

American Thoracic Society Documents

Statement on Home Care for Patients with Respiratory Disorders

THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY WAS APPROVED BY THE ATS BOARD OF DIRECTORS DECEMBER 2005.

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EXECUTIVE SUMMARY

This statement defines home care as currently provided in the United States, identifies respiratory disorders that may require home care, determines the care needs of individuals with such disorders, delineates expected skills and competencies of providers, and describes key aspects of respiratory home care. The statement also addresses psychosocial issues, palliative and end-of-life care, outcomes, cost, reimbursement, and future directions for practice and research. In the United States, home care includes *home health care* (episodic, often postacute care provided on an intermittent basis), *hospice* (palliative and end-of-life

care provided for the terminally ill), *chronic home care services* (private duty services provided on an hourly basis), and *home medical equipment* (e.g., oxygen, respiratory equipment, nebulized medications, infusion therapy, and in-home supplies). Medicare is the largest single source of payment for home care services to respiratory patients; *home health nurses* and other *home health personnel* provide skilled and other care according to federal regulations for Medicare. General goals of home care for individuals with respiratory disorders are to increase survival, decrease morbidity, improve function and quality of life, support independence and self-management, encourage positive health behaviors, and promote optimal growth and development of children with lung disease. For patients with terminal illnesses, home care goals include physical and psychological comfort, and making dying at home possible.

This document is relevant for nurse specialists, chest physicians, pulmonologists, and other health care providers who would benefit from understanding U.S. models of home care. Home care services can offer great potential for patients with respiratory disorders, especially pediatric and geriatric patients, by reducing the amount of time they must spend in the hospital during an acute illness event, or removing altogether the need to be admitted to hospital. The evidence suggests that home care does not have negative effects on patients and, in the case of supported early discharge, there is now fairly strong evidence that home care may reduce the risk of admission to long-term care or hospital readmission. Home care service is thus an important option for nurse specialists, clinicians, chest physicians, and pulmonary specialists to consider in their "tool kit" of community-based interventions available to help patients live with respiratory disorders and maintain their independence. However, there are some important issues that must be addressed to understand who best can benefit from home care services. The U.S. Medicare system has made substantial cuts in the amounts of money available for the delivery of home care, so judicious use is essential. The guidelines in the American Thoracic Society (ATS) document on Home Care for Patients with Respiratory Disorders can be used to establish the need for referral for home care, including identification of those patients with respiratory disorders who have received appropriate hospital care, but could be discharged from the acute care setting to release beds (and save money). It is particularly important for the pulmonary specialist to understand the role of all members of the home care team and communicate explicitly with the primary care clinician and others on the team. The statement is relevant to those who would understand the varied competencies expected from providers of home care services, differentiate available services and psychosocial aspects of home care and palliative care, be sensitized to cost and reimbursement issues, and finally appraise future directions for practice and research.

Home care for respiratory patients in the United States includes a complex array of services delivered in an uncontrolled setting in which patients and families are integral members of the health care team. In Europe, new models for treatment of a variety of medical and surgical problems, including acute chronic

obstructive pulmonary disease (COPD) exacerbation, are being implemented. In *supported discharge* or *hospital at home* programs, patients are assessed for early hospital discharge with follow-up by respiratory specialist nurses through frequent telephone contact and home visits as needed. Another model under investigation is the *acute respiratory assessment service*, in which patients with COPD with acute exacerbations are assessed for suitability to manage the exacerbation at home with support from a home care team. Chest physicians or pulmonologists or nurses determine eligibility for home management on the basis of assessment protocols in the emergency room, with follow-up as in supported discharge models. A third model of care management community-based service is composed of respiratory specialist nurses and physical therapists who make regular, although infrequent, visits to patients with COPD with more than three hospital admissions in the previous year. In this *chronic care management service*, patients receive education and support, and can call the service during regular business hours with questions or concerns.

Chest physicians, pulmonologists, generalists, and nurse specialists providing care need clinical knowledge and skill, a patient-centered perspective, and understanding of the cost and reimbursement structures for home care services. Complexity, lack of provider control, and chronicity of patient health problems all likely contribute to the difficulty in demonstrating improved patient outcomes resulting from home care. Future efforts at identifying effectiveness of respiratory home care will be most successful if they take these factors into account.

Home health agencies, nurses, chest physicians, pulmonologists, and other providers, and their advocates, can contribute to a societal discussion on reframing the goals of home care to include those that are both desirable and achievable. Future goals may include patient and family satisfaction, reduction of complications resulting from hospitalization, maintaining an acceptable quality of life, and enabling a comfortable and dignified death. Cost reduction could become a collateral benefit, instead of a primary goal for home health care.

INTRODUCTION

This statement is a revision of the original American Thoracic Society (ATS) position paper “Skills of the Health Team In-

involved in Out-of-Hospital Care for Patients with COPD” (1), which identified the competencies of the health care team providing outpatient and home care services to patients with COPD. The revised statement is written primarily from the U.S. perspective, but incorporates international research and practice principles throughout. In fact, much research on newer models for home care has been conducted in Europe, Canada, and Australia, with relatively less innovation in the United States. These research studies have implications for care in the United States, and therefore constitute an important part of this statement.

DEFINITION AND MODELS OF HOME CARE

Home care is the provision of services and equipment in the place of residence of individuals and families who have needs resulting from acute illness, long-term health conditions, permanent disability, or terminal illness (2, 3). In the United States, home care includes *home health care* (episodic, often postacute care provided on an intermittent basis), *hospice* (palliative and end-of-life care provided for the terminally ill), *chronic home care services* (private duty services provided on an hourly basis), and *home medical equipment* (oxygen, respiratory equipment, nebulized medications, infusion therapy, and in-home supplies; Figure 1). In this statement, the term *home care* subsumes all four service categories, and the terms *home health care* and *home health care agency* refer primarily to episodic care provided by Medicare-certified home health agencies as ordered by the physician. *Home health nurses* and other *home health personnel* provide skilled and other care according to federal regulations for Medicare. Federal regulations also dictate the care provided by Medicare-certified hospice agencies. Because Medicare is the largest single source of payment for home care services to respiratory patients (3), the primary focus of this statement is on the service delivery models mandated by the Medicare program. Episodic, postacute home health care is limited to a discrete time frame, often triggered by hospitalization or a new diagnosis. Hospice services are provided for patients with a predicted life expectancy of 6 months or less who have elected palliative rather than curative care. Chronic care services include private duty nursing services, home health aide, and chore services to support and maintain chronically ill adults and children at home in collaboration with family members. Home respiratory equipment and

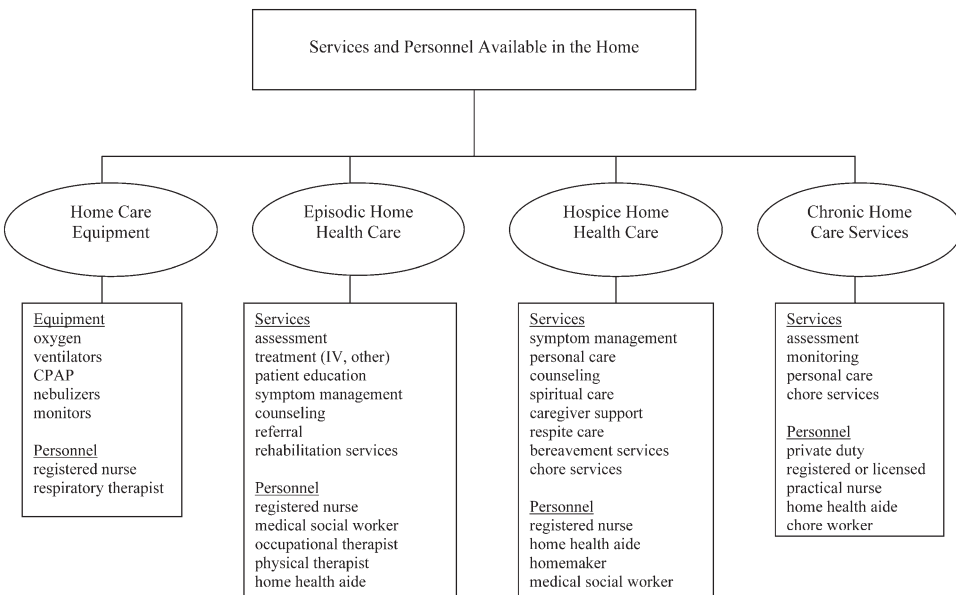


Figure 1. Categories of home services for respiratory-related conditions.

related services may be part of a long-term management plan for patients receiving any or none of these other services.

In Europe, new models for treatment of a variety of medical and surgical problems, including acute COPD exacerbation, are being implemented. In *supported discharge* or *hospital at home* programs, patients are assessed for early hospital discharge with follow-up support by home care personnel (4–7). A typical hospital at home scheme provides follow-up by respiratory specialist nurses through frequent telephone contact. Home visits are made when the patient's condition or ability to manage the care suggests they are necessary.

Another model under investigation is the *acute respiratory assessment service*, in which patients with COPD with acute exacerbations are assessed for suitability to manage exacerbation at home with support from a home care team. Chest physicians or pulmonologists or nurses determine eligibility for home management, using assessment protocols in the emergency room, and home care follow-up is usually similar to that for supported discharge (8–11).

A third model of care management of patients with COPD in the United Kingdom has been described (12). A community-based service composed of respiratory specialist nurses and physical therapists makes regular, although infrequent, visits to patients with COPD with more than three hospital admissions in the previous year. In this *chronic care management service*, patients receive education and support, and can call the service during regular business hours with questions or concerns.

GENERAL GOALS OF HOME CARE

General goals of home care for individuals with respiratory disorders are to increase survival, decrease morbidity, improve function and quality of life, support independence and self-management, encourage positive health behaviors, and promote optimal growth and development of children with lung disease. For patients with terminal illnesses, home care goals include physical and psychological comfort, and making dying at home possible (13). In keeping with contemporary models of patient-centered care and the unique nature of the care setting (i.e., the patient's home), specific goals of care for individual patients are negotiated by patients and families in partnership with home care professionals and the responsible physician (14–18). In addition to benefits for individual patients, home care is sometimes used to meet societal goals to reduce total health care costs, primarily by reducing acute care hospital days (19). For example, the movement of acute care services formerly provided only in hospitals (e.g., mechanical ventilation, infusion therapy) to the home setting is driven, in part, by the desire to reduce costs of prolonged treatment of acute problems such as infection, or chronic problems such as respiratory failure (13).

ESTABLISHING THE NEED FOR HOME CARE SERVICES

Medical Diagnoses and Therapies Commonly Requiring Home Care

Acute and chronic disorders that may require home care are listed in Table 1 (20). The most common diagnosis of patients with respiratory disorders referred for home health care is COPD (21). Approximately 11.1% of the 7.6 million patients receiving home health care in 1998 had respiratory system disease as their primary diagnosis (22). COPD and pneumonia are, respectively, the fourth and fifth most frequent reasons for hospital discharge of Medicare patients to home care, respectively (3). Patients with other diseases receiving home health care who may have significant respiratory care needs include those with paralytic syndromes (1.8% of those receiving home

health care), and malignant neoplasms of the trachea, bronchus, and lung (0.9%) (21).

Complete data on the number of children receiving home care services for chronic respiratory-related conditions are not available, although some data are available for children with cystic fibrosis receiving home medical therapies. In 2003, 19.6% of patients with cystic fibrosis received one or more courses of intravenous antibiotics at home, 6% received home oxygen therapy, and 8.9% used supplemental tube feedings at home (23).

Traditionally, a wide range of medical, nursing, and respiratory therapies has been delivered in the home, including continuous oxygen therapy, inhalation (nebulizer) therapy, tracheostomy care, and others (24). In the past 20 years, the frequency with which other treatments are delivered in the home has increased. These therapies that may involve pulmonary specialists include continuous positive airway pressure therapy for obstructive sleep apnea in adults and children (25), home apnea monitoring, administration of intravenous medications, and mechanical ventilation. The number of ventilator-dependent patients doubled from 1980 to 1990, with about 20% of the estimated 11,419 patients being cared for at home (26).

Guidelines for Referral for Home Care

Medical diagnosis is only one of several factors associated with the need for episodic home health care after hospital discharge for medical or surgical treatment. Factors found in at least one study to be associated with home health referral posthospitalization are complex medical needs (need for skilled nursing care,

TABLE 1. RESPIRATORY DISORDERS THAT MAY REQUIRE HOME CARE

Airway diseases
Asthma
Bronchiectasis
Bronchiolitis obliterans
Chronic bronchitis
Chronic lung disease of infancy (bronchopulmonary dysplasia)
Chronic obstructive pulmonary disease
Cystic fibrosis
Emphysema
Tracheobronchomalacia
Restrictive respiratory conditions
Asbestosis
Chest wall anomalies
Interstitial pulmonary fibrosis
Kyphoscoliosis
Pneumoconiosis
Post-ARDS
Recurrent pneumothorax
Tuberculosis and its sequelae
Neuromuscular disorders
Amyotrophic lateral sclerosis
Muscular dystrophy
Postpolio syndrome
Spinal cord injury
Spinal muscular atrophy
Sleep-related breathing disorders
Other
Central hypoventilation syndromes
Lung cancer
Lung transplantation
Nontuberculosis mycobacterial infection
Pneumonia
Postthoracotomy
Pulmonary hypertension
Recurrent aspiration syndromes

Definition of abbreviation: ARDS = acute respiratory distress syndrome. Adapted from Turner and coworkers (20).

TABLE 2. SUGGESTED CRITERIA FOR PATIENT STABILITY AND READINESS FOR DISCHARGE

Control of sustained dyspnea
Stable airway
Ability to clear secretions and protect airway
Acceptable arterial blood gases, with F_{iO_2} less than 0.40, which can be maintained in the home
Stable metabolic and acid–base status
Absence of acute infectious processes
Stable medical regimen before discharge
Absence of life-threatening cardiac dysfunction or arrhythmias
Other organ systems stable
Adequate nutrition
Progression of growth and development (in children)
Ability to cope with patient's physical and emotional needs in home setting
Without the need for unscheduled or acute readmission or physician/clinician visit within at least 1 mo
If patient on ventilator:
Stable ventilator settings
F_{iO_2} less than 0.40
Assist/control or pressure-limited mode (pediatrics)
Limited use of PEEP
Minimal fluctuations in airway resistance and compliance
Stable "free-time" periods

Definition of abbreviation: PEEP = positive end-expiratory pressure.

Adapted from Gilmartin (33).

or dually diagnosed with COPD and chronic heart failure), activity of daily living (ADL) and instrumental activity of daily living (IADL) limitations, lack of availability of a spouse caregiver, low level of social support, educational attainment of less than 12 years, need for chore or personal care services, and prior home care use (27–30).

Garrard and colleagues (31) developed a "Need for Home Health Services Check List" using expert consensus, including nurses, to identify health, psychosocial, and behavioral problems, and education and coordination needs suggesting the need for home health services after hospital discharge. Although adequate interrater reliability has been reported (31, 32), construct validity of the scale remains to be established. The chest physician or pulmonologist can use the scale as a guide to identifying the need for home health care referral, but without evidence for predictive validity, clinical judgment is the deciding factor in whether to order home care referral.

Discharge criteria for mechanically ventilated patients have been developed on the basis of expert consensus, and include medical, respiratory, and psychological stability, and the existence of a comprehensive discharge plan (26). Gilmartin (33) identified criteria specific to home management of chronically ventilated patients (Table 2). It is important to note that both of these sets of criteria indicate readiness for discharge, not criteria for referral to home care. The American Association for Respiratory Care (34) has developed a clinical practice guideline for hospital discharge planning for respiratory patients going to any setting, including the home. The guideline includes assessment of the patient's medical needs, the site to which s/he will be discharged, and financial resources available for posthospital care. Education and training needs of patients and families must also be assessed, preferably by the respiratory clinicians.

The American Academy of Pediatrics (35) developed guidelines for home care referral for infants and children with chronic disease that include patient, family, home, and community factors that should be in place before the child is discharged. Although not specific to respiratory patients, these factors constitute important criteria for discharge of infants and children with chronic respiratory disorders. The guidelines call for an individualized health care plan to be in place before discharge. Patients, families, a designated case manager, and interdisciplinary team members representing all sites in which care will be provided

must be involved in planning for home care. For respiratory patients, the pediatric pulmonologist can play a central role.

The evidence base for appropriate home care referral for respiratory patients is evolving. On the basis of a consensus of clinical experts and existing knowledge about home care outcomes, the ATS recommends that referral be considered for respiratory patients if one or more criteria in Table 3 are present, as evaluated by clinician specialists, chest physicians, or pulmonologists.

Needs of Respiratory Home Care Patients

Adult and pediatric patients with respiratory disorders living at home may have a wide variety of medical, functional, psychosocial, developmental, and advance care planning needs. These needs are best addressed using a patient- or family-centered model, because the provision of home care services occurs in the patient's context and the provider is a visitor in that setting. A multidisciplinary health care team is needed to address the patient's holistic needs.

The developmental needs of children with respiratory problems that improve over time are different than the needs of adults with similar problems. Children must have early services so that they can achieve normal age-dependent function as a respiratory impairment improves (36). Although the assumption that children develop more normally at home than during prolonged hospitalization has not been studied in controlled clinical trials, some reports have documented normal development among ventilator-dependent children who remain at home (37, 38). Ideally, home health professionals, including nurses, chest physicians, and pediatric pulmonologists, work with parents to develop a daily plan of care that maximizes their child's developmental potential.

SKILLS AND COMPETENCIES EXPECTED OF HOME CARE PROVIDERS

Episodic Home Health

Home health care providers are expected to assist patients and their caregivers to manage day-to-day living with respiratory disease and disability, identify and respond to complications, and use respiratory equipment and procedures safely. Determi-

TABLE 3. AMERICAN THORACIC SOCIETY RECOMMENDATIONS FOR CONSIDERATION FOR HOME HEALTH CARE REFERRAL UPON DISCHARGE

1. Patient has been diagnosed with a new disease or has multiple comorbidities
2. There is a need for complicated assessment and/or health care coordination
3. Patient cannot attend outpatient services and needs monitoring and/or education
4. Patient's best FEV₁ is less than 30% predicted
5. Patient has an unstable or fragile medical status, requires close supervision, and needs frequent cardiopulmonary assessment
6. Multiple medications have been prescribed; medication regimen is new to patient
7. Patient or caregiver is anxious, confused, forgetful, or has poor coping skills
8. Patient is older, living alone, and/or has no support system
9. Patient has functional limitations and requires assistance with activities of daily living (ADLs) such as bathing or instrumental ADLs (IADLs) such as food shopping
10. There is a history of more than one emergency room visit or urgent hospital admission in the past year
11. There is a need for complicated treatment regimens, high technology or other durable medical equipment, and/or intravenous therapy

Adapted from Turner and coworkers (20), Narsavage and Naylor (27), and Hansen-Flaschen (192).

nation of which disciplines are involved in an individual patient's care is based on the primary problems identified and the reimbursement mechanism supporting home care.

Disciplines covered by Medicare to provide home health services include registered and licensed practical nurses, physical and occupational therapists, speech–language pathologists, social workers, and home health aides. Most patients, and particularly those with active comorbid conditions and a high risk of developing complications beyond the respiratory system, require referral by the physician to a home health registered nurse (39). A patient with primary problems of deconditioning, impaired mobility, or the need for home adaptation is best served by referral for physical or occupational therapy. If the primary need is for assistance with ADLs or IADLs, services offering home health aide assistance should be explored. Medicare reimburses for personal care only if skilled nursing or rehabilitation services are also required as determined by the physician's evaluation of the patient's medical condition. Limited chore services are available within the context of home health aide delivery of personal care services.

Nurses who provide home health care in the United States and Canada are generalists who care for patients with a wide range of medical diagnoses (40). They provide skilled care for patients within the context and challenges of the home environment, integrating interventions into the complex interactions between physiologic, family, and environmental needs (41). Home health nurses must be able to function independently and develop collaborative relationships with family members and interdisciplinary team members (14, 17, 18). Care coordination by nurses is common for patients with multiple comorbid conditions and for patients who receive services in addition to those provided by the home health agency (42). Nurses are the primary link to the chest physician or pulmonologist when patients receive home health care. A taxonomy of required practice elements for home health nurses has been developed (Table 4 [43, 44]).

Home health specialty programs, including home management of respiratory patients, were developed in the early 1980s in an effort to provide comprehensive care to complex, chronically ill patients (45). Health care cost containment efforts and an inability to demonstrate cost-effectiveness of specialized respiratory home care services (46–48) led to eventual discontinuation of most of these programs.

More recently, earlier discharge of even sicker patients and marketplace competition have again created a call for specialty practice in the home setting (49, 50). One example described by Nemcek and Egan (51) is a pulmonary disease management program among five specialty programs in place in their agency. A quasi-experimental study of a respiratory specialist advanced practice nurse (APN)-directed home health intervention for pa-

tients with COPD within parameters determined in consultation with pulmonologists found somewhat better patient outcomes compared with patients receiving usual home care, suggesting that availability of a respiratory clinical nurse specialist for consultation and education may be of benefit (52). Naylor and colleagues (53) suggested that cost reductions in an APN-led home health intervention could be attributed to the fact that the APNs were gerontologic, not disease-focused, specialists. These master's prepared gerontologic specialists were able to address comorbid conditions, combined effects of multiple health problems, and social issues, not only the needs related to the diagnosis causing the index hospitalization, and communicate early with the physician specialist.

Traditional Medicare does not reimburse for the in-home services of respiratory therapists (RTs), but private insurance or Medicare Health Maintenance Organizations (HMO) providers may provide reimbursement for these services. Because Medicare now reimburses home health agencies for a physician-ordered episode of care (usually 60 days) rather than for each home visit, there may be an opportunity for home health agencies to use RTs for home visits. Whether use of RTs is permissible reimbursement remains an unresolved question, because RT services are excluded from Medicare home health care reimbursement by statute.

Hospice

Hospice agencies provide palliative, as opposed to curative, medical, social, emotional, and spiritual, services to terminally ill patients and their families (54). More than 90% of the hospice agencies in the United States are Medicare certified (55). Medicare-certified hospices are required to provide inclusive physician, nursing, home health aide, homemaker, social work, counseling, bereavement, and volunteer services. Rehabilitation services (physical and occupational therapy, speech–language pathologist) are provided on an as-needed basis. Hospice care is managed by an interdisciplinary group, whose members work collaboratively with patients and families to plan care that meets the identified needs of the terminally ill patient and family. Among the services provided are pain and symptom management, assistance with the psychosocial and spiritual aspects of the dying process, provision of short-term inpatient or respite care, and bereavement counseling for surviving family members and friends (55). Hospice providers must embrace a philosophy of care that is patient-driven and family-centered, and recognize their role as guests in the homes and lives of their patients at a time of dramatic significance (56). Hospice services to patients with chronic respiratory diseases usually provide home visits by generalist physicians for recertification. However, chest physicians and pulmonologists can play a critical role in the initial determi-

TABLE 4. REQUIRED PRACTICE ELEMENTS FOR HOME HEALTH NURSES

Practice management
Expert in health assessment skills
Organized in approach to time and tasks
Able to analyze a situation and develop an appropriate plan
Able to deal with problems in priority order
Knowledge/skills maintenance
Hands-on technical skills in area of practice
Understands how physical processes of illness and associated complications relate to the patient
Home health care knowledge
Background in principles of teaching/learning for patient/family
Knowledge of nutrition teaching
Communication
Good interpersonal communication skills with patient/family, staff, colleagues, and physicians
Uses referrals to other agency services and community resources to meet patient needs when appropriate
Nursing process
Foundation in formulating nursing diagnoses and measurable goals for patient care
Patient/family management
Provides clear direction to patients during visits
Deals in realistic and practical ways with situations confronting patients
Activities are planned and implemented on the basis of treatment goals for the patient
Views patient as part of a family and community
Encourages patient and family independence
Demonstrates empathy for patient
Recognizes and deals with family concerns related to the patient's health problem
During visits, gives time to psychosocial and physical care
Does not force own values on patient and family

Adapted from Benefield (43, 44).

nation of eligibility, addressing the problem of estimating prognosis with a disease process that is characterized by life-threatening exacerbations but a slow decline in baseline function. COPD is a leading cause of death but without specialist recognition of need, few patients with COPD access the hospice care available.

Home Medical Equipment Companies

As seen in Figure 1, home respiratory therapy and home infusion companies provide equipment and supplies needed by respiratory patients at home. Home respiratory therapy companies provide oxygen systems, home ventilators, sleep apnea equipment, apnea monitors, nebulizers, and nebulized respiratory medications (2, 57). These vendors employ respiratory therapists or registered nurses to teach patients and families use and care of the equipment, and to monitor safe operation of the equipment. The therapist or nurse also documents continuing need for the equipment and patient response to the therapy, communicates relevant patient information to the prescribing chest physician or pulmonologist, troubleshoots, and intervenes to address complications related to the respiratory equipment or therapies (58).

Home infusion therapy companies provide intravenous medications and fluids, enteral or parenteral nutrition, and other injectable therapies. These vendors employ pharmacists to prepare prescribed medications and solutions, and registered nurses who have specialized training in infusion therapy. Registered nurses providing infusion therapy must have the skills to teach the patient how to safely administer prescribed medications using the home infusion equipment, monitor expected and untoward responses, communicate with the prescribing physician, and respond to complications (57, 59). Large companies generally provide both respiratory and infusion services and also may provide bathroom and other adaptive equipment.

Chronic Home Care Services

Chronic home care services, sometimes called hourly care, are the modern day equivalent of early home nursing, in which a registered nurse or other provider gave direct care to a single

patient at home. Unskilled chronic care includes housekeeping or chore services and the provision of bathing, dressing, or other personal care. Chronic care services may be reimbursed by private insurance or by Medicaid for disabled children and for adults who meet Medicaid eligibility requirements. Medicare does not reimburse for these services. Medically fragile or technology-dependent (MFTD) children who require several hours of nursing care per day are most likely to be those receiving mechanical ventilation, although children with less critical but nonetheless multiple or complex care needs may also require such care.

Comprehensive discharge planning that emphasizes clear communication among patient, family, and an interdisciplinary care team is required to ensure successful home care for MFTD children (35, 60, 61). Communication between hospital-based staff, chest physicians/pulmonologists, and providers who will take over patient care after the transition to home is also essential (60). In most situations, family members will provide the majority of direct patient care, but referrals to home care agencies providing hourly care are often required to allow family members to sleep, rest, do household activities and errands, care for other family members, maintain relationships, and work outside the home (62, 63).

Parents of MFTD children expect nurses and physicians to work respectfully and collaboratively with the family, and to allow parents to direct the care of their child (64). They expect nurses and physicians to provide safe, competent, skillful care, delivered with the same level of attention and care that parents themselves use (64, 65). Parents view home care nurses as a resource for increasing the ability of family members and respite care providers to provide quality care through education and training (66). Parents also want nurses to educate the family about available resources, and to help secure these resources through advocacy. Communication among nurses, physicians, and family (65), and recognition of professional boundaries and respect for the family unit, are highly valued (65, 67).

Role of the Physician

The role of the primary care physician in the provision of home care has been categorized into three activities: making home visits, making referrals of patients to home care agencies, and participation in the multidisciplinary team providing care to adults and MFTD children at home (68). Physicians also serve as medical directors of home health and hospice agencies (55, 69). Primary care and internal medicine physicians make regular but infrequent home visits, especially in rural areas (68), but specialists such as chest physicians and pulmonologists may also make home visits to supervise home management of mechanical ventilation or other care (69).

Medicare and other payers require that the physician direct the provision of home health care by the interdisciplinary care team through on-going oversight of the treatment plan. The physician determines the patient's medical needs, approves a treatment plan and orders that meet those needs, and monitors implementation of the plan (35, 70). The physician may assume the role of case coordinator, but is more likely to delegate this role to the home health nurse or other home care agency personnel. Most physicians, including specialists, report that they work with home health agency or hospital staff to determine home health services needed by patients (71).

Regular communication between the physician, the case coordinator, and other home care agency personnel is critical to assure that patients receive appropriate clinical care, and that treatment plans are updated and approved when the patient's condition changes (69). Home care agencies are increasing their use of technology and telemedicine programs to send reports and treatment plan changes to physicians (69, 72). Effective electronic modes of communication, telemedicine, and other home care technologies exist but are beyond the scope of this statement.

HOME HEALTH ASSESSMENT

When episodic care is provided by a Medicare-certified home health agency, under physician orders, the initial home visit is usually made by a registered nurse. General assessment includes relevant history, examination of body systems, and evaluation of the patient's management of and response to medications and treatments. The nurse also evaluates challenges to management of the respiratory condition presented by the living environment, the impact of disease on day-to-day living, the degree to which institutional teaching has been transferred to the home setting, and the effectiveness of family coping. Focused assessment of functional status, potential safety problems, ability to access emergency help, psychosocial and learning needs, patient/family coping resources, and end-of-life issues are also addressed as indicated.

Parameters for in-home assessment of chronic respiratory patients are shown in Table 5. In-depth respiratory assessment includes: pulse oximetry at rest and with ADLs, IADLs, walking, or exercise; a peak expiratory flow rate or portable spirometry; and, if indicated, home apnea monitoring. Observation of inhaled medication technique, evaluation of airway clearance maneuvers, and management of home respiratory equipment are other components of a thorough respiratory assessment. After the nurse clinician's visit, contact is made with the generalist physician, chest physician, or pulmonologist to verify medical care.

HOME HEALTH INTERVENTIONS AND TREATMENTS

The home health plan of care is based on assessment findings and the physician's determination of medical needs. Frequently prescribed home health interventions for common respiratory conditions are described in detail below. Detailed discussion of

less common therapies (e.g., home apnea monitoring, care of adults and children using invasive or noninvasive mechanical ventilation, etc.) are not included in this document. Comprehensive clinical practice guidelines, other guideline statements, and position statements already exist for such specific patient problems. The reader is referred to the website of the National Guideline Clearinghouse initiative of the Agency for Healthcare Research and Quality (AHRQ; www.guideline.gov), other guidelines websites (e.g., the Institute for Clinical Systems Improvement; www.icsi.org/index.asp), and other professional organization statements including medical assemblies of the American Thoracic Society (www.thoracic.org), the American College of Chest Physicians (www.chestnet.org), the American Association for Respiratory Care (www.aarc.org), and the American Academy of Pediatrics (www.aap.org).

Medications

Medications for chronic respiratory disease are prescribed for the general goals of symptom reduction, management of complications, and maintenance of lung function. The Global Initiative for Chronic Obstructive Lung Disease (73) recommends short-acting bronchodilators as needed for symptom management, routine administration of long-acting bronchodilators in moderate to severe COPD, use of short-acting β_2 -agonist and anticholinergic combinations, and annual or biannual influenza vaccination. Routine inhaled corticosteroids are recommended only for severe or very severe COPD. The Global Initiative for Chronic Obstructive Lung Disease recommends treatment of exacerbations with bronchodilators, oral or intravenous corticosteroids, and antibiotics when sputum is purulent or increased in volume. Appropriate use of guidelines involves adaptation by APNs, chest physicians, or pulmonologists to individualize patient care.

The National Asthma Education and Prevention Program (74) recommends inhaled steroids for mild, persistent asthma in patients of any age; low- to medium-dose inhaled steroids plus a long-acting β_2 -agonist for moderate and severe, persistent asthma; and high-dose inhaled steroids plus a long-acting β_2 -agonist and oral corticosteroids as needed for severe, persistent asthma. Antibiotics are recommended for treatment of exacerbations only when there is fever and purulent sputum, pneumonia, or bacterial sinusitis.

Nebulized tobramycin and colistin are commonly administered to patients with cystic fibrosis for maintenance therapy (75–77). Nebulized tobramycin has also been effective against *Pseudomonas aeruginosa* infection in patients with bronchiectasis (78). Acute, serious exacerbations generally require intravenous administration. Primary pulmonary hypertension may be treated by continuous intravenous prostacyclin infusion. Treatment may include oral anticoagulants, diuretics, and calcium channel blockers (79). Administration of oral or parenteral opiates may reduce severe dyspnea that cannot be controlled by nonpharmacologic measures (80, 81).

Successful home administration of medications requires knowledge of the drugs and administration techniques and adherence to the medication regimen. Patient nonadherence with prescribed medications is well documented. In one study, a sample of 342 patients at high risk for rehospitalization was counseled regarding medications to be taken at home (82). At a home visit 1 week later, nearly half the patients had mixed the discharge medications with preexisting supplies or medications prescribed by other practitioners. Approximately half of those patients for whom a pill count could be made were nonadherent with medications prescribed at discharge. Most patients could not identify adverse effects or special instructions for prescribed medications. The only predictor of nonadherence was the number of prescribed medications.

TABLE 5. ASSESSMENT/TREATMENT/INTERVENTION COMPONENTS OF HOME HEALTH CARE FOR PATIENTS WITH CHRONIC RESPIRATORY DISEASE

A. Assessment components	
<ul style="list-style-type: none"> • History <ul style="list-style-type: none"> Current status and past respiratory disease chronology Current smoking and past history in pack-years Respiratory signs/symptoms: cough, sputum, wheezing, dyspnea, nasal discharge, sinusitis, pain Respiratory and drug allergies Conditions currently affecting other body systems and associated signs/symptoms Patterns of activity, fatigue, sleep, weight loss/gain Relevant psychosocial history Current and past use of alcohol and other recreational drugs Current and past work and residence history, education level Children: age-appropriate development • General physical assessment <ul style="list-style-type: none"> Cognitive Vision and hearing Cardiovascular Nutrition Neuromuscular Elimination Activities of daily living (ADL; bathing, dressing, grooming, feeding, toileting)/instrumental ADL (medication management, cooking, shopping, ability to use telephone and transportation) • In-depth respiratory assessment <ul style="list-style-type: none"> Respiratory physical examination: inspection, palpation, percussion, auscultation Pulse oximetry at rest and with activities of daily living, walking, or exercise Peak expiratory flow rate or screening portable spirometry or at-home apnea monitor • Treatments and equipment <ul style="list-style-type: none"> Inhaled respiratory medications and appropriate administration technique Other medications: oral, parenteral, over-the-counter Oxygen: equipment, use, maintenance Nebulizer equipment: use, cleaning Other equipment used in home: positive airway pressure devices, ventilator Tracheostomy care • Home environment <ul style="list-style-type: none"> Structural barriers Safety problems Hygiene problems • Psychosocial environment <ul style="list-style-type: none"> Language Family/patient coping Family conflict Potential abuse • Learning needs <ul style="list-style-type: none"> Disease and symptom management Equipment use Oxygen Medications Energy conservation and pacing techniques Home exercise and strengthening techniques Coping skills 	
B. Treatment/intervention components	
<ul style="list-style-type: none"> • Administer prescribed medications • Administer procedures, such as chest physical therapy • Set up respiratory equipment, e.g., oxygen, continuous positive airway pressure, ventilator • Titrate oxygen dose to ADLs, exercise, sleep needs • Obtain blood, sputum, or other specimens for laboratory analysis • Establish/monitor in-home walking/exercise plan • Rearrange home environment to reduce energy expenditure • Counsel regarding family dynamics, alternate living arrangements, options for financial assistance, spiritual concerns, end-of-life issues • Assist with bathing and other ADLs • Assist with chores such as housework and shopping • Provide adaptive equipment • Provide long-term ventilator care • Provide care related to other body systems, such as wound care • Smoking cessation • Arrange community support services, such as day care, respite, meal delivery, transportation 	
C. Patient/family education	
<ul style="list-style-type: none"> • Disease process • Signs and symptoms to report • Symptom management • Oral/intravenous medication use • Inhaled medication technique, equipment management • Home oxygen management, cleaning, and troubleshooting • CPAP, BiPAP, ventilator equipment management, cleaning, and troubleshooting • Airway management • Secretion clearance 	<ul style="list-style-type: none"> • Breathing techniques • Energy conservation techniques • Exercise/strengthening techniques • Management of ADLs and IADLs • Nutrition techniques • Use of community resources • Adherence to treatment regimen • Advanced care planning • Terminal care

Definition of abbreviations: CPAP = continuous positive airway pressure; BiPAP = bilevel positive airway pressure.

Of concern to nurses, chest physicians and pulmonologists is medication noncongruence between 74% of physician and clinic patient pairs (83). Yang and coworkers (84) studied adherence in 50 elderly patients, without cognitive impairment, who were instructed to bring all their medications to a clinic visit. A subsequent home visit was conducted to determine medications actually taken. When clinic and in-home medication lists were compared, nearly half the clinic lists missed at least one medication being taken at home. Omitted prescription medications included such drugs as oxycodone, warfarin, and insulin. Barat and coworkers (85) found that living alone, dementia (i.e., a Mini-Mental State Examination score below 24), more than one prescriber, and three or more prescribed medications were associated with nonadherence. Gray and coworkers (86) found that 44% of 147 elderly home health agency patients were over- or underadherent with at least one medication. Risk of nonadherence increased with Mini-Mental State Examination scores below 24 and with each added prescribed medication.

Medication knowledge alone did not predict adherence. Ho and colleagues (87) administered knowledge questionnaires to parents of asthmatic children as part of a longitudinal study on treatment adherence. Knowledge scores did not predict medication adherence or asthma outcomes, such as number of emergency room visits. The investigators could not support the assumption that knowledge directly leads to improved self-management and health outcomes and emphasized the complexity of factors associated with adherence.

Poor adherence has been demonstrated with use of metered dose inhalers (MDIs) (88–91), and loss of correct technique over time has been shown as well (92, 93). Incorrect MDI use has been correlated with asthma instability (94). Addition of a spacer reduces technique problems related to coordination of firing and inhalation (95). Although dry powder inhalers (DPIs) are more often used correctly (96–98), technique errors are possible, particularly in elderly patients (99).

Because MDI and DPI administration techniques differ, patients must be able to demonstrate the correct technique for each device. The risk of incorrect use may increase when patients use both MDIs and DPIs (100). Patients must also know how to determine the number of doses remaining. DPI dispensers that include medication counters may be preferable to MDIs (101) because floating an MDI canister in water may cause contamination (102). Patients must clean the device and spacer correctly. To reduce the accumulation of electrostatic charge that decreases respirable dose, spacers should be washed with diluted household detergent, left unrinsed, and allowed to drip dry (103). APNs, chest physicians and pulmonologists must assess multiple factors in making prescribing decisions, including patient cognition, dexterity, and administration skill.

Home nebulizers are used to deliver maintenance antibiotic therapy for patients with cystic fibrosis or bronchiectasis. Nebulizers are preferred for patients with asthma or COPD if they are unable to master MDI or DPI technique despite repeated instruction, have an extremely low inspiratory capacity or flow rate, cannot breath hold, or need high bronchodilator dosages (104, 105).

Home nebulizers are potential reservoirs for respiratory pathogens, among them *Staphylococcus aureus* and *Pseudomonas aeruginosa* (106, 107). Although no evidence-based guidelines exist for cleaning of home nebulizers, usual recommendations include rinsing after each use, disinfecting three times per week, and air drying (108). Quaternary ammonium compounds have been shown to be effective against both *S. aureus* and *P. aeruginosa*, whereas acetic acid (white distilled household vinegar) has been shown to be effective against *P. aeruginosa* but ineffective against *S. aureus* (109). However, washing with

household detergent removes *S. aureus* (110). Thus washing followed by a vinegar soak has been accepted practice.

Chatburn and coworkers (110) compared the effectiveness of two concentrations of acetic acid, quaternary ammonium compound, and household detergent against a mixture of *P. aeruginosa*, *S. aureus*, and *Pseudomonas cepacia*. Washing in detergent followed by a 60-minute soak in a 1.25% acetic acid solution (1 part vinegar to 3 parts distilled water), then air drying, was as effective as detergent washing followed by a 10-minute soak in a quaternary ammonium compound solution, then air drying. However, neither technique removed all organisms. Note that quaternary ammonium solutions can be reused and are less expensive over time than acetic acid solutions.

More stringent home nebulizer cleaning guidelines are recommended for patients with cystic fibrosis and include: detergent prewashing; disinfection by boiling, immersion in bleach, alcohol or hydrogen peroxide; rinsing with sterile or filtered water; and air drying. These guidelines recommend against use of acetic acid (111).

Riethmueller and colleagues (112) found in-home administration of intravenous antibiotics for patients with cystic fibrosis with chronic *P. aeruginosa* infection to be as effective as in-hospital administration. Community-acquired pneumonia and COPD exacerbations have also been treated by intravenous antibiotic administration in the home. However, patients must be evaluated for factors precluding safe home administration, such as no telephone, active substance misuse, history of anaphylaxis, unsafe home situation for home care staff visits, or language barriers that cannot be overcome by interpreter use (75, 113). Patients or their caregivers must be able to recognize complications, including loss of access, infection, and drug side effects (113). The recommendation of a European Consensus Conference is that the first dose should be administered in the hospital setting under medical supervision (75). However, several studies examining cost-effectiveness of outpatient intravenous therapy in the United States and Canada reported that treatment often started in an outpatient setting (114–116). The role of a team's (as nurse, physician, pulmonologist) communication was critical in providing safe and effective pharmacotherapy.

Exploring barriers to adherence, providing education, and assisting patients to use medications correctly are essential in-home interventions. If patients are to adhere to their prescribed regimens, it is necessary to ensure correct administration technique, assist in the development of a realistic medication schedule, teach how to order medications, and ensure correct maintenance and cleaning of the administration system. Involving family caregivers is indicated for cognitively impaired patients. Fostering communication among multiple prescribers, such that a chest physician or pulmonologist is aware of the number of drugs a patient is taking, may reduce polypharmacy or complexity of medication regimens (117–119).

Oxygen Therapy

Two randomized controlled trials demonstrated the survival benefit of long-term oxygen therapy (LTOT) for patients with COPD with chronic hypoxemia (120, 121). Although specific to COPD, the findings have been extrapolated to other chronic respiratory diseases (122).

Current ATS guidelines stipulate LTOT for a Pa_{O_2} less than or equal to 55 mm Hg (or an Sa_{O_2} less than or equal to 88%). LTOT is also recommended for patients with cor pulmonale who have a Pa_{O_2} of 55–59 mm Hg (or an Sa_{O_2} less than or equal to 89%) and EKG evidence of “P” pulmonale, hematocrit greater than 55%, or congestive heart disease. ATS standards (123) recommend an arterial blood gas analysis rather than pulse oximetry to initially establish long-term oxygen need. Evidence

suggests that 30 to 60% of patients who initially qualify for LTOT no longer qualify when retested 1 to 3 months later (124, 125). Current recommendations for patients initially prescribed LTOT at hospital discharge are for physicians to retest after 90 days (126).

Concentrators, liquid oxygen, and compressed oxygen are used to deliver LTOT. Oxygen concentrators are the least expensive but do not deliver 100% oxygen or usually permit portability. Only one portable concentrator is currently Medicare approved. Concentrators deliver at least 95% oxygen when the flow rate is less than or equal to 2 L/min. Liquid systems are costly but deliver 100% oxygen regardless of flow rate and easily refill portable containers. Compressed oxygen systems deliver 100% oxygen and are supplied in heavy cylinders designed for stationary use, and in light-weight aluminum cylinders designed for portability (127). Cost containment efforts have driven development of oxygen-conserving devices, such as pulsed systems that deliver oxygen only during early inspiration. Some oxygen-conserving devices deliver insufficient oxygen during activity (128, 129). Patients must have the oxygen flow rate individually titrated for the specific device to be used (126, 130, 131).

The Nocturnal Oxygen Therapy Trial empirically recommended increasing the oxygen dose by 1 L/minute during sleep for patients hypoxemic at rest (120). Plywaczewski and colleagues (132) confirmed desaturation during sleep in nearly half of patients with COPD who were receiving a nocturnal oxygen flow rate sufficient to maintain a daytime Pa_{O_2} greater than 60 mm Hg. Mohsenin and colleagues (133) found that daytime oxygen saturation values did not accurately predict nocturnal oxygen need, but continuous oximetry monitoring during sleep permitted precise dosing (123). Note that oxygen supplementation in nocturnal hypoxemia without daytime hypoxemia at rest has not demonstrated a long-term survival benefit (134, 135). O'Donohue and Bowman (136) recommend sleep studies for patients without daytime hypoxemia who exhibit right heart failure or other clinical evidence of nocturnal desaturation to determine the need for oxygen or other therapy.

Supplemental oxygen reverses exercise-induced hypoxemia and may improve exercise performance (137). However, the long-term benefit of oxygen supplementation for exercise-induced hypoxemia without hypoxemia at rest has not been clearly demonstrated and remains controversial (131, 138). Although the Nocturnal Oxygen Therapy Trial empirically recommended increasing the oxygen dose by 1 L/minute during exercise for patients hypoxemic at rest, current guidelines recommend dose titration to achieve an Sa_{O_2} exceeding 90% during exertion (123, 126, 131, 139). A walking protocol using pulse oximetry to determine dose requirements produced comparable results in hospital and home (140).

Supplemental oxygen is recommended for chronic lung disease of infancy to promote repair of developing lungs, provide adequate exercise tolerance, and reduce pulmonary arterial hypertension and right ventricular workload. Monitoring oxygenation is essential during activity, feeding, and sleep, when oxygen levels are known to fluctuate. Recommendations for assessment of oxygenation level as well as parameters and techniques for supplemental oxygen administration are described in detail in the ATS Statement on the Care of the Child with Chronic Lung Disease of Infancy and Childhood (141).

Although chest physicians and pulmonologists are using appropriate criteria for prescribing LTOT, the order alone does not assure appropriate use in the home. LTOT patients report using oxygen for less than the prescribed time (142), and overestimate their use when self-reports are compared with metered values (143). Kampelmacher and colleagues (144) found that of 528 patients receiving LTOT only 33% had been given any instruction for oxygen use, and more than 40% did not know

their oxygen prescription or guidelines for use. Reported reasons for nonadherence included difficulty in managing equipment, absence of dyspnea, restricted autonomy, fear that the therapy would not work when it was "really needed," and feelings of shame. The investigators concluded that more education, motivation, and monitoring of patients was needed, and suggested that support at home was more cost-effective than additional outpatient visits.

Depression, anxiety, less independence in IADLs (such as shopping), and poor health-related quality of life were described in LTOT patients (145–147). LTOT patient experiences of impaired mobility, restriction, and social isolation have also been described (148). APNs, chest physicians, pulmonologists, and other clinicians along with home care providers must assist patients in adapting to the many challenges posed by LTOT. Pulse oximetry in the home has the advantage of replicating the patient's usual environment and activities and can be used for flow rate titration during rest and exercise. Many aspects of LTOT use can be initially taught or reinforced in the home. Examples include correct usage guidelines, determining when replacement or refill is needed for compressed or liquid systems, safe filling of liquid portable devices, maintaining a back-up system for concentrators, and avoidance of fire hazards (149). Patients can be helped to incorporate oxygen use into ADLs and IADLs, and can be assisted with activities they cannot manage independently. Psychological support and identification of situations requiring professional intervention can also be provided in the home setting.

Smoking Cessation

All patients with respiratory disease should be advised to stop smoking (73, 123). Nurses, chest physicians, pulmonologists, and home health providers should follow the U.S. Surgeon General's recommendations and ask every patient at every encounter, "Do you smoke?" and "Do you want to quit?" The clinical practice guideline "Treating Tobacco Use and Dependence" provides a framework for treating tobacco dependence, including treatment measures for patients who are willing to quit, motivational interventions for patients unwilling to quit, and relapse prevention for patients who have recently quit (150).

Research supports recommendations for encouraging and assisting patients to quit, but data are insufficient to make definitive recommendations for parents (151). However, clinical practice guidelines encourage smoking cessation interventions in parents to eliminate second-hand smoke exposure in their children (152), and application of knowledge about the risks posed by such exposure suggests these recommendations are warranted. Although guidelines do not distinguish between potential harms to well children and those with acute or chronic lung disease, smoking cessation for parents of ill children is especially important.

Pulmonary Rehabilitation

The goal of pulmonary rehabilitation is to help patients with lung disease achieve and maintain maximum functioning and independence in the community (153). Programs are most often conducted in the outpatient setting, but successful in-home pulmonary rehabilitation has been reported (154–159). Greater improvement in exercise tolerance and dyspnea with activities of daily living (ADLs) has been demonstrated with supervised outpatient exercise than self-monitored home exercise (160, 161). However, Strijbos and coworkers (162) compared 12 weeks of outpatient rehabilitation with supervised home exercise and found that the gains in exercise tolerance and dyspnea persisted at the 18-month follow-up for the home group, but not for the outpatient group. The investigators theorized that the home exercise group maintained their gains because they had incorporated exercise into the home environment. Others have demon-

strated improvement (157), no decline (163), or reduced rate of decline (164) in exercise tolerance in patients with COPD or cystic fibrosis, respectively, when compared with control groups. Oh (157) also found lower exertional dyspnea and better health-related quality of life (HRQL) in a small sample of Korean patients with COPD after a nurse-led home pulmonary rehabilitation intervention than in control subjects who received educational advice only. The ATS statement on pulmonary rehabilitation (165) outlines known benefits and recommended components of pulmonary rehabilitation, and compares potential advantages and disadvantages of home versus outpatient settings for rehabilitation.

PSYCHOSOCIAL ASPECTS OF HOME CARE FOR PATIENTS AND FAMILIES

The psychosocial needs of patients with chronic respiratory disorders are significant. Managing even basic tasks such as bathing and dressing increases dyspnea and undermines confidence and self-esteem (166, 167). Greater levels of dyspnea are associated with more impaired physical and psychosocial functioning in community-dwelling patients with COPD (168). Chronic fatigue and recurrent exacerbations contribute to impaired muscle endurance with a negative cycle of inactivity and progressive deterioration in functional and psychological status (169). Home oxygen may represent a significant barrier to previous activities (148).

The prevalence of depression is high in elderly patients with COPD, and is associated with lower self-rated HRQL (146, 170) and reduced ability to perform ADLs (170). Poor emotional functioning and living alone are associated with earlier mortality in female patients with COPD receiving LTOT (171). Dow and Mest (172) recommend screening for depression in patients with chronic respiratory disease, as well as a full family assessment to identify family coping patterns and the level of support required for the patient. Home care team-led interventions that may be beneficial include counseling (individual and group therapy), treatment with antidepressants when indicated, home-based or outpatient exercise programs, teaching of relaxation techniques, and formal education classes with other chronic respiratory disease patients.

Family or other caregivers also experience a significant impact on their quality of life (173, 174) and mental health (175). Chronic pulmonary disease can reduce the patient's wage-earning ability and cause financial distress. Family members become involved in direct care as the patient loses the capacity for self-care and social activities gradually decrease.

Family caregivers to patients with COPD report dissatisfaction with recreational or free-time activities for themselves and for patients (176, 177). However, these perceived reductions may be common to aging people, not just patients with COPD (177). Wicks (178) found that the only patient factor significantly affecting family health was cognitive impairment (i.e., poor memory), a common condition of elders with and without physical impairments.

Cain and Wicks (179) found that COPD caregiver burden was lower among black individuals and among family caregivers over age 55 years, but did not differ by sex, relationship to the patient, caregiver education, perceived adequacy of financial resources, or employment status. Wives of patients with COPD interviewed by Bergs (176) reported that outside employment reduced their perceived caregiver burden. These wife caregivers also reported dissatisfaction with the amount of social support received from others, although the overall caregiving experience can be rewarding. Families of stable Finnish patients living at home with LTOT had better overall family functioning than families of patients with COPD experiencing repeated hospitalizations, although functioning in both groups was good (180).

Families of LTOT patients had more emotional closeness, and were more flexible and independent than families of inpatients.

In the pediatric asthma population, depression, anxiety, recent loss, and denial of symptoms are associated with increased morbidity and mortality (181). Parents of asthmatic children experience multiple stressors as they attempt to manage their child's asthma by monitoring symptoms, giving prescribed treatment, providing emotional support, and handling the everyday responsibilities of parenting. The impact of stress can result in family dysfunction manifested by excessive worry, denial, and noncompliance, anxiety about parenting and discipline, and over-protectiveness. Pediatric pulmonologists and specialist nurses can play a definitive role in providing access to appropriate resources. Asthma self-management courses and peer support groups can enhance parents' abilities to manage their child's asthma and associated stressors (182).

Families of medically fragile or technology-dependent (MFTD) children experience an ongoing crisis owing to the seriousness of the situation and, often, uncertainty about the child's future (64, 66). Parent caregivers may feel inadequate to the task of caring for their MFTD child, or experience social isolation, fatigue, and emotional exhaustion due to the demands of care (66). Parents and families use multiple strategies to manage the stress of the situation, including use of respite care (below). They draw on informal social support resources such as family and friends (183), and formal sources such as pediatric pulmonologists and home care professionals (64). Emotional expression, physical exercises, distraction, positive self-talk, and humor are also used to manage stress (66). Prayer (66, 183) and meaning-making experiences ("we are special," fate, faith) are used to move to acceptance of the situation (183).

Home health agencies frequently provide the first link for patients and families to address these psychosocial adjustments. Chest physicians and pulmonologists can provide access to community or home-based rehabilitation. Where access to rehabilitation programs is not possible, home health nurses assess the impact of chronic illness on the patient and family. The nurse plays a primary role in providing education, making appropriate referrals to other health care professionals, and coordinating care. Home health nurses need to assist families to identify their own strengths and support networks, and to make appropriate referrals for additional resources (184). Community support resources are listed in Table 6.

When the home health nurse identifies psychosocial concerns, referral to a medical social worker is indicated. The social worker can facilitate the identification and use of community resources, including negotiating appropriate financial assistance, providing counseling for long-term care planning, end-of-life decision-making, and short-term family therapy (185).

Formal respite care has been promoted as an appropriate preventative health intervention for stressed family caregivers, allowing them time away from caregiving activities (186). Respite services include in-home aides or nursing services, overnight respite programs, short-term group home or nursing home placement, day treatment centers, and camps for MFTD children (187). Physician support can facilitate access to these services.

Respite care may be especially important for families caring for a medically fragile or technology-dependent child, particularly those using an apnea monitor or mechanical ventilator. Parent caregivers to MFTD children value the opportunities provided by respite care to attend to other family responsibilities, including time for siblings of the ill child and to engage in spontaneous family activities; to allow for rest and recovery from exhausting, sometimes 24-hour care; to accomplish personal goals; to strengthen relationship with a partner, including having time alone; and just to have time away from the child (62, 63). The

TABLE 6. COMMUNITY RESOURCES FOR HOME CARE

Regional lung association, other voluntary organizations for chronic respiratory diseases
Home medical equipment company (e.g., home respiratory or home infusion therapy services, oxygen, supplies)
Meals on Wheels and other meal delivery services
Grocery delivery services
Housekeeping services
Financial planning services
Income assistance services
Legal services
Respite care services
Day care providers for chronically ill—adults and children
Home attendant, personal care, homemaking services, and professional nursing services
Supported housing or assisted living arrangements
Internet resources

pediatric pulmonologist and nurse's awareness of the available services and appropriate referral are key to caregiver support.

Although respite care has been identified by caregivers as the most needed service (188), barriers to using respite care have been identified. Barriers include lack of knowledge about respite resources, inability to access care because of lack of qualified caregivers for children with complex care needs, insufficient financial resources to cover respite care, and selected agency requirements that respite care be planned weeks in advance of need (187, 189). Even when respite care is available, it is often unaffordable or is not compensated by insurance programs (190).

PALLIATIVE AND END-OF-LIFE CARE

As lung function progressively deteriorates, the emphasis of care for patients with chronic lung disease shifts toward palliation of symptoms and preparation for eventual death. Patients with advanced lung disease need to consider options for end-of-life care, ideally in collaboration with their primary care physician, chest physician or pulmonologist, nurse, and family members. *A priori* decisions as to whether care can be maintained at home, under what circumstances to hospitalize, whether to initiate life support, and when to discontinue life support should be made whenever possible (191, 192). The hospice care team is specially trained to assist.

Admittedly, determination of the terminal phase of COPD is difficult (193–195). On the basis of reviewing recent research findings, Hansen-Flaschen (192) recommends that the following profile be considered indicative of high risk of death within the next year: best FEV₁ less than 30% predicted, declining performance, increasing dependence on others for ADLs, uninterrupted walk distance limited to a few steps, more than one urgent hospitalization within the past year, left-heart and/or other chronic comorbidity, older age, depressed mood, and unmarried status.

End-of-life issues are especially important for patients undergoing long-term mechanical ventilation (LTMV). The patient receiving LTMV at home may be faced with determining when it is appropriate to consider the withdrawal of treatment. When 50 patients with amyotrophic lateral sclerosis who were receiving LTMV were interviewed, most of the interviewed patients stated they were glad to be alive on LTMV (196). However, 76% wanted limits placed on LTMV, such as in the event of permanent unconsciousness, and 58% did not wish cardiopulmonary resuscitation (CPR) to be performed. Legal and ethical issues can complicate the decision to withdraw ventilator use from patients and family members of children or others who are unable to make decisions for themselves (197, 198). Physician/nurse recognition of these issues is essential.

Advance health care directives are formal, legal documents

that allow patients to describe their treatment wishes in the event they are incapacitated. Living wills describe instructions for care and durable powers of attorney name proxy decision-makers (199). The federal Patient Self-Determination Act enacted in 1990 requires that hospitals, nursing homes, and home health, home care, and hospice agencies that receive Medicare or Medicaid funds provide written information to each adult patient regarding the right to formulate advance directives (ADs) (200). Heffner and colleagues (201) distributed a questionnaire regarding ADs to patients with chronic lung disease enrolled in pulmonary rehabilitation programs. Although 99% of respondents indicated that they would welcome a discussion about advance directives with their physicians, only 19% had actually had such a discussion and only 14% believed that physicians understood their wishes. After participating in an educational workshop regarding AD held in a pulmonary rehabilitation clinic, patients were more likely to complete a durable power of attorney for health care (72%), discuss life support options with their physicians (58%), and believe that physicians understood their wishes (44%) (202).

Dales and colleagues (203) tested a structured decision-making instrument describing risks and benefits of intubation and mechanical ventilation with a convenience sample of 20 patients with severe COPD. All patients reached a decision. The decision was unchanged for 16 of the 18 patients who were able to complete a follow-up interview 1 year later. The authors recommended further testing of the instrument in clinical settings to facilitate discussion of end-of-life decision-making between patients, families, and physicians. These findings suggest that patients with chronic respiratory disease are able and willing to discuss end-of-life decision-making in advance of the need. Physician/nurse involvement can assist in decision-making.

Home health personnel have a unique opportunity to facilitate discussion about patients' goals and wishes related to the end of life. Ratner and colleagues (204) offered advance planning discussions in the homes of patients receiving care from a large home health agency. Eighty-four home health patients judged by home health nurses to have a life expectancy of less than 2 years were referred to social work staff trained in advance care planning (ACP). All but one of the referred patients participated in the ACP process, which included discussion of the patients' preferences regarding location of care at the end of life. When appropriate, information about hospice was provided and patients were assisted to complete advance directives. Over half the patients expressed the preference to die at home. Physician involvement for referral ensued.

Because emergency medical services (EMS) responders are required to initiate life-saving measures unless otherwise directed by valid physician orders, AD are insufficient to prevent

community patients from unwanted CPR and other aggressive resuscitation efforts if 911 is called (205). Physician DNR orders must be obtained in advance and clearly posted in the home for EMS. A telephone survey conducted in 1999 revealed that 40 states had implemented some form of EMS-DNR (Do Not Resuscitate) laws or protocols (206). Home health personnel should offer assistance to patients living at home with chronic respiratory disease to complete the forms recognized in their community if they wish to have decisions to forego CPR, intubation, or mechanical ventilation honored. Home health staff should also work with physicians to provide families with anticipatory guidance about what to expect during the dying process (205).

Services provided by home health and hospice agencies in the United States allow patients with end-stage chronic respiratory disease to remain at home for their final days. Medicare-certified hospice agencies and many private insurance programs offer a wide spectrum of services including comprehensive symptom management, financial coverage for medications and equipment related to the terminal illness, respite care, and counseling. Hospice referral requires physician certification that the patient is expected to die within 6 months if the illness runs its normal course. Prediction of the terminal phase of illness is inexact (207). Such predictions are easier for metastatic cancers, in which weight loss and functional decline characterize the last months of life, than for COPD and other diseases involving chronic organ failure (193). Hence, hospice programs predominantly serve patients with cancer, even though patients with COPD and other lung diseases can benefit from the comprehensive end-of-life care provided through hospice. For example, in 2000 over 50% of hospice patients had cancer diagnoses, whereas only 6.5% had lung disease (21). Chest physicians, pulmonologists, and nurses should recognize those patients with COPD who could benefit from hospice care and assist patients to explore options.

Terminally ill patients and their care providers identified characteristics of a "good death" as pain and symptom management, clear decision-making, preparation for death, completion, contribution to others, and affirmation of the whole person (208). Interviews with terminally ill patients revealed five domains of quality end-of-life care: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones (209).

Symptoms frequently experienced by lung disease patients nearing death are dyspnea, cough, insomnia, depression, and delirium (191). An individualized approach to management of dyspnea includes treatment of reversible underlying causes such as pleural effusion, use of opiates, facial cooling with fans, positioning, anxiolytics, and corticosteroids (210–212). Although commonly provided, there is little objective evidence supporting the use of supplemental oxygen in the absence of hypoxemia. Cough, often contributing to dyspnea, musculoskeletal pain, and vertebral fractures, can be managed with opioids, corticosteroids, and palliative radiation. Treatment of underlying causes, such as hypoxemia, anxiety, and dyspnea, may contribute to relief of insomnia, anxiety, and depression. Anxiolytics and antidepressants are often suitable therapy (212). Specialist clinician judgment plays a critical role in this complex decision-making.

Clark and Heller (213) described a comprehensive case-management program for patients with congestive heart failure and COPD. The home health and hospice agency expanded its mission to include a palliative care program to which patients could be admitted without having a life expectancy defined as 6 months or less. Goals for patients admitted to the palliative care program were to reduce the number of exacerbations resulting in emergency room visits or hospitalization, to improve palliative symp-

tom management, and to increase patient, family, and staff sense of control over the disease process and symptom management. Among the features of the case-management program were a 24-hour on-call service, intensive teaching regarding disease and symptom management, an urgent in-home medication kit authorized by the patient's physician, and use of a calendar system to track symptoms by which to evaluate precipitating factors or disease progression. Patients were transitioned to hospice care when needed. The author described decreased hospitalization rates for symptom control. However, this and similar programs must be subjected to outcome evaluation in a randomized clinical trial for confidence.

OUTCOMES OF HOME CARE

Despite the widespread assumption that home care is helpful and cost-effective in achieving stated goals, data supporting assumptions of efficacy are limited (32, 214, 215). This section of the document focuses on outcomes of traditional models of home health care, in which patients are referred for care after an encounter with the health care system (e.g., hospitalization, emergency room visit, outpatient encounter). Discussion of newer home care models (hospital at home or acute respiratory assessment service) in lieu of acute hospitalization is also included when relevant. Details on studies that focused on cost-effectiveness are described later.

Mortality

Few data support reduced 1-year mortality in patients with COPD receiving specialized respiratory home care services. Two early studies of home care delivered by specialist respiratory nurses in the United Kingdom found reduced risk of death in patients receiving the intervention compared with those not receiving home care (47, 48). However, home health care delivered by respiratory specialist nurses in the United States and Australia produced no survival advantage at 1-year follow-up compared with usual care (46, 216) or with home health care provided by generalist nurses (46). Spanish LTOT users receiving usual care or regular and on-demand telephone and home visit follow-up did not differ in mortality over 1 year (217). Australian general medical-surgical (including COPD) patients randomized to a home-based intervention delivered by a nurse and pharmacist, versus usual care (i.e., no home care), had reduced overall mortality, but in-hospital deaths were similar (218). Two hospital at-home services in lieu of acute hospitalization in the United Kingdom and Spain found no difference in mortality between patients treated for acute COPD exacerbation in hospital and those treated at home (4, 10).

Functioning and Health-related Quality of Life

Some improvements in health-related quality of life (HRQL; general health perceptions, functional status, symptoms) have been demonstrated in several trials of specialist- or generalist-provided home care to patients with COPD or cancer. Terminal patients with a variety of diagnoses reported modest improvements in HRQL in a trial of a large home-based primary care intervention conducted in a Department of Veterans Affairs setting (219), and patients with lung cancer receiving home care had later onset of symptom distress and less social dependency than usual care patients (220). Canadian patients with COPD who received self-management education at home had significant improvements after 4 months on the impact and activity scales of the St. Georges Respiratory Questionnaire, but only the impact improvements were maintained at 12-month follow-up (221). Patients receiving respiratory APN-directed home care had fewer depressive symptoms and better ADL functioning

than patients receiving usual care, but there were no differences between groups in dyspnea or IADL ability (52). A variety of other respiratory home care interventions in several countries have found no differences in HRQL between treatment and control patients (46–48, 216–218, 222, 223).

Studies examining HRQL outcomes for programs providing home care in lieu of acute hospitalization have produced mixed results. One hospital at home system found no difference in HRQL between patients treated for COPD exacerbation at home and those treated in hospital (4), but another found higher ratings of HRQL in the home treatment group than in the hospitalized group (10). No difference was found in HRQL ratings between patients randomized to home and hospital treatment of COPD exacerbation in a study of outcomes of an acute respiratory assessment service (11). Acuity levels and availability of care could explain the varied outcomes.

Canadian patients who received exercise teaching and an initial training session at home as part of a COPD self-management program showed no improvement in 6-minute walk distance at 4- and 12-month follow-up (221). In contrast, Strijbos and colleagues (162) found improvements in exercise and dyspnea in patients receiving home and outpatient pulmonary rehabilitation, and higher levels of well-being in patients receiving home rehabilitation compared with a control group. The home rehabilitation group maintained improvements in exercise and dyspnea longer than the outpatient group. The difference could relate to one home session (221) versus continued care (162).

Positive Health Behaviors

There is evidence supporting success in changing health behaviors as a result of respiratory home care interventions, although the extent of change has been modest. Despite only slight improvement in knowledge about disease and medication use in patients with COPD receiving visits by respiratory specialist nurses in the United Kingdom, these patients had a higher rate of smoking cessation than patients not receiving the intervention (47). Hermiz and coworkers (222) tested a brief, but comprehensive, home care intervention for patients with COPD discharged from hospital or emergency room. Although patients in the treatment group had increased knowledge about disease management, there were no differences in the number of patients who smoked, or received influenza or pneumonia immunizations. Hernandez and coworkers (10) found greater disease knowledge, better compliance, better inhaler technique, and home rehabilitation (airway clearance maneuvers, nutrition, and upper extremity strength) in hospital at home patients compared with patients treated for exacerbation in hospital. Bourbeau and colleagues (224) found more frequent use and higher skill level in controlled breathing techniques in patients receiving a COPD self-management program than in usual care patients. Qualitative interviews with self-management patients revealed they had made significant lifestyle changes as a result of the program, including use of energy conservation techniques, an action plan for exacerbations, controlled breathing techniques, and a regular exercise program. All studies that supported positive health behavior change involved protocol development with both physicians and nurses.

Patient and Caregiver Satisfaction

Few studies of traditional home care have examined patient and caregiver satisfaction. An early study in the United Kingdom found equal levels of satisfaction with care in the group receiving respiratory home care and those not receiving it (48), but another early clinical trial found that many patients thought they benefited from respiratory nurse visits and wished for them to continue (47). Veterans Administration patients with a variety of

nonterminal medical (including COPD) or surgical conditions who received home-based primary care services reported greater satisfaction with care; their caregivers experienced improved HRQL and decreased burden (219). Dutch respiratory patients reported greater satisfaction with knowledge, and information and advice, given by respiratory specialist nurses compared with general community nurses (223).

Several studies of home care in lieu of hospitalization have included patient and caregiver satisfaction as an outcome of care. Patient satisfaction in studies looking only at respiratory patients is consistently rated higher by patients receiving acute care at home than by those treated in hospital (8, 10, 11, 225). However, a small subgroup of patients with COPD included in a study of general medical and surgical patients receiving hospital at home care was the only subgroup that preferred hospital care to home care (7). The small subgroup sample size limited generalizability of the findings. In another study led by nurses, patients enrolled in a community-based chronic home management program were very satisfied (91%) or quite satisfied (9%) with the service (12).

Hospital Readmission, Emergency Care, and Related Outcomes

Because the hospital is the most expensive setting for health care, a major goal of traditional and innovative home care programs is reduction of hospital days and emergent care. Evidence that traditional home care models reduce the use of these acute care services is mixed.

Hospital episodes were fewer for treatment patients than control subjects after 1 year in two studies (217, 221), and for patients receiving home health care from respiratory APN-directed nurses throughout a home health episode of care (52), but no differences were found in most other studies (48, 216, 219, 220, 222, 223). Total hospital days were reduced in two quasi-experimental studies (226, 227), and two randomized controlled trials (217, 221). However, total hospital days did not differ for patients with lung cancer receiving specialized home health care, generalist home health care, or usual care (220). Length of stay was reduced in the two quasi-experimental studies (226, 227), and one clinical trial (221), but was unchanged in three additional controlled trials (48, 216, 220). In one early clinical trial in the United Kingdom, patients receiving respiratory home care had the same number of admissions, and spent more time in the hospital for respiratory problems than did patients not receiving home care. Hospitalizations for nonrespiratory problems did not differ between groups (47).

Three studies found reduced emergency room use with home care intervention (217, 221, 226), but two others did not (216, 227). One study (227) found fewer clinic visits made by patients receiving home care, and another saw fewer acute care (presumably unscheduled clinic) visits with respiratory APN-directed home care (52). Two other studies (48, 216) saw no difference in outpatient visits with respiratory home care intervention. Bourbeau and coworkers (221) found a reduction in unscheduled physician visits, but no difference in scheduled visits, between intervention and control patients. Length of stay in home health care was shorter for patients receiving home health services from specialist-led nurses than for those receiving usual care (52).

As expected, home care in lieu of acute hospitalization produced shortened hospital lengths of stay in several studies (6, 9, 10). Hernandez and coworkers (10) also found fewer emergency room visits for the hospital at home group. However, most studies found no difference in number of hospitalizations (4, 6, 7, 10, 228), total hospital days, or use of outpatient services (11) as a result of hospital at home or acute respiratory assessment services. Increased positive outcomes were seen in studies that

provided home care as a substitute service for hospitalization, with physician-integrated protocols, rather than home care as an add-on service at home with minimal physician contact after hospitalization (10). Most U.S.-based studies provided an add-on service. Still, one descriptive study of a chronic home management program for patients with COPD with three or more hospitalizations in the year before entering the program revealed that 40% of patients had no hospitalizations and 25% had only one admission in the subsequent year (12).

COST AND REIMBURSEMENT ISSUES

Cost of Home Care

Two economic analyses of the direct costs of COPD in the United States estimated the proportion attributable to home health care. Wilson and colleagues (229) looked at emphysema and chronic bronchitis separately. Overall, home health care accounted for \$263 million of a total COPD expenditure of \$14.5 billion per year. Estimated home health care costs for emphysema were 1.6% of total costs, and for chronic bronchitis, 2.8% of total costs. Ward and coworkers (230) estimated total costs at \$6.6 billion, of which 5%, or \$309 million, was attributable to home health care. Despite the differences in these analyses, it is clear that home health care represents a small proportion of total expenditures currently used to treat COPD.

Two additional analyses of COPD treatment costs found that hospitalization represented the largest portion of total treatment costs (231, 232). Neither analysis included home health care costs in their evaluations. Sullivan and coworkers (232) noted that nearly 50% of Medicare costs are incurred by about 10% of patients with COPD. Hilleman and coworkers (231) stratified their sample by COPD severity, finding significant increases in hospital and emergency room costs with increasing disease severity. These results suggest that reducing frequency or length of hospitalization is the key to reducing total costs of COPD. Chest physicians and pulmonologists need to recognize that earlier hospital discharge, and avoidance of emergency room or hospital care altogether, are important premises on which home health referrals can be based.

Moreover, the value of unpaid informal caregiving by family members is often ignored in economic evaluations of health care costs. Bergner and coworkers (46) imputed the cost of unpaid assistance to patients with COPD receiving home care by respiratory specialist nurses and generalist nurses, and those receiving usual (office-based) care. No differences were found between groups, but the informal caregiving cost for male, married patients (i.e., wives foregoing salary) with COPD was three times the cost of such care for all other patients. An estimate of the extent of family caregiving to patients with chronic lung disease and associated family activity limitations is that these patients received 5.1 more hours per week of assistance than elders without lung disease (233). Extrapolation of these hours to the national population of chronic lung disease patients resulted in an estimated \$2 billion annual cost for informal caregiving. These estimates of demands for caregiver time have potentially important ethical implications as family members are asked to take on increasingly complex health care interventions, as well as economic and practical implications in the face of changes in home health reimbursement and other cost containment efforts. Chest physicians and pulmonologists should address the policy implications, such as Medicare home care limitations, of these "hidden" costs of caring for their patients with COPD.

Cost-effectiveness of Home Care

Because hospital care is the most expensive mode of health care delivery, it is expected that the same services provided in the

home are less expensive. However, home health services also incur costs, and they may be ordered for the sickest patients, or in addition to hospital care. It is difficult to demonstrate cost savings for postacute home health care under these conditions. Research to date has not demonstrated significant cost savings for traditional postdischarge respiratory home care, although a meta-analysis of studies examining reduction in hospital days for general medical-surgical adult home care recipients did find a small to moderate effect on cost savings with home care (19).

Early studies attempted cost comparisons of specialized respiratory home care with standard home care. The single randomized controlled trial of this type in the United States found that both interventions were expensive, and that home health care delivered by specially trained respiratory nurses was more expensive than standard home health care while producing similar health-related quality of life outcomes (46). Two quasi-experimental studies (226, 234) found some cost savings with specialized respiratory care, in large part due to a reduction in hospital costs in the year subsequent to the intervention. Hughes and colleagues (235) compared severely disabled Veterans Administration patients receiving hospital-based home care with a control group on several outcomes; about 10% of patients in both groups had primary respiratory diagnoses. No significant difference in cost was found, but diffusion of findings due to varied severity is likely.

U.S. data demonstrating cost-effectiveness of home care for respiratory patients are not available. A small sample of patients with COPD was included in a multicenter Department of Veterans Affairs clinical trial that examined outcomes of a home-based primary care program aimed at identifying high-risk patients and providing continuity of care across settings and organizational boundaries (219). Program costs were higher for patients receiving home-based primary care than for those not receiving it, without equivalent clinically significant outcomes. This suggests that physician/APN clinic-based visits for primary care are cost-effective.

Older data suggest that home care is less costly than hospital care for patients with chronic respiratory conditions, especially for home care of patients receiving long-term intravenous therapy or chronic ventilator care (116, 236-238). However, reduced mortality (47), and increased length of hospital stay for patients receiving a home care intervention (48), were identified as potential causes of increased health care costs for British patients with chronic lung disease. Patients receiving home care services were living longer and using more resources over time.

More recently, Canadian patients administered intravenous antibiotic therapy at home for a variety of infections, including pneumonia, experienced significant cost savings compared with the same course of treatment administered in hospital (115). However, a review of studies examining cost-effectiveness of home intravenous antibiotic therapy for cystic fibrosis identified a number of serious deficiencies in study design that make it difficult to conclusively argue that home administration is less costly than inpatient treatment (239). Factors such as avoidance of negative consequences, and patient and family satisfaction, were not reported in the clinical trial studies.

Evidence for cost savings with hospital at home and acute respiratory assessment programs is mixed. Two randomized controlled trials of supported discharge in the United Kingdom (hospital at home) using cost minimization analysis produced estimates of cost savings for patients discharged early from general medicine, general surgery, geriatrics, and orthopedics (240), but cost increases for patients with COPD discharged early (241). Although patients with COPD in the latter study spent fewer days in hospital, home care costs offset savings from early discharge. On the other hand, studies in Spain and the United

Kingdom compared costs for patients with COPD evaluated by a nurse/physician acute respiratory assessment service and randomized to treatment of exacerbation at home or hospital. Postdischarge protocols were clearly defined. Significant cost savings were gained when patients were cared for at home instead of the hospital (9–11).

Payment Structure in the United States

In the United States, the federal government reimburses episodic home health care through the Medicare program. Medicare was legislatively designed to cover acute episodes of illness, and reimburses skilled professional (nursing, medical social services, and physical, occupational, and speech therapy) care ordered by a physician for homebound patients (242). Nonmedical personal care services are reimbursed only when authorized by a physician for a patient who is receiving skilled services. Most other payers follow the Medicare lead in setting policies for coverage of home health care services.

Respiratory care equipment and home oxygen therapy may be reimbursed under Medicare, Medicaid, the Department of Veterans Affairs, or private insurance. As with home care in general, private payers usually follow Medicare's lead in determining coverage. Criteria for Medicare coverage of home oxygen are the same as the prescription criteria described earlier in this statement, and are consistent with the Global Initiative for Chronic Obstructive Lung Disease (73) standards for long-term oxygen prescription. Although home medical equipment companies also make home visits to deliver, maintain, and instruct in the use of medically necessary equipment and supplies such as nebulizers and oxygen, they are not reimbursed for their teaching and monitoring activities.

Escalating Medicare expenditures for home health care and a desire to limit future increases led to implementation of a home health care prospective payment system in 2000 (242). The Balanced Budget Act of 1997 reduced the fee for home oxygen by 25% in 1998 and an additional 5% in 1999 (2). The results of these programmatic changes for patients with chronic respiratory disease have often been a reduced number of skilled visits per episode of care, and cost shifting from insurance to patients for oxygen and supplies. Monitoring of mortality rates, health-related quality of life outcomes, hospital readmissions, and rates of nursing home placement is needed to assess the long-term effect of the prospective payment system on care outcomes.

In summary, reimbursement issues are a driving force in allocation of home health care to respiratory patients in the United States. Although home health care may offer a less costly alternative to hospital or institutional care, inconsistent research findings and suboptimal research designs have been inadequate to demonstrate cost-effectiveness of traditional home care. Innovative models for home respiratory care show some potential for reducing total costs of caring for respiratory patients if they can produce significant reductions in hospital costs. Systems in which home care demonstrates cost savings are those such as in Canadian provinces and Spain, in which home care and hospital care are funded from the same source. Systems in which home care is substituted for hospital care (not added to posthospital care as in the United States) are cost-effective (10). Nurses, chest physicians, and pulmonologists must work daily within U.S. policy limits.

FUTURE DIRECTIONS FOR PRACTICE AND RESEARCH

This statement has identified several potential areas for practice innovation and scholarly exploration to improve outcomes for respiratory patients receiving home care services in the United States. These areas are summarized below.

In the absence of national health care reform, changes in home care reimbursement policy and care delivery structures are unlikely in the near future. Continuing efforts at cost containment will likely drive ongoing efforts to provide all health care interventions in the most cost-effective manner while maintaining acceptable patient health outcomes and satisfaction. These realities suggest that innovative approaches to respiratory patient care within existing structures represent the most productive avenues for efforts to improve outcomes.

Few data are available to support benefits from the use of respiratory specialists in traditional home care or Medicare-certified home health care. Data are available to suggest that the problems of elderly chronic respiratory patients and their families are typical of elders in general (177), and their home care needs may best be assessed by expert gerontologic advanced practice nurses (53). Because most elders have more than one chronic condition, home health nurses with knowledge and competence in the care of common problems of aging patients may provide quality care to patients with chronic respiratory disorders. The availability of respiratory clinical nurse specialists and respiratory therapists for consultation about unusual or complex cases may be sufficient support for generalist home health nurses to provide excellent respiratory home health care (243). This proposition requires testing in controlled clinical trials.

Inability to consistently demonstrate better outcomes in patients receiving respiratory home health care compared with those not receiving it makes it difficult to validate referral criteria for those who can benefit from such care. Expert consensus led to the recommendations for consideration of home health referral for respiratory patients in this statement, but these recommendations differ from correlates of home health referrals found in studies of general home health samples (28–30) and in patients with COPD and congestive heart failure (27). At present, guidelines for referral should be applied on the basis of medical judgment by chest physicians and pulmonologists. There is a need to determine clear evidence as to desirable and achievable outcomes for respiratory home care, and to identify patients for referral who can benefit most from that care.

Several investigators have proposed that data collected by home health care providers for the Medicare quality improvement initiative, using the Outcomes and Assessment Information Set (OASIS), can be used for research purposes. Researchers have assessed the ability of home health care nurses to use OASIS items to screen for depression in home health patients (244), to predict functional status from admission to discharge from home health services (245), and to identify home health patients at risk for rehospitalization (246). Although OASIS developers achieved satisfactory interrater reliability for most items, using specially trained clinicians (247), other researchers have found inadequate intra- and interrater reliability when the raters were agency clinicians (248–250). Sensitivity and positive predictive value of home health nurse ratings of OASIS depression items were fair when compared with a research diagnostic standard (244). Additional work to identify possible knowledge deficits in specific areas by those completing the instrument (244), and other efforts to ensure adequate reliability, are needed. The Centers for Medicare and Medicaid Services is actively working to improve accuracy of data by a variety of methods including web-based home health care clinician training (251, 252).

The emphasis on cost containment in the United States, known risks of hospitalization (e.g., iatrogenic infection), and increasing interest in quality of life outcomes suggests that alternative models for treatment of acute COPD exacerbation, similar to those being studied in Europe, should be tested in the United States. Payers continually seek ways to deliver care outside of the acute care hospital, and well-developed protocols for

urgent care or emergency room assessment, as well as follow-up of patients at home by knowledgeable and skilled providers may produce equally good health and HRQL outcomes at comparable or lower cost than hospital treatment. Use of home intravenous therapy in lieu of hospitalization also offers the possibility of reduced cost, especially for pneumonia. Movement of acute care services into the home has psychosocial and ethical implications as formal care providers expect patients and families to help achieve societal goals for cost containment, representing additional areas for scholarly inquiry.

Many home health interventions are based on empirical recommendations rather than research data. Refinement of protocols for cleaning respiratory equipment and use of long-term oxygen therapy is needed, although absence of data suggesting adverse clinical events, such as infection due to inadequate cleaning, argues in favor of this research taking lower priority than other important questions. More pressing needs relate to adherence to prescribed therapies of known benefit. Theory-based (e.g., health belief model, self-efficacy) interventions to improve adherence should be designed and tested in chronic respiratory patients.

Many patients with chronic lung disease have one or more comorbidities that limit their ability to participate in or benefit from rehabilitation. In addition, patients with advanced disease may benefit most from pulmonary rehabilitation focused on achieving functional improvement in ADLs and IADLs. Future research on home rehabilitation should examine functional outcomes and patient satisfaction in addition to improvements in exercise capacity.

The difficulty in predicting life expectancy has limited hospice referrals for patients with COPD and other chronic respiratory diseases. Chest physicians and pulmonologists logically have the knowledge and skill needed to best predict patients with COPD who would benefit from hospice care. This and models of home-based palliative care to improve symptom management and reduce hospitalization should be formally tested. In keeping with other recommendations for research, outcomes should be carefully selected for feasibility and desirability from patient, family, and provider perspectives.

Data on the effectiveness of various kinds of educational interventions in home care programs are inconclusive. Because most of these interventions are not described in detail in research reports, potential areas for improving effectiveness are difficult to identify. Like many psychobehavioral interventions, education interventions tend to be weak in frequency or intensity, and changes in knowledge and behavior are difficult to measure. Investigation is needed to determine the content, frequency, and intensity of education interventions required to produce a unit increase in knowledge and positive health behaviors in recipients of home care.

The prevalence of depression in chronic respiratory patients at home and the known burdens of caregiving for families of adults and children with chronic respiratory disease suggest that home health nurses and other personnel need the knowledge and skills to identify potential psychosocial problems during home visits. The limited ability of home health nurses to recognize depressive symptoms has been demonstrated (244). Programs to provide needed knowledge and skills to home care providers should be developed and tested. At minimum, physicians, nurses, and other providers should know how to conduct basic psychosocial screening for depression and other problems, know the community resources available to patients and families, and recognize the need for referral to a medical social worker or other resource.

Issues arising from the care of elders and MFTD children at home (64, 66, 183, 253), and the need for respite care services

and barriers to their use (62, 63, 187), have been well described. Needed areas of research and practice innovation include assessment of different models of case coordination before discharge and in the home setting, identification of the most appropriate coordinators, and the knowledge and skills required to enact the role in a way that best serves patients and families.

CONCLUSIONS

Home care for respiratory patients in the United States includes a complex array of services delivered in an uncontrolled setting in which patients and families are integral members of the health care team. Chest physicians, pulmonologists, generalists, and nurse specialists providing care need clinical knowledge and skill, a patient-centered perspective, and understanding of the cost and reimbursement structures for home care services. Complexity, lack of provider control, and chronicity of patient health problems all likely contribute to the difficulty in demonstrating improved patient outcomes resulting from home care. Future efforts at identifying effectiveness of respiratory home care will be most successful if they take these factors into account.

Home health agencies, nurses, chest physicians, pulmonologists, and other providers, and their advocates, can contribute to a societal discussion on reframing the goals of home care to include those that are both desirable and achievable. Future goals may include patient and family satisfaction, reduction of complications resulting from hospitalization, maintaining an acceptable quality of life, and enabling a comfortable and dignified death. Cost reduction could become a collateral benefit, instead of a primary goal, for home health care.

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