# American Thoracic Society Statement on Research Priorities in Respiratory Nursing

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# Introduction

Risk Assessment and Risk Modification Health Disparities Tobacco Use, Control, and Cessation Work-related Pulmonary Disease Genetic Predictors of Risk Disease Self-Management Symptom Perception and Management Adherence to Therapy Outcomes Functional Status Health-related QOL Quality of Care System-based Care of Chronic Respiratory Conditions Acute/Critical Care Processes End-of-Life Care

# INTRODUCTION

Research priorities are dynamic and change in response to changes in society, advances in science, and shifting threats to public health. The American Thoracic Society (ATS) published its first set of research priorities for respiratory nursing in 1990 (1), followed by an update in 1998 (2). This is a revised document prepared by an *ad hoc* committee of the Nursing Assembly of the ATS. The *ad hoc* committee was composed of experienced nurse researchers and clinicians with expertise in health promotion, care of people with acute and chronic illness, and care of the very young and elderly.

Priorities were established and refined through a consensusbuilding process. Key components of the process included a review of the scientific literature, a 1-day workshop, committee meetings by conference call, consultation with external experts in selected areas, and critique by three experts from the ATS. The final document is a synthesis of ideas that emerged from this process. Important dimensions to be addressed within each priority include the effects of the following: age and sex, from very young to old age; culture, across multiple ethnic groups; stage of the disease, from care of the acutely ill to care of the chronically ill; and the delivery of care in different settings, from community-based to acute care settings. Because space limitations do not permit full discussion, the document is organized into a brief summary followed by specific recommendations.

The purpose of this document is to articulate the current research priorities for respiratory nursing. These research priorities focus on issues important to the advancement of nursing care of people at risk for respiratory health problems as well as those with acute and chronic respiratory diseases. It is anticipated that this document will provide direction for new investigators in the field and inform the work of agencies that fund research. The research priorities are listed below.

# **RISK ASSESSMENT AND RISK MODIFICATION**

Reducing health risks is an ongoing priority for respiratory nursing research. The components of risk assessment include surveillance; population and case identification; recognition of personal, environmental, and community risk factors; and the identification and use of genetic and phenotypic markers of risk. Risk modification includes prevention, reduction, protection, and elimination of risk factors for the development of respiratory disease and injury. The specific areas of focus are tobacco use, work-related lung disease, infectious disease, genetic risks, and risks associated with health disparities.

## **Health Disparities**

In the past decade, it has become clear that, among patients with pulmonary conditions, there are substantial disparities in outcomes that cannot be solely explained by differences in access to care. Some examples include patients with asthma, lung cancer, and cystic fibrosis, and those who receive influenza vaccination (3-6). The antecedents of these disparities are complex and incompletely understood (3-5, 7). Health disparities are the result of individual differences that have their origins in biological (e.g., genetic, comorbidity), personal (e.g., race, ethnicity), environmental (e.g., occupational, geographic), socioeconomic (e.g., income, education), and behavioral (e.g., knowledge, attitudes) factors. Health care disparities result from differences in the process of delivering health care (e.g., ease of use [8]), how care is delivered (process), and organization of the system (structure). Together, these two types of disparities interact to create disparities in health care outcomes (8). Prior studies strongly support that a complex series of factors-from genetic endowments to individual attitudes and preferences to clinician communication styles-interact and contribute to create health disparities and health care disparities (3-5, 7). The patient's perspectives of the importance of symptoms and the need to follow the treatment plan are critical determinants of behaviors that affect health care outcomes (7). Given this, it is important that clinicians develop the communication skills needed to elicit subtle factors that underlie patient concerns, motivations, and barriers to becoming active participants in their treatment. Research has shown that clinicians have poorer communication with minority patients than with others, but strategies to improve communication have received little attention (9). In addition, attention needs to be given to developing better-designed and more comprehensive systems of health care delivery, with the goal of decreasing disparities in health care outcomes.

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# Recommendations:

- 1. Studies are needed to improve understanding of modifiable cultural, racial, and gendered factors that influence decisions to access preventive, ongoing, and emergent care and to follow the advocated management plan. Given the absence of sensitive quantitative measures, it is likely that these studies will have a qualitative focus.
- 2. Studies are needed to identify strategies to improve patient–clinician communication, with the goal of improving satisfaction, adherence, and outcomes in ways that reduce health care disparities.
- 3. Individuals with pulmonary conditions could benefit from a better-designed and more comprehensive delivery system. Attention must be given to testing new methods of care that improve heath care outcomes among racial/ethnic and economic groups of patients.

# Tobacco Use, Control, and Cessation

Smoking prevalence remains a major health risk, with 50 million adults and children using cigarettes in the United States (10). Of concern is an increase in the smoking prevalence of young adults (10). Although adolescent smoking prevalence has declined slightly in the past 5 years, currently 28% of adolescents are cigarette smokers (11). Smoking prevalence varies considerably by ethnicity, with high rates among American Indians/Alaskan Natives and low smoking quit rates among African Americans (10). Another group of people who are of particular health concern are the 25% of expectant mothers in the United States who smoke throughout their pregnancies. The proportion of children exposed to environmental tobacco smoke (ETS) ranges from 25 to 85% depending on socioeconomic status (12, 13). In children, ETS causes bronchitis and pneumonia and additional episodes and increased severity of asthma (14). The tobacco industry divides markets, targets smokers of all ages according to consumer attitudes, aspirations, activities, and lifestyles, and is particularly active in communities with a low socioeconomic profile (15-17).

Clinical practice guidelines for treating tobacco use and dependence were updated (18) and identified the efficacy of four forms of nicotine-replacement therapy and bupropion sustained release (SR), which in general doubled the quit rate compared with placebo. Beyond individual treatment, comprehensive tobacco control programs at the community and state levels have been successful in reducing smoking prevalence and cancer incidence (10, 19). Tobacco use is a growing threat to global public health, with smoking prevalence rates of 50 to 60% in some countries (20) and 3 million tobacco-related deaths per year currently, with 10 million per year projected in 2025.

## Recommendations:

- 1. In light of the tobacco industry's targeted marketing to women, young people, and racial/ethnic populations, it is critical to develop and evaluate culturally appropriate tobacco control programs.
- 2. Innovative strategies are essential to developing and evaluating accessible evidenced-based treatment of tobacco dependence, such as school-based programs, Web-facilitated support, and consistent integration in primary health care settings.
- 3. Unique approaches to tobacco cessation are needed to reach low-income and other high-risk populations, including geographically identified groups with higher smoking prevalence (e.g., rural and Appalachian) and the gay, lesbian, bisexual, and transsexual community.

- 4. Evaluation is warranted of comprehensive tobacco control programs and population-based interventions to reduce tobacco use. Further research is needed to determine the impact of cigarette tax increases, policy changes, and coalition building within comprehensive programs.
- 5. To address childhood respiratory illnesses, research is needed to examine barriers to adopting ETS risk-reducing behaviors in the home.

## Work-related Pulmonary Disease

Occupational exposures contribute to both the development and aggravation of respiratory disease throughout the world. Lung diseases such as asbestosis, pneumoconiosis, byssinosis, tuberculosis, and asthma can be caused by various workplace exposures. The prevalence of work-related asthma (the most common form of occupational lung disease in industrialized countries) continues to rise in the United States in working-aged adults, and is one of the leading medical conditions associated with the limitation or loss of the ability to work (21, 22). Latex sensitivity has emerged as a new concern for the development of asthma in health care workers. Recent findings from ongoing occupational disease surveillance in the United States indicate that exposure to nonspecific irritants can contribute to both new-onset and work-aggravated asthma (21, 22). Irritant exposures commonly occur in nontraditional, nonindustrial workplace settings.

#### **Recommendations:**

- 1. Studies are needed to identify high-risk industries and occupations for both new-onset and work-aggravated conditions.
- 2. Methods are needed to assist occupational health nurses to identify workers at risk for the development or aggravation of work-related lung disease and to assist in providing a safe and healthy work environment for those workers able to return to work.
- 3. Research is needed to test interventions (both at work and away from work) that are most effective in improving health outcomes for patients with occupational lung disease.

## **Genetic Predictors of Risk**

Major gaps exist in the knowledge of genetic and environmental interactions that influence susceptibility to asthma, smoking-related diseases (e.g., chronic obstructive pulmonary disease [COPD], lung and airway cancers), sleep apneas (central or obstructive), and acute lung injury/acute respiratory distress syndrome (ALI/ARDS). Even when triggering conditions or circumstances are alike (e.g., smoking, trauma, sepsis), not all patients go on to develop these pulmonary conditions or experience a similar level of severity, suggesting that genetic features or gene–environment interactions influence susceptibility, onset, pathogenesis, and response to treatment (23–25).

## Recommendation:

1. Studies are needed to correlate biochemical and biological markers with clinical variables to address issues of susceptibility, onset, natural history, and response to treatment and to facilitate clinical trials of new therapies.

# DISEASE SELF-MANAGEMENT

Interventions for chronic pulmonary diseases rely on individuals' judgment concerning their symptoms, medication use, and activity patterns. Recent research suggests that self-management strategies are important for controlling symptoms, enhancing functional status or quality of life (QOL), and ensuring adherence to prescribed therapies (26). Most research, testing ways to improve self-management, has focused on people with asthma, and in particular adherence, using symptom reporting and peak flow monitoring (27). Important components of disease selfmanagement that involve lifestyle modification have not been as intensively studied, especially in conditions other than asthma. For example, little is known about the effects of economic burden, perceived treatment efficacy, or developmental aspects in pediatric and adolescent populations on the use of self-management interventions. Of note, a recent meta-analysis found that there was inadequate evidence to conclude that self-management education improved outcomes in people with COPD (28). The specifics remain unclear of how and when disease self-management improves QOL and decreases health care use.

#### **Recommendations:**

- 1. Research aimed at understanding how to promote good self-management is a major priority. Disease-specific self-management programs must be designed and tested to determine what components are essential and when these components enhance QOL, decrease health care use, and are cost-effective.
- 2. Developmental aspects of self-management training need to be investigated for pediatric populations.

## Symptom Perception and Management

To date, most research in this area has focused on the symptom of dyspnea as experienced by people with asthma and COPD. Inadequate attention has been given to other related and coexisting symptoms (e.g., fatigue, cough, and excessive daytime sleepiness) and other populations (e.g., people with restrictive lung disease, neuromuscular disease, or obstructive sleep apnea [OSA], and those at the end of life). Furthermore, the literature is dominated by studies of an isolated symptom, with less attention given to the fact that multiple symptoms occur together and interact to affect the symptom experience. The study of symptoms is challenging: patients with respiratory disease suffer from multiple symptoms (29), the relationship between disease severity and symptoms is not linear (30, 31), and most symptoms are complex and have multiple underlying mechanisms that interact.

Self-appraisal or perception of symptoms is a central component of self-management and care-seeking behavior that is dependent on cognitive development (children) and cognitive function (impaired adults). The individual (or in the case of young children, the parent/caregiver) must perceive a change and then make judgments concerning the appropriate course of action. Very little is known about how an individual with chronic pulmonary disease makes the judgment to self-treat versus to seek care. Furthermore, the process relies on intact cognitive functions that enable the individual to perceive and evaluate internal and external sensory cues. Even less is known about the role cognitive function plays in self-management decisions (32) or about the impact of chronic respiratory disease on cognitive and executive function. To fully understand the perception of signs and symptoms and to effectively support the self-management of symptoms, we need to understand the self-appraisal process and the effects of cognitive function as well as development.

Management of symptoms, especially self-management, requires a range of treatments (24, 25). Unfortunately, treatment of complex symptoms has mainly focused on classic modalities such as medications, exercise, and education, with the overwhelming majority of research in this area focused on medications (32, 33). Little systematic research has been done that looks at combi-

Although it is widely recognized that symptoms are multidimensional, the specific dimensions measured with a given instrument are not well established, making it difficult to compare results across studies. Many tools designed to assess symptoms are designed for people in rehabilitation and are not appropriate for people at the end of life. Other tools are designed to assess symptoms in the context of common activities or behaviors and were developed before recent changes in understanding and definitions, thus potentially limiting their measurement sensitivity and specificity. Existing instruments have not been examined to determine if they are culturally appropriate. For example, research findings suggest that minority populations may not use the same word descriptors to characterize breathlessness (33). Last, many of the instruments assess a single symptom, making it difficult to study clusters of symptoms and relevant dimensions (34).

# Recommendations:

- 1. A better understanding is needed of symptoms such as fatigue, cough, and daytime sleepiness, including the underlying mechanisms and reasons for the differential vulnerability, and how they cluster and interact to affect functioning and QOL. This should take into account the presentation of symptoms in diverse respiratory populations.
- 2. Research is needed to understand the relationship between self-appraisal, self-management, and care seeking associated with key pulmonary signs and symptoms (dyspnea, fatigue, cough, and sputum production). Factors need to be determined that influence patients' judgment to seek care for a particular sign or symptom, including cognitive function, symptom familiarity, and the self-care management or treatment strategies available.
- 3. Patterns of presentation associated with signs and symptoms of an exacerbation of disease must be examined. Areas for investigation include the differences in presentation of chronic versus acute (or acute on chronic) signs and symptoms and the effects of standardized symptom reporting using multiple symptoms and relevant dimensions.
- 4. Effective therapies need to be identified for relief of symptoms experienced with acute and chronic illness and at the end of life, including complementary therapies and cognitive-behavioral interventions.

## Adherence to Therapy

Adherence to clinician recommendations for controlling pulmonary symptoms and preserving functional status is critical to the success of overall management goals. Adherence behavior is highly variable and dependent on the burden of the task from the patient's perspective. Adherence to medication, exercise, and device use recommendations requires different levels of commitment and skill from the patients who are given these directions. The research priorities are focused in three main areas relevant to respiratory disease management.

Adherence to medication. Chronic pulmonary conditions frequently require prescribed medications, but research shows that patients typically take fewer than half the prescribed doses of medications. For asthma, inhaled corticosteroid therapy is a cornerstone of treatment, known to be safe and efficacious. Yet adherence to this potentially life-saving therapy is shown to be poor across all patient groups. In patients with COPD, knowledge about the illness and treatment and faith in and satisfaction with the treatment were shown to influence intentional and unintentional deviations from the recommended treatment (35). In addition, race, lower academic achievement, lower household income, and parental concerns about medications prescribed for their children have been associated with poor adherence (36). Interventions to improve long-term adherence and treatment outcomes are often complex combinations of information, education, self-monitoring, reminders, reinforcement, and attention from the health care provider. But even the most effective interventions have not led to large improvements in adherence (37). Once patients have adopted a treatment regimen, adherence problems may be due to life demands rather than attitude.

## **Recommendations:**

- 1. Poor adherence due to fear of medications or the belief that risks outweigh benefits requires a different approach than do the pragmatic problems of long-term daily adherence. Similarly, parental concerns about medications prescribed for their children need to be addressed. More effective strategies need to be identified to help patients consistently take prescribed medications as part of overall self-management of chronic illness and to make informed decisions about benefits of adherence to the prescribed therapy.
- 2. When attitude toward therapy is good but adherence behavior is too inconsistent for therapeutic benefit to be realized, interventions targeted at specific adherence issues need to be developed and tested (e.g., reminder systems). These strategies must be simple, cost-effective, and associated with better treatment outcomes as well as improved adherence.
- The role of specialized nurses, respiratory therapists, and pharmacists must be explored to find team-based solutions for improving medication adherence and therapeutic outcomes.
- 4. Mood disturbance and psychologic problems such as depression are associated with difficulties in self-management of chronic illness. Research is needed to investigate clinically useful ways of identifying and managing psychologic problems to promote adherence and self-management behavior.

Adherence to exercise. Physical inactivity is an important modifiable risk factor for many chronic diseases, and exercise is a cornerstone of treatment for COPD. Pulmonary rehabilitation includes exercise training, nutritional counseling, and patient education. Pulmonary rehabilitation produces beneficial effects (38), but improved health and disease control depend on longterm maintenance of exercise after pulmonary rehabilitation. Many individuals are discharged from these programs and told to continue walking for exercise. The effect of this advice on long-term adherence to daily exercise is unlikely to be successful, as exercise adherence over time requires support and reinforcement of accomplishments. In general, at least 50% of people receiving an exercise prescription stop exercising within 6 months, and, in those monitored for 2 years, only 20% are still exercising regularly (39).

Measurement and theoretical issues have hampered research on exercise adherence for people with lung disease. Few studies have used measurement approaches that do not depend on selfreport. This is especially important when assessing long-term exercise adherence in the home setting. Factors that affect exercise adherence in these populations are poorly understood—for example, depression, anxiety, fear, social interaction, QOL, and perceived health status. Self-efficacy for exercise is the only consistent predictor of exercise adherence across studies (40, 41). Patients with COPD are often elderly, and the potential impact of altered cognitive state on adherence behavior is unclear. Little is known about the nature of adherence in elderly or in subpopulations who may need modified approaches to exercise training and adherence.

## Recommendations:

- 1. Predictors of long-term adherence to healthy behaviors such as exercise must be identified and studied to fully understand the theoretical and scientific basis of adherence behavior.
- 2. Specific strategies to improve and maintain long-term exercise adherence must be identified and tested. Strategies useful in promoting medication adherence are unlikely to be successful for exercise, which requires a different behavior activity.
- 3. Innovative measurement approaches are needed to objectively document exercise and physical activity in daily life.

Adherence to device use recommendations. Patients diagnosed with OSA are told to wear a mask attached to a continuous positive airway pressure (CPAP) device at night. OSA is a model disease for studying the adherence problems patients experience when attempting to integrate a recommended device into their lives. Laboratory studies have shown that, with appropriate mask pressure, continuous positive airway pressure effectively eliminates apneas and hypopneas during sleep, leading to improvements in daytime functioning (42-44). To be effective, CPAP must be applied during sleep every night. However, recent evidence indicates that only about half of all patients who receive CPAP therapy actually follow this prescription (43, 45). There is emerging evidence that pretreatment factors, such as selfefficacy (46, 47) and coping patterns (46, 47), affect the decision to adhere to CPAP therapy. Recent evidence also suggests that cognitive-behavioral intervention improves adherence in the elderly, but it is not known if this intervention works for all age groups (46, 47).

# Recommendations:

- 1. Factors associated with adherence to treatment devices, such as those recommended for OSA, need to be identified, as does the interaction among salient variables.
- 2. A better understanding is needed of the cognitive processes related to CPAP treatment and how they are affected by cognitive-behavioral interventions.
- 3. There has been limited exploration of therapy adherence by the elderly and different ethnic groups. Interventions to promote adherence based on identified predictors should be developed and tested.

# **OUTCOMES**

# **Functional Status**

A substantial body of research describes functional status in chronic pulmonary disease, but most of the work focuses on the loss of functioning (disability) and describes factors that contribute to loss of function (48–51). Less is known about factors that affect the activities people choose to perform on a daily basis—that is, their functional performance (52). This is a complex issue, and improving physical fitness does not necessarily

lead to increases in physical activity and functional performance. The goal is to maintain an active lifestyle and to be fully engaged in life; to date, however, interventions have not been very successful in this regard.

The efficacy of and scientific basis for pulmonary rehabilitation are well established. Much of the research describes the effects of comprehensive rehabilitation, but less is known about the functional outcomes of individual components of pulmonary rehabilitation and how to tailor programs to meet specific needs. At least six studies describe the long-term effects of pulmonary rehabilitation, but most of the work addresses the effects on functional capacity (maximal level of exercise) and symptoms; little attention is given to functional performance (usual activities performed on a daily basis) and overall QOL. Issues related to the maintenance of exercise were described above, and they are especially important considering that exercise training can be interrupted by exacerbations.

The existing body of functional status research focuses on older adults with COPD and adults/children with asthma. Less is known about functional status in people with other conditions such as cystic fibrosis, restrictive lung disease, and lung cancer. The physiologic changes associated with extreme aging and societal expectations of older adults are likely to affect functional status, either directly or indirectly, but these issues have not been adequately explored in people with lung disease.

#### **Recommendations:**

- 1. A better understanding of the factors that affect functional performance is needed to guide the development of interventions to optimize physical activity and functional performance.
- Research is needed to describe the functional outcomes of individual components of rehabilitation and to devise methods for tailoring activities to specific needs.
- 3. Further research is needed to describe the long-term effects of pulmonary rehabilitation in terms of symptoms, functional status, and overall QOL.
- Research related to functional status and pulmonary rehabilitation must be expanded to include people with cystic fibrosis, those with restrictive lung disease, and long-term survivors of lung cancer.
- As people with lung disease live longer, it will be important to learn more about the effects of geriatric-specific issues on functional status in this population.

## Health-related QOL

QOL is considered an important indicator of disease burden and a key outcome of treatment in patients with respiratory disease. Although there is no explicit, universally accepted definition of QOL, there is agreement that it is a multidimensional concept that includes physical, psychologic, cognitive, social, spiritual, and economic dimensions. The term "health-related quality of life" (HRQL) is used to address the specific impact of disease and treatment on physical, psychologic, and social functioning and well-being (53). The quality and quantity of HRQL measures have increased in recent years. Generic and utility measures enable investigators to capture and compare HRQL across patient populations, whereas condition-specific instruments quantify the impact of disease and treatment specific to the underlying disease. As such, the latter are generally more sensitive to treatment effects. As measurement has improved, more emphasis has been placed on guidelines for interpretation (54).

Empiric evidence is increasing about the impact of various respiratory diseases and treatment on HRQL. Cross-sectional,

There is a growing body of evidence on the HRQL benefits of treatment in respiratory populations. HRQL in uncomplicated post–lung transplant recipients, for example, is dramatically improved compared with their pretransplant state (55, 56), whereas the HRQL of lung transplant recipients has been shown to be better than in lung transplant candidates. There is also evidence to suggest that pulmonary rehabilitation can improve HRQL in patients with COPD (57). Although these results are promising, more controlled clinical trials are needed in a wide variety of respiratory populations to evaluate the HRQL effects of treatment, including pharmacologic, rehabilitative, surgical, educational, self-care–related, and psychosocial interventions.

Recommendations:

- 1. There is a need for reliable and valid instruments that are sensitive to specific respiratory conditions (e.g.,  $\alpha_1$ antitrypsin deficiency acute bronchitis) and treatments (including nursing care–sensitive measures), that are applicable to specific age groups (particularly young children and frail elderly), and that use alternative data capture techniques (including ambulatory monitoring devices, handheld computers, interactive voice response systems, and Web-based systems).
- Longitudinal and multivariate studies are needed to understand naturally occurring changes in HRQL over time, identify patients at high risk for decreased HRQL, and/ or identify patients most likely to respond to interventions to improve HRQL.
- 3. Large comparative studies are needed to examine HRQL subgroup differences in relation to diagnosis, sex, and illness severity, as well as cultural and ethnic differences.
- Randomized clinical trials are needed to test interventions to improve HRQL (directly or indirectly) in specific patient populations, including lung transplant candidates and/or recipients.

# QUALITY OF CARE

#### System-based Care of Respiratory Conditions

An enormous and rapid growth in the prevalence and burden of chronic disease has occurred in the past two decades in the United States. The current health care system was designed primarily to meet acute and emergency health care needs, not to manage chronic illness. A major redesign of the health care system is needed that incorporates the principles of populationbased health care using system-based interventions to meet the challenge of burgeoning chronic illness and prevent excessive reliance on acute/emergent care. For example, a computer-based checklist could be used to promote the administration of vaccinations for influenza and pneumonia in vulnerable populations. Key to this goal of population-based health is health literacy, the ability to read and comprehend directions on medications and treatment devices. The delivery of care for chronic illness needs to be redesigned to incorporate care management, decision support, and community relationships. Within acute care settings, redesign is needed to better prepare patients and families to meet the challenges they will encounter after discharge.

Specially trained nurse practitioners, clinical nurse specialists, and pharmacists figure prominently in the team approach to illness management in this model. Self-management support is critical, because patients and their families are the primary caregivers in chronic illness and acute exacerbations of illness. Interventions that include self-management support show strong evidence of success. Some changes in the design and delivery of care have occurred, but these are not widespread. Low health literacy remains a significant barrier.

## *Recommendations*:

- 1. Methods of quickly improving health literacy among patients with chronic respiratory disease must be developed and tested for efficacy and cost-effectiveness.
- Registries of patients with respiratory disease within health care systems must be developed to facilitate quality improvement interventions and to track outcomes.
- 3. Because pneumonia and influenza are preventable causes of death and the cause of substantial morbidity, strategies must be explored that would change clinical and systembased care to increase the proportion of at-risk adults who are vaccinated annually.
- 4. Studies are needed to test efficacy of care delivery in nontraditional settings, such as churches, senior centers, barbershops, salons, school systems, or daycare settings, with the goal of reaching individuals who do not access health care in typical settings.

# Acute/Critical Care Processes

Four areas were selected for emphasis: preventing complications, minimizing adverse neuropsychologic sequelae, improving nurse-patient communication, and promoting recovery from prolonged mechanical ventilation.

Critically ill patients experience a high risk of complications that escalates as time in the intensive care unit (ICU) increases. Evidence suggests that how nursing care is delivered affects this risk. A number of nursing interventions can decrease the risk of nosocomial infection, including attention to mouth care, upright positioning, maintaining appropriate cuff pressure, and secretion mobilization (58). Tight glucose control (80–110 mg/dl), a nurse-titrated therapy, has been shown to reduce mortality and morbidity in surgical ICU patients, with benefits attributed to a reduction in infection (59). Acute/critical illness may be precipitated by exacerbation of a chronic illness. Evidence suggests that improved disease management strategies can markedly reduce the incidence of acute exacerbations, but these are not consistently applied.

There is increasing evidence that neuropsychologic and functional deficits persist for extended intervals after discharge from the ICU. Some of these deficits may be preventable or minimized as a consequence of assessment, monitoring, and interventions directed by the bedside nurse (e.g., daily sedation interruption, sedation assessment and titration, diagnosis of delirium). Several reliable and valid tools exist to assist nurses in titrating sedation and analgesia, yet these are not consistently used (60, 61). Delirium, a complication not typically monitored in ICU patients, is extremely common due to the use of psychoactive medications and older age of patients, but limited information exists on ways to monitor or manage this condition (61).

The literature clearly establishes that loss of speech is a frightening experience. Yet, ICU nurses receive little or no training in facilitating or interpreting nonvocal communication or in using devices to facilitate communication. It is therefore not surprising that assistive and augmentative devices, though available, are rarely used (62).

For some patients, mechanical ventilation continues after the resolution of critical illness, due to inability to wean from mechanical ventilation. Such individuals commonly experience substantial decrements in functional ability that persist long after the individuals have been discharged from the ICU (63). In addition, they may also experience neuropsychologic deficits (64).

#### Recommendations:

- Studies are needed to test ways to decrease risks for complications, with emphasis on nursing interventions that decrease the incidence of ventilator-associated pneumonia, optimize secretion management, and improve oxygenation during acute/critical illness.
- 2. Studies are needed to test the benefits of tight glucose control in nonsurgical ICU populations. If this is found to be effective, studies are needed to test the most effective protocols for initiating and maintaining this nurse-titrated therapy.
- Studies are needed to test interventions to improve nursepatient communication, including interpretation of nonvocal behaviors. In addition, studies are needed to determine ways of best assisting patients to use available communication devices.
- 4. Studies are needed to better understand the factors that facilitate survival and recovery in mechanically ventilated patients, including weaning from prolonged mechanical ventilation and discharging to home. In this analysis, the focus should be on potentially modifiable risk factors.
- 5. Studies are needed to characterize the frequency, severity, and potential causes of persistent neuropsychologic and functional deficits in critically ill patients, with the goal of testing interventions to decrease their impact.

# End-of-Life Care

Four priorities were identified for research related to care at the end of life: care delivery models, home care and home caregivers, terminal weaning, and end-of-life decision making. Respiratory disease is the fourth leading cause of death in the United States, yet there is no national model of care or plan for management of these patients at the end of life to provide high-quality care. Although care of patients with end-stage respiratory disease has been advocated to occur in the home (65), there is little focus on teaching caregivers how to manage end-stage respiratory disease. The detrimental effect of caregiving on health has been documented for patients with other diseases (66, 67), but the impact of providing care for the patient with respiratory disease has received little attention.

When the patient with end-stage respiratory disease is treated on a ventilator and does not recover, often there is a decision to withdraw the ventilatory support, referred to as terminal weaning. Families have tremendous needs at this time (68). Little research is available to determine the best process for withdrawal of the ventilator in this situation. Patients at the end of life are rarely managed in the place or manner that they prefer (69, 70). Different ethnic groups use of end-of-life care differently.

#### Recommendations:

- 1. Models of care need to be developed and tested that incorporate indicators for the initiation of palliative care.
- 2. Home care models for patients and caregivers need to be developed and tested to better prepare family and support caregivers with the goal of achieving a quality death experience for the patient and family during the time the patient is dying and afterward for the family.

- 3. Strategies need to be tested to increase discussion of advanced care planning before an acute exacerbation or episode of critical illness.
- 4. Strategies need to be tested to improve health care provider communication skills when discussing treatment limitation of withdrawal.

This ATS Statement on Research Priorities in Respiratory Nursing was prepared by an *ad hoc* subcommittee of the Nursing Assembly.

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