added that address hazards of rising interest and concern, such as latex, enzymes, and exposures in the baking industry. Other welcome additions are new chapters on entities often associated with occupational asthma or its diagnosis, including upper airway involvement, hypersensitivity pneumonitis, and building-related illnesses.

The final section of the text contains several valuable compendiums, such as the comprehensive and well-referenced tables listing the major agents that cause occupational asthma, as well as some important United States and European databases and resources.

This is an outstanding and unique volume that has only improved on the first edition, already the definitive landmark work on occupational asthma. It is rare to find a book that is so comprehensive and detailed yet remarkably readable and lucid. The editors, I Leonard Bernstein, Moira Chan-Yeung, Jean-Luc Malo, and David I Bernstein, unchanged from the first edition, are unquestionably leading experts in the field. The book benefits from the expertise of over 50 additional individual contributors representing numerous disciplines and countries—a list that includes almost every major authority in the field. Despite the large number of contributors, the editors are authors or co-authors on over half of the chapters, providing remarkable consistency for a multi-author book and uniform excellence. The figures and tables are clearly presented and provide valuable information. Each chapter is meticulously referenced with up-to-date references. The well-designed layout with frequent subheadings adds to the readability of the text. This book succeeds in providing a comprehensive resource on occupational asthma that will be useful to a wide audience of both specialists in the field and primary care providers. It has outstanding content and organization and an easily readable style. One can obtain a valuable, thoughtful, and concise summary of a topic as well as much greater detail if interested. There are few limitations with this book. One area that might deserve greater attention in future editions is the evaluation and management of work-aggravated asthma, underlying asthma that is exacerbated rather than primarily caused by factors in the workplace. This second edition will become an invaluable resource to all who take care of patients with work-related asthma or are involved in the investigation or prevention of this important health problem.

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In his introduction to this volume, Claude Lenfant alludes to recent controversies about the role of traditional immunotherapy in asthma management. He answers "certainly
not!" to the question of whether immunotherapy has lost the place that it deserves in asthma treatment, and then predicts that the future holds "important new roles" for immunologically-based therapies for asthma. This thread of optimism about future possibilities runs throughout the 33 chapters from 78 contributors, drawn largely from recognized European and American authorities on aeroallergen immunotherapy, the chemistry and biology of allergens, the immune regulation of allergic immune responses, and the genetics and prevention of allergic diseases and asthma. The editors, Jean Bousquet and Hans Yssel, have succeeded in bringing together in a single text an expansive consideration of not only current indications and limitations of traditional immunotherapy for allergic respiratory disease, but also a pondering of future possibilities for asthma intervention based on a variety of immunological approaches.

Part I deals with "Mechanisms of Allergic Asthma" and includes reviews of the current paradigm of T helper 1 and T helper 2 lymphocyte subsets and evidence that asthma is phenotypically a T helper 2 disease. It includes a chapter by LM Wheatley and TAE Platts-Mills arguing that allergy is the major identifiable cause of asthma, a review by editor Bousquet and his colleagues on inflammation and airway remodeling in asthma, and a chapter on the natural history of asthma by the pulmonary epidemiology group at Groningen, Netherlands, headed by DS Postma.

Part II deals with allergen-specific immunotherapy. The first chapter is the executive summary of the World Health Organization position paper on allergen immunotherapy, with its somewhat oxymoronic assertion that allergen immunotherapy should be more properly considered as a "therapeutic vaccine." Thereafter follow chapters on the immunochemistry of allergens, a useful and balanced overview of immunotherapy "past and present" by one of its pioneers, PS Norman, and a brief chapter summarizing the postulated mechanisms of immunotherapy. In an incisively written critique of immunotherapy, AJ Frew carefully separates what is known from what is speculated about the clinical benefits of immunotherapy and outlines what must be done to clarify its appropriate role in asthma management. In a very useful chapter, MJ Abramson, RM Puy, and JM Weiner extend their previously published meta-analysis of immunotherapy for asthma to include studies published since 1990. The details and discussion provided here usefully elaborate and extend their earlier paper, which was relatively brief. Subsequent chapters review attempts to perfect oral and sublingual immunotherapy regimens, discuss special considerations in children, and detail a useful consensus statement by HJ Malling on indications and guidelines for traditional aeroallergen injection therapy. Thereafter, 6 chapters deal with novel forms of immunotherapy, including the use of allergen peptides, recombinant allergens and their fragments, allergen-specific antibodies, and other attempts to manipulate the idiotypic network to down-regulate immunoglobulin E (IgE) responses.

Part III deals with the regulation of IgE inflammation and begins with a review of anti-IgE therapy for asthma. Three chapters deal with interventions to compete with or modulate the high affinity IgE receptor, and the last chapter speculates on the role of anti-IgE autoantibodies in immune regulation.

Part IV details efforts to use cytokines and anti-cytokines to down-regulate IgE synthesis. One chapter focuses on experimental models of asthma treatment with inhaled interferon gamma, and another chapter addresses anti-interleukin 5 therapeutic strategies. It is interesting that both of these treatments looked very promising in animal models of asthma, but neither has shown much effect in recently published clinical trials.

Part V focuses on the possibilities for preventing allergic asthma. In one of the volume's most fascinating chapters, PG Holt reviews the possibilities for prophylactic strategies for primary prevention during in utero development or early life. E Von Mutius critically reviews outdoor air pollution in asthma, followed by a conceptual overview of the genetics of asthma and allergy by PJ Ameilung and ER Bleecker. The final chapter, by editor Bousquet and his colleagues at Montpellier University, France, usefully reviews the potential targets and strategies for gene transfer therapy of asthma.

This book provides a useful compendium of authoritative and current reviews on a wide assortment of topics related to traditional and novel forms of allergen immunotherapy, including the immunologic underpinnings of asthma and its potential regulation by immunotherapy, as well as anti-inflammatory and genetic strategies for treatment now under development. The targeted audience is respiratory physicians, allergists, immunologists with an interest in T helper 2 diseases, and advanced students of these disciplines who need to acquire an overview of current thought along with a heavy dose of future possibilities. Interested readers will need to have some background in asthmology and immunology for some of the chapters, but by and large the chapters are approachable by those not well versed in these subjects. The book will be of particular interest to scientists and physicians who are seeking to chart future research on immunologic approaches to asthma therapy, either as investigators or funding agencies.

The editors and their contributors have achieved their primary goal of setting forth a rationale for the current practice of allergen immunotherapy, as well as unveiling a number of promising possibilities for refinements and radical new approaches to immunotherapy for allergic asthma. The volume is appropriately seen as an apologia for traditional allergen immunotherapy. The editors chose not to directly address current controversies about the relative role of immunotherapy vis-à-vis pharmacotherapy in asthma treatment. There were no attempts to consider how immunotherapy and pharmacotherapy are to be used together, or even which patients are most likely to benefit from immunotherapy, except for the brief commentaries by Frew and Malling.

The volume is extensively referenced, with citations in most chapters through 1997 and in some cases 1998. This means that the subject matter considered is quite current, considering the usual delay in publishing a large multi-authored book. There are tables and diagrams in most chapters, and all but one figure is of high quality. There is an extensive author index that includes all citations in the text, and a more limited subject index that is nevertheless useful. Typographical errors are quite rare. The book is a thick tome, published with the familiar white cover that is a consistent feature of all volumes of the Lung Biology in Health and Disease series. It is a useful and well-done addition to this series and belongs in every pulmonary reference library as well as the collections of asthmologists and allergists with an interest in allergic respiratory disorders.

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According to the National Asthma Education and Prevention Program (NAEPP) Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma, asthma affects an estimated 14–15 million people, including almost 5 million children. It is the most common chronic disease of childhood. Dr Thomas Plaut is well known for his efforts on behalf of asthmatic children with his book, Children with Asthma: A Manual for Parents. And for anyone who has had the pleasure of visiting with him personally, it is easy to see why asthmatic children and their parents would admire this man. He is lively, humorous, and clearly passionate about this syndrome and its effects on children.

Dr Plaut, with assistance from Teresa B Jones MA, has written a guide to asthma care for people of all ages—clearly a challenge because I am sure he would readily agree that one cannot just treat children with asthma as little adults. He dedicates this book to “patients, parents, and professionals who are willing to learn.” This book has an introduction and 10 chapters, with a resource section at the end. Each chapter contains figures, tables, and sidebars that serve to support the accompanying text.

The introduction is strong and promises to give the reader a blueprint for achieving excellent asthma control. He advises the reader that in order to achieve this control, he or she must learn 3 important things: how to take medication, how to monitor asthma signs and symptoms, and how to follow a written action plan. It is nice to see that he acknowledges respiratory therapists as having an important role in providing care. He takes great care to be politically correct by providing a detailed explanation of how he has alternated the use of the male and female pronouns by chapter and by role: male caregiver and female patient in one chapter, and female caregiver and male patient in the next.

True to the style used in his other books, Dr Plaut likes to insert what he calls “asthma stories” into the text with the intent of emphasizing how asthma has affected the lives of his patients. Chapter 1 is made up entirely of patient stories from the 1980s and 1990s. Almost 20 years and 24 pages later, the reader knows lots about how it used to be, but is this an effective way to capture the attention of those who are looking for information about how to manage their asthma symptoms today? Another question is, “Where do these stories come from?” Dr Plaut answers later in Chapter 8, wherein he tells the reader that he requires his patients to write a narrative describing their asthma and how they have dealt with it before meeting with him. He says that this allows patients and their families to organize their thoughts, give an accurate history, gain perspective, and emphasize what is important.

Chapter 2, “The Basics of Asthma,” begins by telling the reader that having the information from this chapter will help facilitate good communication with the doctor. The illustrations in this chapter are well done and correspond effectively with the text. He emphasizes that having high expectations for quality asthma care is the patient’s right, but undermines this message when he implies that using peak flow as a diagnostic tool is good medicine! Component 1, “Measures of Assessment and Monitoring,” a key section of the aforementioned NAEPP guidelines, clearly states that peak flow should not be considered to be a substitute for spirometry to establish the diagnosis of asthma. We are introduced to the concept of “scoring” asthma on Page 41, but must wait until Page 47 to get any kind of an explanation. The bullet on washing bedding in the sidebar titled “To Reduce Bed Dust” is incorrect. Bedding should be washed weekly, not every other week, again according to the NAEPP expert panel. The last section in this chapter on basics gives us a very brief overview of a wide range of topics, such as allergies, immunotherapy, other diagnoses, and treatment issues in pregnancy.

Chapter 3 covers asthma medicines and begins with 10 bullets under the heading of “Understanding Your Medicines.” He accurately states that the responsibility for understanding how medicines work and how to take them is a shared one—with the patient and the physician equally responsible for this crucially important component of asthma disease management! What follows is an extensive discussion for each medication class. Maneuvering through all this information could be confusing to a patient. Avoiding the traditional 3-inch columns may have enhanced readability. Using the 12 inches available on the 2 exposed pages could accommodate all the information on one class of medication, avoiding having to shift the eye up and down over multiple columns and multiple pages. It is estimated that allergens are responsible for triggering asthma in up to 70% of patients, so not including at least some mention of allergy medications is an important deficit in this chapter. The quiz at the end of the chapter is a unique touch for a book clearly written for the patient.

“Devices for Inhaling Medicines” gives a good overview of the various options and tools available for the effective delivery of aerosol medications. The illustrations are very useful and for the most part accurately reflect the text accompanying them. In the section titled “Proper Use of a Metered-Dose Inhaler,” he states that “open mouth technique” is the preferred method. While this is deemed an acceptable method, adding a spacer/holding chamber (described later in this chapter) improves taking medication via metered-dose inhaler, which he does note, 5 pages later.

Every chapter opens with a statement or two in bold letters. To introduce the chapter on peak flow, he emphasizes an important point: “Peak flow monitoring will make little sense until you know your personal best peak flow.” This is one of the strongest and most well written portions of the book. He directly addresses the most common critiques of the value of this instrument in monitoring asthma symptoms. The only fault with this chapter is that Dr Plaut again reports that peak flow can be used as a diagnostic test. This chapter is a perfect segue into Chapter 6, “Using an Asthma Diary.”

As evidenced by references to it throughout the book, Dr Plaut believes that the asthma diary is probably the most important tool of asthma disease management. He has spent his whole career perfecting this tool—and one would be hard-pressed to find anything missing from the diary or this chapter! He uses 10 full pages to describe and illustrate the diary that he suggests for those who can use a peak flow meter. He then uses the same amount of space and detail to describe his “signs” diary—a diary for those who cannot use a peak flow meter, so they use the scoring system based on signs and symptoms. This is a super chapter—filled with details helpful to both patients and clinicians! The take-home message is clear: an asthma diary is useful to all concerned and is especially helpful if filled out (no other time than) in the week before a scheduled appointment with the doctor.
"Ask your doctor to give you an individualized written plan to guide your asthma treatment." Doctors, are you listening? Chapter 8 serves as a review of the points he has made in previous chapters. Dr Plaut marries the home-based treatment plan to the diary by having both a "peak flow plan" and a "signs based plan." Each type of plan has been dissected by zone, so that the reader can follow the steps a patient might take as asthma symptoms worsen.

Patients who take the contents of Chapter 8, "Working with your Doctor," to heart may find themselves looking a long time to find Dr Right. However, thanks to the increased awareness of asthma, doctors and patients are beginning to use the expertise of other health care providers such as respiratory therapists. While the doctor may have only minutes with each patient, these clinicians can take what Dr Plaut acknowledges as "many hours" to provide the training that the patient and family need to be considered co-managers of their asthma. He suggests that all patients read this book and the Practical Guide for the Diagnosis and Management of Asthma. Using the Flesch-Kincaid Grade Level tool in Microsoft Word, I randomly picked two topics from each document (beta agonists and spacers/holding chambers) to help evaluate how understandable the material might be to the lay person. On beta agonists, Plaut's section measured 11.5 and the Practical Guide's section measured 12.0. For spacers/holding chambers, Plaut’s section measured 9.9 and the Practical Guide's section measured 10.1. So if one were to take Dr Plaut's advice, the reader would need at least a tenth grade education to comprehend the material.

The information contained in Chapter 9 on asthma issues at school is an excellent guide for parents to follow to ensure that their asthmatic child is safe while at school. He provides information on national policy on school-based health care, environmental considerations, along with his suggestions on what is reasonable for the parent to expect from the school, whether that school has a dedicated school nurse or not.

Dr Plaut is certainly on target when he says that asthma is a family affair! His last chapter focuses on the goal of maintaining good control of asthma in order to have a normal life—normal for parents, asthmatic children, and their siblings. The single mother's story of the frightening and unforgivable experience she and her family experienced during the 1980s illustrates just how far we have come in our treatment of asthma and the families it impacts. That chapter and the resource section remind us all that there is still much to learn.

Dr Plaut is to be complimented on his continued dedication to increasing patients' understanding of asthma. With this book he wanted to reach every age group. The result of that admirable effort is a book that does not read well and seems disorganized. Information on issues of childhood asthma is mixed in with those for adults. A person who says, "I am 40 years old and I want to know more about the usefulness of peak flow monitoring," would have to sift through several chapters to find the answer. There is little specific information on environmental triggers and no mention of allergy medications that clearly have a role in asthma control. To summarize, this book provides some helpful information for patients, and could also be considered one resource for clinicians on a specific topic such as public health policy.

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REFERENCE


Tuberculosis (TB) remains a leading cause of infectious disease mortality worldwide. Because the bacteria is transmitted in an airborne manner, infection remains an important occupational concern for those involved in aerosol-intensive procedures such as bronchoscopy, spatum induction, airway maintenance, and ventilator management. Indeed, infection with the organism that causes TB (Mycobacterium tuberculosis or Mtb) has been estimated to be 10-100 fold more likely in physicians, respiratory therapists, and nurses than in the general population. Tuberculosis and Nontuberculous Mycobacterial Infections brings together a group of 65 well known contributors from around the globe, including the United States, Europe, and Asia, as well as the World Health Organization and the Centers for Disease Control. The book is organized as a series of essays, and is intended to comprehensively cover all aspects of tuberculosis, including pathophysiology, epidemiology, diagnosis, and therapy. Its target audience is physicians, although many of the chapters will be of general interest to nurses and respiratory therapists.

The book is divided into 3 broad categories: general considerations, clinical tuberculosis, and nontuberculous mycobacterial infection. For the casual reader, the first section will provide a thorough and well-written overview of tuberculosis. Each chapter is independently written and can be read without necessarily having to read the preceding chapters. Conversely, some areas, such as the role of Bacille Calmette-Guerin in post-exposure prophylaxis, are redundantly discussed. Each chapter is well written and extensively referenced, with figures and illustrations that serve to illustrate key points. Throughout, the research supporting central points is provided, leading to a consistently academic tone.

For the physician, respiratory therapist, and nurse, the chapters on epidemiology and host factors (Chapter 1), tuberculin skin testing (Chapter 5), chemotherapy of tuberculosis (Chapter 6), prophylaxis (Chapter 9), tuberculosis in enclosed populations such as hospitals, prisons, shelters, and nursing homes (Chapter 11), and role of the health department (legal and public health considerations) (Chapter 12) are clearly and concisely presented and are worthy of review. The chapters on diagnosis and susceptibility testing (Chapter 4), chemotherapy for tuberculosis (Chapter 6), and therapy for multidrug-resistant tuberculosis (Chapter 7) may be of greater interest to pulmonary specialists and those involved directly in the management of persons with active TB.

One issue that will be of interest to all respiratory practitioners is that of whom to suspect of active infection, and consequently, whom to isolate. In this regard, Chapter 11, "Tuberculosis in Enclosed Populations," could be more helpful. While the author of this chapter emphasizes the central importance of identifying and isolating patients entering an acute care facility for which active TB is a concern, little practical guidance is offered. An emergency-room-based algorithmic approach is discounted.
and the table on potential isolation criteria for acute care facilities relies heavily on
known infection or exposure to Mtb, and does not mention the importance of an abnor-
mal chest radiograph in the setting of chronic symptoms or the need to evaluate the likeli-
hood of Mtb infection based on the country of origin of the person under evaluation.

The chapter on pathophysiology, "Basic Aspects" (Chapter 2) is well written and
takes a comprehensive view of understanding the relationship of the bacterium with
its human host. The plethora of recent studies that have employed gene-disrupted
("knock-out") mice are not extensively discussed, in part because the author feels that
potential interactions and interdependency may fatally flaw these experiments. The
chapter titled "Pathogenesis, Pathophysiology, and Immunology: Clinical Orienta-
tions" attempts to put the characteristics of the bacterium and its relationship with
the host-immune system in clinical perspective. While much of the material is redundant
with that found in subsequent chapters, it does provide a different perspective. Unfor-
unately, insights gained from recent studies demonstrating the unique susceptibility of
persons with genetic mutations in the recep-
tors for the cytokines interferon-gamma and interleukin-12 are not discussed.

Part II, "Clinical Tuberculosis," is a se-
ries of essays, each focused on a particular
clinical manifestation of TB infection. While these chapters may not be of general inter-
est, they may prove a valuable resource for
health care practitioners faced with specific clinical questions. Each chapter is compre-
nhensive and extensively referenced. The chapters on tuberculosis in infants and chil-
dren (Chapter 29) and human immunodefi-
ciency virus and tuberculosis (Chapter 31)
are both comprehensive and offer a wealth of
clinically useful information.

Part III, "Nontuberculous Mycobacterial Infection," contains 7 chapters, each devoted
to infection with a specific mycobacterium.
These chapters are well written and referenced,
and will serve as a valuable resource to practitioners faced with managing patients with
these challenging infections.

The book is thoroughly referenced and
indexed and contains a plethora of useful illustrations. Production quality is excellent.
While the first section can be read as a gen-
eral overview of tuberculosis, there is suf-
ficient detail in Parts II and III to be clini-
cally valuable. This book is reasonably
priced, and would be extremely useful in a
departmental library or in the individual li-
brary of a practitioner with an interest in
tuberculosis.

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Case Presentations in Clinical Tuberculosis.
Peter DO Davies MA DM and L. Peter
Ormerod BSc MD. London: Arnold Pub-
lishers. 1999. Soft-cover, illustrated, 299
pages, $49.90.

Tuberculosis is still a serious problem
worldwide, especially in endemic areas and
in association with acquired immuno-
deficiency syndrome. The most recent estimates
of the global burden of tuberculosis were
published by the World Health Organiza-
tion in 1997. The number of new cases of
tuberculosis was estimated at 7.9 million,
including 3.5 million cases of infectious pul-
monary disease (smear positive), and there
were 16.2 million existing cases of disease.
An estimated 1.8 million people died of tu-
berculosis, and the global case fatality rate
was 23% but exceeded 50% in some Afri-
can countries with high human immuno-
deficiency virus rates. Eighty percent of all
incident tuberculosis cases were found in
22 countries, with more than half of the
cases occurring in 5 Southeast Asian coun-
tries. The global burden of tuberculosis re-
 mains enormous at this time.

Peter Davies studied tuberculosis at the
Medical Research Council's Tuberculosis
and Chest Diseases Unit under Wallace Fox,
where he coordinated a survey of tubercu-
losis in the United Kingdom. He established
the Tuberculosis Research Unit in Liver-
pool. He is the editor of Clinical Tuberculosis,
and he is the co-author of the section on
tuberculosis for the Oxford Textbook of
Medicine. His expert and ample experience
in tuberculosis has led to numerous over-
seas lectures and visits. He also has acted
for the World Health Organization in India.

Peter Ormerod himself had tuberculosis
at the age of 7, which led him to become a
physician. Since 1981 he has been chest
physician at Blackburn Royal Infirmary,
United Kingdom. He has been a member of
the Joint Tuberculosis Committee of the
British Thoracic Society since 1987 and is
the current chairman of that society. He is
co-author of the United Kingdom national
tuberculosis guidelines on treatment and on
control and prevention. Dr Davies and Dr
Ormerod are the proper people to write this
kind of book, given its analyses of a variety
of clinical tuberculosis cases.

Case studies are probably one of the most
effective ways to learn about clinical as-
pects of medicine for clinicians and train-
ees. These 120 cases of tuberculosis are thor-
oughly reviewed and contain many
interesting points. The authors try to solve
various cases of tuberculosis from diagnostic
and therapeutic points of view. This book
is divided into 11 chapters, including tu-
berculosis and pulmonary disease, adverse drug
reactions, patients with adverse risk factors,
drug resistance, poor compliance, extrapul-
monary diseases (with numerous interesting
cases), childhood disease (especially for
pediatricians), human immunodeficiency virus-associated disease (with Center for Dis-
 ease Control guidelines and potential regi-
nens), complications, environmental mycobacteria with atypical mycobacteria,
and altered diagnosis with common or un-
common differential diagnosis. Each case
consists of presenting complaint, history of
presenting complaint, physical examination,
and results from various informative tests.
Clinical findings or diagnoses are described
in "Outcome" sections, and practical views and
important points appear in "Comment" sec-
tions for easy understanding of the processes
of the cases.

This book gives us many opportunities
to review clinical findings, including spu-
tum smear, culture, skin test, careful review
of chest radiographs, differential diagnosis,
history of Bacille Calmette-Guérin, bron-
choscopy, and contact tracing.

I would like to comment that there is
only a short explanation about anti-tubercu-
losis drug components, which may cause a
little difficulty for the readers, especially
readers outside England, because of unfa-
miliar drug names.

This book will be of value to trainees in
infectious disease or respiratory medicine,
but also will be useful as a ready reference
for practicing clinicians, particularly those
practicing in the endemic areas of tubercu-
losis or in the developing countries.

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Palliative Care, End-of-Life Care, Death and Dying
(reviewed September 25—October 5, 2000)

The Brown University Center for Gerontology and Health Care Research (http://www.chcr.brown.edu) provides an extensive listing of Web-based publications. It includes access to the Brown Atlas Site of Death, which shows a trend toward an increase in the number of people with chronic illness dying at home. However, the increase is not related to patient desires but, rather, to availability of resources. In fact, more than 70% of patients with chronic illnesses express a desire to die at home, but a little more than 70% die in institutions. There are also survey tools for measuring end-of-life care. A current study listed on the site (Palliative Care Outcomes Collaborative, or PCOC) explains how to use these tools to improve and enhance palliative care.

The Medical College of Wisconsin offers the End of Life Physician Education Resource Center (EPERC) (http://www.eperc.mcw.edu), a repository that educators can use to locate high-quality, peer-reviewed training materials. Registered users are allowed to search the site database and to submit course material for review and addition to the database. Registration is free and very brief.

Another starting point is Growth House Inc (http://www.growthhouse.org), which provides an extensive compilation of sites conveniently grouped by categories such as hospice, eldercare, and grief. The palliative care category lists about 80 resources. Each listed resource is conveniently followed by a short explanatory paragraph, relieving the reader of the need to check each site.

Growth House also provides a type of rating for the listed sites, but the objectivity of the ratings may be suspect. Growth House owns or manages several other domains, each of which has, coincidentally, been given the highest rating. Despite what appears to be self-promotion, there are many useful links.

One of the Growth House associated domains, Medicaring.org (http://www.medicaring.org), is intended as a forum for health care workers to discuss topics related to end of life. It has a simple method for joining, which enables access to chat groups. There are a number of interest areas from which to choose. As a reminder, anything that one discusses in a chat session should be considered public.

Another domain, Americans for Better Care of the Dying (http://www.abcd-carin.g.org), has excellent advice for beginning community discussions on death. They offer a 12-step “Agitator’s Guide” for lay people to become involved in community awareness, as well as 20 no-cost ideas for improving end-of-life care. Unfortunately, the messages from these sites may be lost in the blatant promotion of the owners’ various books.

Dyingwell.com (http://www.dyingwell.com) is a site managed by Ira Byock, the principal investigator of the Missoula Demonstration Project—a 15-year project to improve quality of life. The initial phase involved collecting information about the “pervasive denial of death.” They recognize that the prevailing attitudes do not properly serve the needs of patients, families, or caregivers at the end of life. The preliminary research has produced an instrument to assess quality of life: the Missoula-Vitas Quality of Life Index (MVQLI). It uses information about symptoms, function, interpersonal relations and wellness or disease. The survey is intended for care planning and team building and showing the effectiveness of a community-based palliative care program.

Another aspect of palliative care involves the caregiver. Many caregivers are not aware of programs that provide respite care for times that they feel overwhelmed. In Minnesota, for example, respite care is a reimbursable service (http://www.revisor.leg.state.mn.us/arule/9525/1860.html). In addition, the Minnesota Multiple Sclerosis chapter (http://www.mnms.org/programs/equipment_respite.html) has started a pilot program to pay for respite care for people who would not otherwise qualify. Utah provides a state-funded respite care program (http://www.rules.state.ut.us/publicat/code/r510/r510–401.htm). A list of many statewide respite contacts can be found at CHTOP Inc (http://www.chtop.com/coalitions.htm).

Finally, PBS aired a special program in September 2000, produced by Bill and Judith Meyers, entitled On Our Own Terms (http://www.pbs.org/wnet/onourownterms), which posed difficult questions about end-of-life decisions and attempted to answer them through the eyes of patients, caregivers, and health professionals. In the program, the illnesses ranged from amyotrophic lateral sclerosis to chronic lung disease. Many interviews touched on the idea that impending death brought a new, clarifying light with which to see. Judith Meyers, in an interview with Modern Maturity (http://www.aarp.org/mnaturity/sept_oct00/lasttaboo.html), asks the readers, regardless of age or health, to start thinking, “Maybe I should start living in the light of death now before I get to the end.”
CORRECTION

In the article, “Pressure Support and Pressure Assist/Control: Are There Differences? An Evaluation of the Newest Intensive Care Unit Ventilators”, by P Williams et al (Respir Care 2000;45[10]:1169-1181), Figure 5 on Page 1175 is in error. In the Expiratory Time Delay (top) diagram, open squares were inadvertently used to indicate two sets of data. The correct diagram is below:

Expiratory Time Delay \( (D_E) \)

![Corrected Expiratory Time Delay Diagram](image-url)
Appreciation of Reviewers

The Editors of RESPIRATORY CARE are deeply grateful to the following persons who have contributed their expertise and time to the reviewing of manuscripts and OPEN FORUM abstracts during the past year.

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Final deadline July 17, 2001
American Association for Respiratory Care

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- [ ] Active
- [ ] Associate
  - [ ] Foreign
  - [ ] Physician
  - [ ] Industrial
- [ ] Special
- [ ] Student

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**Primary Job Responsibility (check one only)**

- [ ] Technical Director
- [ ] Assistant Technical Director
- [ ] Pulmonary Function Specialist
- [ ] Instructor/Educator
- [ ] Supervisor
- [ ] Staff Therapist
- [ ] Staff Technician
- [ ] Rehabilitation/Home Care
- [ ] Medical Director
- [ ] Sales
- [ ] Student
- [ ] Other, specify

**Type of Business**

- [ ] Hospital
- [ ] Skilled Nursing Facility
- [ ] DME/HME
- [ ] Home Health Agency
- [ ] Educational Institution
- [ ] Manufacturer or supplier
- [ ] Other, specify

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Have you ever been a member of the AARC?

If so, when? From __________ to __________

Preferred mailing address: [ ] Home [ ] Business

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An individual is eligible if he/she lives in the U.S. or its territories or was an Active Member prior to moving outside its borders or territories, and meets ONE of the following criteria: (1) is legally credentialed as a respiratory care professional if employed in a state that mandates such, OR (2) is a graduate of an accredited educational program in respiratory care, OR (3) holds a credential issued by the NBRC. An individual who is an AARC Active Member in good standing on December 8, 1994, will continue as such provided his/her membership remains in good standing.

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Individuals who hold a position related to respiratory care but do not meet the requirements of Active Member shall be Associate Members. They have all the rights and benefits of the Association except to hold office, vote, or serve as chair of a standing committee. The following sub-classes of Associate Membership are available: Foreign, Physician, and Industrial (individuals whose primary occupation is directly or indirectly devoted to the manufacture, sale, or distribution of respiratory care equipment or supplies). Special Members are those not working in a respiratory care-related field.

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Individuals will be classified as Student Members if they meet all the requirements for Associate Membership and are enrolled in an educational program in respiratory care accredited by, or in the process of seeking accreditation from, an AARC-recognized agency.

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**Length of program**

- [ ] 1 year
- [ ] 2 years
- [ ] Other, specify

**Expected Date of Graduation (REQUIRED INFORMATION)**

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Demographic Questions
We request that you answer these questions in order to help us design services and programs to meet your needs.

Check the Highest Degree Earned
☐ High School
☐ RC Graduate Technician
☐ Associate Degree
☐ Bachelor's Degree
☐ Master's Degree
☐ Doctorate Degree

Number of Years in Respiratory Care
☐ 0-2 years
☐ 3-5 years
☐ 6-10 years
☐ 11-15 Years
☐ 16 years or more

Job Status
☐ Full Time
☐ Part Time

Credentials
☐ RRT
☐ CRT
☐ Physician
☐ CRNA
☐ RN
☐ LVN/LPN
☐ CPFT
☐ RPFT
☐ Perinatal/Pediatric

Salary
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☐ $10,001-$20,000
☐ $20,001-$30,000
☐ $30,001-$40,000
☐ $40,000 or more

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I hereby apply for membership in the American Association for Respiratory Care and have enclosed my dues. If approved for membership in the AARC, I will abide by its bylaws and professional code of ethics. I authorize investigation of all statements contained herein and understand that misrepresentations or omissions of facts called for is cause for rejection or expulsion.

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Date ________________________________

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The American Association for Respiratory Care and its science journal, RESPIRATORY CARE, invite submission of brief abstracts related to any aspect of cardiorespiratory care. The abstracts will be reviewed, and selected authors will be invited to present posters at the OPEN FORUM during the AARC International Respiratory Congress in San Antonio, Texas, December 1-4, 2001. Accepted abstracts will be published in the October 2001 issue of RESPIRATORY CARE. Membership in the AARC is not required for participation. All accepted abstracts are automatically considered for ARCF research grants.

SPECIFICATIONS—READ CAREFULLY!

An abstract may report (1) an original study, (2) the evaluation of a method, device or protocol, or (3) a case or case series. Topics may be aspects of adult acute care, continuing care/rehabilitation, perinatology/pediatrics, cardiopulmonary technology, or health care delivery. The abstract may have been presented previously at a local or regional—but not national—meeting and should not have been published previously in a national journal. The abstract will be the only evidence by which the reviewers can decide whether the author should be invited to present a poster at the OPEN FORUM. Therefore, the abstract must provide all important data, findings, and conclusions. Give specific information. Do not write such general statements as “Results will be presented” or “Significance will be discussed.”

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Method, device, or protocol evaluation. Abstract must include (1) Background: identification of the method, device, or protocol and its intended function; (2) Method: description of the evaluation in sufficient detail to permit judgment of its objectivity and validity; (3) Results: findings of the evaluation; (4) Experience: summary of the author’s practical experience or a lack of experience; (5) Conclusions: interpretation of the evaluation and experience. Cost comparisons should be included where possible and appropriate.

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Accepted abstracts will be photographed and reduced by 40%; therefore, the size of the original text should be at least 10 points. A font like Helvetica or Times makes the clearest reproduction. The first line of the abstract should be the title in all capital letters. Title should explain content. Follow title with names of all authors (including credentials), institution(s), and location; underline presenter’s name. Type or electronically print the abstract single spaced in one paragraph on a clean sheet of paper, using margins set so that the abstract will fit into a box no bigger than 18.8 cm (7.4") by 13.9 cm (5.5"), as shown on the reverse of this page. Insert only one letter space between sentences. Text submission on diskette is allowed but must be accompanied by a hard copy. Data may be submitted in table form, and simple figures may be included provided they fit within the space allotted. No figure, illustration, or table is to be attached to the abstract form. Provide all author information requested. Standard abbreviations may be employed without explanation; new or infrequently used abbreviations should be spelled out on first use. Any recurring phrase or expression may be abbreviated, if it is first explained. Check the abstract for (1) errors in spelling, grammar, facts, and figures; (2) clarity of language; and (3) conformance to these specifications. An abstract not prepared as requested may not be reviewed. Questions about abstract preparation may be telephoned to Linda Barcus at (972) 406-4667.

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Update: A report of subsequent developments in a topic that has been critically reviewed in RESPIRATORY CARE or elsewhere. Same structure as a Review Article.

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Kittredge's Corner: A brief description of the operation of respiratory care equipment. Should include information from manufacturers and editorial comments and suggestions.

PPT Corner: A brief, instructive case report including pulmonary function testing, accompanied by a review of the relevant physiology and appropriate references to the literature.

Test Your Radiologic Skill: A brief, instructive case report involving pulmonary medicine radiography and including one or more radiographs. May involve imaging techniques other than conventional chest radiography.

Review of a Book, Film, Tape, or Software: A balanced, critical review of a recent release. RESPIRATORY CARE does not accept unsolicited book reviews; please contact the Editor if you have a suggestion for a book review.

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For VOLUNTARY reporting by health professionals of adverse events and product problems.
ADVICE ABOUT VOLUNTARY REPORTING

Report experiences with:
- medications (drugs or biologics)
- medical devices (including in-vitro diagnostics)
- special nutritional products (dietary supplements, medical foods, infant formulas)
- other products regulated by FDA

Report SERIOUS adverse events. An event is serious when the patient outcome is:
- death
- life-threatening (real risk of dying)
- hospitalization (initial or prolonged)
- disability (significant, persistent or permanent)
- congenital anomaly
- required intervention to prevent permanent impairment or damage

Report even if:
- you're not certain the product caused the event
- you don't have all the details

Report product problems – quality, performance or safety concerns such as:
- suspected contamination
- questionable stability
- defective components
- poor packaging or labeling
- therapeutic failures

How to report:
- just fill in the sections that apply to your report
- use section C for all products except medical devices
- attach additional blank pages if needed
- use a separate form for each patient
- report either to FDA or the manufacturer (or both)

Important numbers:
- 1-800-FDA-0178 to FAX report
- 1-800-FDA-7737 to report by modem
- 1-800-FDA-1088 to report by phone for more information
- 1-800-822-7967 for a VAERS form for vaccines

If your report involves a serious adverse event with a device and it occurred in a facility outside a doctor's office, that facility may be legally required to report to FDA and/or the manufacturer. Please notify the person in that facility who would handle such reporting.

Confidentiality: The patient's identity is held in strict confidence by FDA and protected to the fullest extent of the law. The reporter's identity, including the identity of a self-reporter, may be shared with the manufacturer unless requested otherwise. However, FDA will not disclose the reporter's identity in response to a request from the public, pursuant to the Freedom of Information Act.

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Antibiotic for Respiratory Infections. According to the Pharmaceutical Division of Bayer Corporation, the US Food and Drug Administration has approved Avelox™, a once-a-day antibiotic indicated for the treatment of common respiratory tract infections including acute bacterial exacerbations of chronic bronchitis, community acquired pneumonia of mild to moderate severity, and acute bacterial sinusitis. A company spokesperson says he is happy the drug has been approved because many of the pathogens responsible for respiratory infections have developed resistance to the most commonly prescribed antibiotics which, he says, creates a real need for new agents to fill the void. The recommended therapeutic dose for Avelox is 400 mg taken once daily for 5-10 days, depending on the specific infection. For more information from Bayer Corporation, circle number 183 on the reader service card in this issue, or send your request electronically via "Advertisers Online" at http://www.aarc.org/buyers_guide/

Stat Profile pHox® Plus Analyzer, a device the company says incorporates a combination of advanced optical and electrode technology and integrates the key ten test critical care menu into the smallest analyzer currently available in the industry (12" wide x 15" deep). According to Nova Biomedical, the pHox® Plus provides oxygen saturation, hematocrit, and hemoglobin in addition to the standard blood gas menu of pH, P(CO2), and P02. The device also incorporates glucose, sodium, potassium, and a choice of ionized calcium or chloride to provide the essential test menu for the ICU, OR, ED or stat laboratory. For more information from Nova Biomedical, circle number 184 on the reader service card in this issue, or send your request electronically via "Advertisers Online" at http://www.aarc.org/buyers_guide/

QC Statistical Program. ALKO Diagnostic Corporation now offers a Quality Control Statistical Program they describe as easy-to-use and complimentary to ALKO customers placing a minimum standing or stocking order of ALKOntrol™ Quality Controls. The company says the statistics package includes monthly, cumulative, and peer group data on one report; after two months of enrollment in the program, ALKO says forms are customized to reflect each laboratory’s instrument mean and standard deviation ranges. For more information from ALKO Diagnostic Corporation, circle number 186 on the reader service card in this issue, or send your request electronically via "Advertisers Online" at http://www.aarc.org/buyers_guide/

Blood Gas and Stat Chemistry Analyzer. Nova Biomedical introduces its new

Economy ECG. Futuremed introduces P80-Power, an ECG the company says has capabilities found in larger, more expensive instruments and delivers professional-looking reports. Company press materials say users can preview tracings on a large LCD screen to prevent unwanted printing and that a full alphanumeric keyboard lets you personalize reports. Up to 40 tests can be stored for future reference and electrical power is backed by a rechargeable battery that can acquire and print 300-400 tracings per charge. For more information from Futuremed, circle number 185 on the reader service card in this issue, or send your request electronically via "Advertisers Online" at http://www.aarc.org/buyers_guide/
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<td>WVSRS: Jay Wildt, (304) 442-7474, <a href="mailto:jay.wildt@mghwv.org">jay.wildt@mghwv.org</a> or Anna Parkman (304) 357-4837, <a href="mailto:aparkman@ucwv.edu">aparkman@ucwv.edu</a></td>
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<td>March 7-9</td>
<td>8th International Conference on Home Mechanical Ventilation; Lyon, France</td>
<td>JIVD: Brigitte Hautier, +33 (0) 78 39 08 43, <a href="mailto:brigitteHautier_JIVD@compuserve.com">brigitteHautier_JIVD@compuserve.com</a>, <a href="http://www.jivd-france.com">www.jivd-france.com</a></td>
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Scheduled Professor's Rounds 2001

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Program #2 Pulmonary Rehabilitation: Standard Care for Chronic Lung Disease Patients—Trina Limberg BS RRT; Host Thomas J Kallstrom RRT FAARC—Video March 27 Audio April 17

Program #3 Noninvasive Ventilation: The Latest Word—Dean R Hess PhD RRT FAARC; Host Richard D Branson BA RRT FAARC—Video April 24 Audio May 29

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Program #5 ARDS: The Disease and Its Management—Leonard D Hudson MD; Host David J Pierson MD FAARC—Video June 26 Audio July 17


Program #7 Invasive Ventilation: The Latest Word—Richard H Kallet MS RRT; Host Richard D Branson BA RRT FAARC—Video September 25 Audio October 16

Program #8 Test Your Lungs-Know Your Numbers-Prevent Emphysema—Thomas L Petty MD FAARC; Host David J Pierson MD FAARC—Video October 23 Audio November 20

Helpful Web Sites

American Association for Respiratory Care
http://www.aarc.org
— Current job listings
— American Respiratory Care Foundation fellowships, grants, & awards
— Clinical Practice Guidelines

National Board for Respiratory Care
http://www.nbrc.org

RESPIRATORY CARE online
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— Subject and Author Indexes
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For information about other services or fees, write to the National Board for Respiratory Care, 8310 Nieman Road, Lenexa KS 66214, or call (913) 599-4200, FAX (913) 541-0156, or e-mail: nbrc-info@nbrc.org
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