The Acute Decompensated **Heart Failure National Registry** (ADHERE™): Opportunities to Improve Care of Patients **Hospitalized With Acute** Decompensated Heart Failure

Gregg C. Fonarow, MD,* for the ADHERE™ Scientific Advisory Committee[†]

Heart failure is a leading cause of hospitalization for adults in the United States. Patients hospitalized with acute decompensated heart failure (ADHF) face a substantial risk of in-hospital mortality and rehospitalization. Despite the large number of patients hospitalized and this substantial risk, data on these patients have been limited and there has been little effort to improve the quality of care for patients hospitalized with ADHF. The Acute Decompensated HEart Failure National REgistry (ADHERE TM) was designed to bridge this gap in knowledge and care by prospectively studying characteristics, management, and outcomes in a broad sample of patients hospitalized with ADHF. Participating community and university hospitals identified patients with a primary or secondary discharge diagnosis of heart failure and collected medical history, management, treatments, and health outcomes via secure web browser technology. As of July 2003, 65,180 patients have been enrolled from 263 hospitals. Initial data have provided important insights into the clinical characteristics, patterns of care, and outcomes of these patients. ADHERE documents significant delays in diagnosis and initiation of ADHF therapies as well as substantial under-use of evidence-based, guideline-recommended chronic heart failure therapies at hospital discharge. As such, there are substantial opportunities to improve the quality of care for ADHF patients in the nation's hospitals. The ADHERE Hospital Toolkit has been designed to provide hospital teams with effective proactive instruments to improve the quality of care for patients with ADHF. If successfully implemented, the improvements in shortand long-term clinical outcomes for ADHF patients are expected to be substantial. [Rev Cardiovasc Med. 2003;4(suppl 7):S21-S30]

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eart failure is a chronic progressive disease accounting for substantial morbidity and mortality.1 There are 5 million Americans with chronic heart failure and these patients are at significant risk for decompensa-

^{*}Ahmanson-UCLA Cardiomyopathy Center, Division of Cardiology, The David Geffen School of Medicine at UCLA, Los Angeles, CA

[†]The ADHERE™ Scientific Advisory Committee members are listed at the end of this article.

tion and resulting hospitalization.2 Hospitalizations for acute decompensated heart failure (ADHF) in the United States have increased from 377,000 in 1979 to 999,000 in 2000.2 ADHF has emerged as a major public health problem and heart

hospitals from across the United States including large and small, academic and community sites were invited to participate. Individual sites require hospital and Institutional Review Board approval for their data to be entered into the Registry. As of

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failure has become the leading cause of hospitalization in persons over 65 years of age.1 The major expenditure for heart failure care is on hospitalizations; an estimated 12.7 billion dollars will be spent on the inpatient management of ADHF this year.2 Patients hospitalized with ADHF face a substantial risk of readmission, as high as 50% by 6 months after discharge.3 High readmission rates for heart failure highlight potential deficiencies in care and opportunities to implement and meaningful interventions patient education.

ADHERE

The characteristics, management, and outcomes of patients hospitalized with ADHF are poorly defined despite the high prevalence and public health importance of this syndrome.1 Several registries in outpatient settings for heart failure have been implemented, however, similar studies have not been undertaken in patients hospitalized with ADHF.4,5 The Acute Decompensated HEart Failure National REgistry (ADHERETM) was developed as a large, observational, national, multicenter study of characteristics, patterns of care, and outcomes of patients hospitalized with ADHF in order to better define and improve care of these patients.6 Representative

July 2003, 263 sites have enrolled patients. Patients are eligible for enrollment if admitted to the acute care hospital with a discharge diagnosis of heart failure. As an observational database, there is no preselection of patients or predetermined treatment in the Registry. ADHERE documents current practice and treatment patterns in hospitals across the United States. The large database also allows subgroup analysis, which typical clinical trials cannot accurately assess due to limited study size and population. The subgroup analyses permit assessment outcomes based on differences in geographical regions, types of hospitals, demographic characteristics or clinical patient features, and patients who received specific types of treatments or procedures.

Information on patient characteristics, treatments, and outcomes from initial presentation, throughout the hospitalization, and at discharge are collected by chart review. The data are then entered into the ADHERE database, using a web-based electronic data capture (EDC) system via an electronic case report form. Because personal identifiers (such as social security numbers) are not entered into the database, it is possible that individual patients may be enrolled in the registry more than once, if they are readmitted to an

ADHERE site. Timing of therapy is captured, as well as clinical status at discharge and the occurrence of significant morbidities. Information related to the 4 specific core performance measures mandated by the Joint Commission for Accreditation of Healthcare Organization (JCAHO) is collected.

Detailed benchmark reports are provided quarterly to all hospitals that participate in ADHERE, to facilitate quality improvement efforts. The reports present key data regarding patient characteristics, treatments, quality measures, and clinical outcomes from the participant's own institution for each quarter. Changes over time in patient characteristics, treatments, and clinical outcomes can be monitored. The individual hospital data is also compared to aggregate national data, data from other academic or community hospitals, and data sorted by broad geographical region, ie, Northeast, South, Midwest, West, and Mid-Atlantic.

Characteristics of Patients Hospitalized With Heart Failure

The first patient was enrolled in the ADHERE Registry in October 2001. As of July 2003, 65,180 patients have been enrolled through 263 participating academic and community hospitals. Data reported here include enrollments from April 1, 2002 through March 31, 2003 as reported in the ADHERE 1st Quarter 2003 National Benchmark Report.⁷

Demographic characteristics and medical history of Registry patients (n = 52,047) are presented in Table 1. The median age of patients was 75.2 years and more than half (52%) were female. Most patients were either white (73%) or black (19%), and most (78%) were covered by Medicare or Medicaid. The majority of Registry patients (75%) have a history of heart failure, and 23% of patients had been hospitalized for this diagnosis within the prior 6 months. Three percent of patients had 3 or more heart failure-related hospitalizations in that period.

The combination of medical history, hospitalization history, and clinical presentation reveals that this population of heart failure patients is quite ill.7 Seventy-two percent of patients had a history of hypertension and 50% of Registry patients had a systolic blood pressure greater than 140 mm Hg at hospital admission. Several other conditions were common in the medical history of these patients. These include coronary artery disease (58%), diabetes (44%), atrial fibrillation (31%), and obstructive pulmonary disease or asthma (31%). Moreover, renal dysfunction is emerging as a critical feature of patients hospitalized with heart failure, as 29% of Registry patients have a history of chronic renal insufficiency. Upon hospitalization, 20% have a serum creatinine greater than 2 mg/dL and 14% of Registry patients have an admitting diagnosis of renal insufficiency or failure (Tables 1 and 2). Upon admission, most patients presented with dyspnea (89%; dyspnea at rest in 36%), rales (67%), or peripheral edema (66%).7

Treatment of Patients Hospitalized With Heart Failure

The emergency department (ED) is clearly the treatment location to which most heart failure patients initially present. In the ADHERE program, 77% of all patients who get admitted for an acute episode of congestive heart failure initially present to the ED, while 21% go directly to an inpatient unit. An additional 2% are admitted to an inpatient unit on observation and

Table 1 Demographic Characteristics and Medical History of ADHERE Enrollees		
Discharged Betwe	en April 1, 2002 and March 31, 200	03 (n = 52,047)
Median Age (y)		75.2
Gender	Male	48%
<u> </u>	Female	52%
Race/Ethnicity	Asian	< 1%
	Black	19%
	Hispanic	2%
	White	73%
	Other	1%
Primary Insurance	Medicare	72%
	Medicaid	6%
	Commercial FFS/PPO	8%
	HMO	8%
	None/Self-pay	3%
	VA/Champus	1%
	Other	2%
	In Experimental Trial	1%
Heart Failure History	Prior Heart Failure	75%
	Prehospital LVEF Assessed	44% (n = 22,857)
	< 40% or Moderate/Severe Impairment	59%
	Prior Cardiac Transplant	< 1
	Listed for Cardiac Transplant	1%
Hospitalized for Heart Fail	lure in Past 6 Months	
	None	9%
	One Hospitalization	15%
	Two Hospitalizations	5%
	Three or More Hospitalizations	3%
	No Mention of Hospitalizations	44%
	Not Applicable, No History of HF	25%
NYHA Class Assessed		7% (n = 3,849)
	Baseline NYHA CLASS II	21%
	Baseline NYHA CLASS III	42%
	Baseline NYHA CLASS IV	34%
Medical History	Coronary Artery Disease	58%
	Myocardial Infarction	32%
	Hypertension	72%
	Hyperlipidemia/Dyslipidemia	34%
	Cardiac Valvular Disease	23%
	Stroke or TIA	17%
	Atrial Fibrillation	31%
	Ventricular Tachycardia	8% 1%
	Ventricular Fibrillation Pacemaker or ICD	20%
	LVAD	< 1%
	IABP	< 1%
	Peripheral Vascular Disease	18%
	Chronic Renal Insufficiency	29%
	Chronic Dialysis	5%
	Diabetes	44%
	Insulin-Dependent Diabetes	18%
	Liver Disease	3%
	Thyroid Disease	17%
	COPD or Asthma	31%
	Active Malignancy	5%
	Ever Smoked	48%
	Current Smoker	13%
CD = implantable cardioverter	defibrillator, LVAD = left ventricular assist device, IAE	
COPD = chronic obstructive pr		and the second

less than 1% of patients are seen in an observation unit as their first point of care. Once hospitalized, only 14% patients are admitted directly to an intensive care unit (ICU) setting. The vast majority of hospital care for heart failure is provided in telemetry (66%) and step-down units (7%).⁷

There are striking differences in the timing of the initiation of treatment between EDs and inpatient units. When diuretics are started in the ED, the mean door-to-needle time is 2 hours. However, the mean time-to-initiation of treatment is 7.7 hours for all patients (ED and inpatient), demonstrating that door-toneedle time is prolonged in the inpatient setting. In either case, there is an opportunity to improve the efficiency of care. Among ADHERE participants, 64% of patients received intravenous (IV) diuretic therapy alone and 27% of all admissions received IV vasoactive therapy. If IV vasoactive therapy is not started until after admission to an inpatient unit, the door-to-needle time is more than 23 hours, whereas, if started in the ED, the time-to-treatment is 2 hours. When IV vasoactive therapy is initiated, the duration of therapy is approximately 3 days.7

The difference in time-to-initiation of treatment in the ED compared to that in inpatient settings has a significant impact on patient outcome. It has previously been reported that the length of hospital stay was 3 full days shorter when patients had vasoactive therapy initiated in the ED compared with initiating vasoactive treatment after admission.8 If early heart failure care and time-to-treatment are to be improved, quality improvement efforts will need to involve the ED. Application of streamlined diagnostic guidelines, initiation of appropriate treatment strategies, and triage

Table 2
Clinical Presentation and Admitting Diagnosis of ADHERE Enrollees
Discharged Between April 1, 2002 and March 31, 2003 (n = 52,047)

Any Dyspnea	89%	
Dyspnea at Rest	36%	
Fatigue	33%	
Rales	67%	
Peripheral Edema	66%	
NYHA Class Assessed	10% (n = 5,003)	
NYHA Class II	9%	
NYHA Class III	40%	
NYHA Class IV	50%	
Systolic Blood Pressure Assessed	100% (n = 51,812)	
SBP < 90 mm Hg	3%	
SBP 90 to 140 mm Hg	47%	
SBP > 140 mm Hg	50%	
Initial ECG Assessed	94% (n = 49,091)	
Atrial Fibrillation	20%	
Other Abnormal Rhythm	26%	
Initial CXR Assessed	90% (n = 47,072)	
Pulmonary Congestion	76%	
Initial Serum Sodium Assessed	98% (n = 51,109)	
Sodium < 130 mmol/L	5%	
Mean Serum Sodium (mmol/L)	138	
Initial Serum Creatinine Assessed	98% (n = 51,134)	
Creatinine > 2.0 mg/dL	20%	
Initial BNP Assessed	30% (n = 15,850)	
Median BNP (pcg/mL)	839	
LVEF Assessed	56% (n = 29,371)	
< 40% or Moderate/Severe Impairment	47%	
Admitting Diagnoses		
Heart Failure	93%	
MI or Unstable Angina	4%	
Arrhythmia	3%	
Respiratory Infection	5%	
COPD/Asthma	12%	
Renal Insufficiency or Failure	14%	

NYHA = New York Heart Association, ECG = electrocardiogram, CXR = chest radiograph, BNP = B-type natriuretic peptide, LVEF = left ventricular ejection fraction, COPD = chronic obstructive pulmonary disease.

based on reasonable prognostic indicators should be aggressively pursued in this setting. ADHERE data show that during the course of hospitalization, there is some improvement in the utilization of key chronic heart failure treatment regimens prior to discharge. Pre-hospitalization use of angiotensin-converting (ACE) inhibitor (41%) or ß-blocker (47%) increased to 55% and 58%, respectively, upon discharge from the hospital. Confining the analysis to the 12,754 patients with documented left ventricular ejection fraction (LVEF) less than 0.40, ß-blockers were newly started in 27% of patients during the hospitalization, ACE inhibitors in 28%, and angiotensin-receptor blockers in 4%.7

In ADHF patients with documented measurement of left ventricular function, fully 51% of patients had preserved systolic function (LVEF \geq 0.40). These patients were older (76.3 years), more likely to be female (62%), and more likely to have a history of hypertension (77%) or diabetes (45%) than patients with reduced systolic function.7 Clinical trials often exclude ADHF patients with these conditions. However, the high prevalence of preserved systolic function and the even higher prevalence of hypertension in this cross section of typical ADHF hospital admissions demonstrates that much more focus is needed regarding optimal treatment strategies and guidelines for this common patient.

Clinical Outcomes of Patients **Hospitalized With Heart Failure**

Hospital Course

and Symptomatic Status

Twenty percent of patients received care in the ICU or cardiac care unit and the median length of stay was 2.5 days. The median length of stay in the hospital for all hospitalized patients was 4.3 days. Upon discharge, 44% of patients were asymptomatic; 30% were improved but still symptomatic. Less than 1% was worse or had no change, and 11% had no mention of status at discharge.7

Hospital Discharge and **Mortality Outcomes**

Patient outcomes varied tremendously. Sixty-three percent of patients were discharged home and an additional 12% went home with additional care. Other patients were transferred to other hospitals (2%) to outpatient care (1%) or had unknown status (2%), and 16% went to hospice care. The in-hospital mortality rate was 4%.7 This mortality rate is well above that reported in heart failure clinical trials. In OPTIME CHF (Outcomes of a Prospective Trial of Intravenous improve the outcome of ADHF should be identified and implemented in a very aggressive pattern to address this striking risk of death observed in ADHERE.

Performance Measures in Hospitalized **Heart Failure Patients**

Registry data on the Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) Quality of Care Indicators show that only 30% of patients were receiving patient instructions on diet, weight monitoring, activity level, worsening symptoms, follow-up appointments, and medication management at discharge (JCAHO indicator

The use of nesiritide or other vasodilators is associated with better outcomes than the use of inotropic agents, even after extensive adjustments for co-variates and treatment propensity matching.

Milrinone for Exacerbations of Chronic Heart Failure), the inpatient mortality rate was 2.3% in the standard care group.8

Preliminary analysis of ADHERE suggests that outcomes such as mortality may vary by treatment. The use of nesiritide or other vasodilators is associated with better outcomes than the use of inotropic agents, even after extensive adjustments for co-variates and treatment propensity matching.10 Ongoing analysis of the database will build predictive models to help better understand the clinical factors that predispose to death and complications, and determine length of stay.

Outcome data on patients enrolled in the ADHERE database demonstrate that admission for heart failure is a high-risk event for patients, with death or significant adverse consequences a common occurrence. Treatment strategies that HF-1). Assessment of left ventricular systolic function (HF-2) was either documented or scheduled in 83% of patients. Only 73% of eligible patients with left ventricular systolic dysfunction received an ACE inhibitor at discharge (HF-3). Counseling on smoking cessation for current smokers (HF-4) was given to only 40% of eligible patients (Figure 1). These data suggest that there are substantial opportunities to improve the quality of care for patients hospitalized with ADHF.

The combined findings of ADHERE regarding compliance with JCAHO heart failure care indicators, in-hospital mortality rate, significant morbidity, less than optimal treatment patterns and the impact of early, appropriate treatment on outcomes, demonstrates the need for quality care improvements and interventions. With prospective

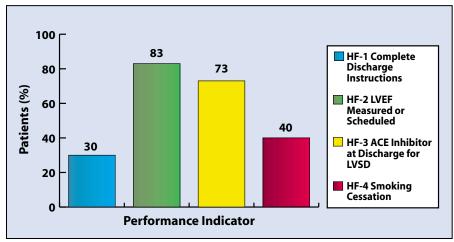


Figure 1. JCAHO Quality of Care Indicators for Heart Failure. Heart Failure-1: Discharge instructions documented Heart Failure-2: Assessment of left ventricular function documented or scheduled; Heart Failure-3: ACE inhibitor at discharge for left ventricular dysfunction and no recorded clinical contraindication: Heart Failure-4: Smoking cessation counseling for current smokers. These data represent all enrolled discharges from April 1, 2002 to March 31, 2003 with a principal diagnosis of heart failure (based on ADHERE Benchmark 2003 first quarter national data).

ongoing data collection in ADHERE, participating hospitals are able to evaluate and closely study any effects of interventions to improve short- and long-term care and outcomes. Studies in other areas of cardiovascular care have demonstrated that this strategy improves the delivery of care and is very likely to have a beneficial effect on the outcomes of patients admitted with ADHF.11,12 The ADHERE database can also provide information about trends and changes in care and outcomes over time, throughout geographical regions, and even within a single hospital. Determining actual practice patterns can help identify gaps in treatment, resulting in the development of improved treatment strategies and standards of care. This will ultimately help improve treatment, management, and clinical outcomes in ADHF.

ADHERE Hospital Toolkit Rationale

It has been demonstrated that hospital-based systems improve quality of care and clinical outcomes for

patients hospitalized with coronary artery disease and heart failure.11-12 Hospital-based heart failure management programs designed to improve the use of ACE inhibitors through in-hospital initiation have resulted in higher utilization rates, reduced rates of rehospitalization, and reduced mortality.13,14 An analysis was performed in more than 19,000 heart failure patients in 10 institutions with discharge medica-

tion programs. It resulted in an increase in the administration of ACE inhibitors from 65% to 95% and a decrease in readmission and death rates at 1 year from 46.5% to 38.4% (*P* < .001), and from 22.7% to 17.8% (P <.0001), respectively.¹² These studies strongly indicate that implementing comprehensive heart failure management programs with lifesaving medications prescribed before hospital discharge can be instrumental in significantly increasing the use of evidence-based therapy for heart failure and in reducing hospital readmission and mortality.

ADHERE data show that there are a large number of eligible ADHF patients that are not receiving evidence-based, guideline-recommended diagnostic tests, patient education, and medications. Structured programs can help physicians, nurses, and hospitals address deficiencies in ADHF care. Hospitals are well suited to initiate and maintain such programs because of their ability to provide a variety of resources. The ADHERE program seeks to improve the quality of care of patients hospitalized with heart failure. The ADHERE Hospital Toolkit program

Table 3 **ADHERE Hospital Toolkit**

- Emergency medical center diagnosis and treatment algorithms
- · Critical pathway
- Preprinted order sets (emergency medical center and hospital admission)
- Admission checklist
- Discharge checklist
- · Patient education materials
- Patient medication fact sheets
- · Wall charts
- Pocket cards
- Patient compliance contract

aims to foster rapid diagnosis and treatment of ADHF, accelerate adoption of evidence-based, guidelinerecommended therapies in eligible patients without contraindications, and, as a result, improves short- and long-term clinical outcomes.

ADHERE Heart Failure Toolkit Instruments

As part of an enhanced treatment and discharge plan, the ADHERE Hospital Toolkit provides evidencebased best practices algorithms, critical pathways, standardized orders, discharge checklists, pocket cards, chart stickers, and a variety of other elements to assist hospitals in improving ADHF management (Figures 2 and 3). These aids are provided in an electronic format for the hospitals to modify at their choosing. The ADHERE Toolkit also provides algorithms and dosing guides to facilitate the initiation and titration of guideline-recommended heart failure therapy. The materials are based on the current American College of Cardiology/American Heart Association (ACC/AHA) heart failure guidelines,1 recent clinical trials, and the collective expertise of the ADHERE Scientific Advisory Committee members. These tools are designed to help health care providers rapidly diagnose ADHF and provide therapies that will achieve compensation efficiently and costeffectively. The ADHERE Toolkit also provides instruments for health care providers to identify and initiate guideline-recommended treatments in appropriate heart failure patients without contraindications.

The tools also aim to facilitate physician and nursing identification of patients with contraindications or who are not yet clinically stabilized for treatment. Therapies that are under Class III in the ACC/AHA heart failure clinical practice guide-

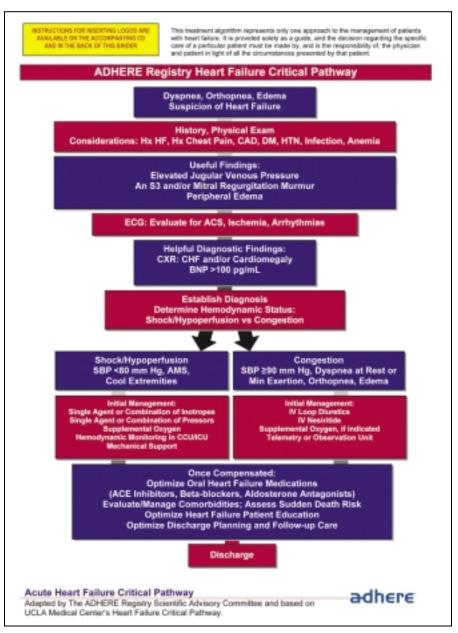


Figure 2. ADHERE Hospital Toolkit Heart Failure Critical Pathway Treatment Algorithm

lines (conditions for which there is evidence and/or general agreement that a proce-dure/therapy is not useful/effective and in some cases may be harmful) are targeted for discontinuation (type 1 anti-arrhythmic agents, nonsteroidal anti-inflammatory drugs (NSAIDs), and calciumchannel blockers), unless the potential benefits are viewed to outweigh the documented risks.1 The tools also provide guidance on identifying and managing factors that may exacerbate heart failure, major comorbidities, and concomitant risk factors (sudden death risk, lipids, diabetes, chronic obstructive lung disease, anemia, and depression).

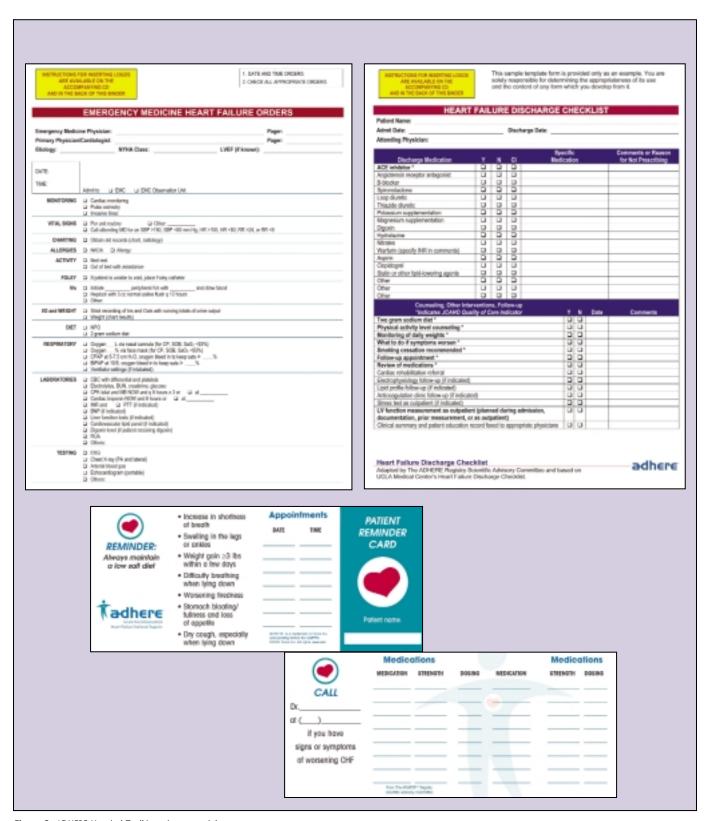


Figure 3. ADHERE Hospital Toolkit patient materials.

The critical pathways also aim to enhance provision of patient education, assessment of social support, discharge planning, follow-up, and outpatient monitoring.

The ADHERE Toolkit contains a comprehensive spectrum of patient education materials and resources to encourage patients to become actively involved in their heart failure management process. There are patient education materials on relevant medical topics and fact sheets on medications that may be used in the patient's treatment. There is a template for a patient compliance contract. There is a patient pocket card that can be used to list all medications, follow-up appointments, and the warning signs of worsened heart failure. The patient educational materials are available to the hospital teams in printed version or modifiable electronic versions by CD.

Hospitals are encouraged to create collaborative teams to review ADHERE data as well as design and implement plans of action to implement the ADHERE Hospital Toolkit and improve care. It is recommended that these hospital teams include cardiologists; hospitalists; primary care physicians; emergency medicine physicians; emergency medicine, cardiac and general medicine nursing; pharmacists, nutritionists,

The ADHERE™ Registry Scientific Advisory Committee

William T. Abraham, MD, FACP, FACC, The Ohio State University Heart Center, Columbus, OH

Kirkwood F. Adams, Jr., MD, University of North Carolina, Chapel Hill, NC Robert L. Berkowitz, MD, PhD, Hackensack University Hospital, Hackensack, NJ Maria Rosa Costanzo, MD, Midwest Heart Specialists, Naperville, IL Teresa De Marco, MD, University of California, San Francisco, CA Charles L. Emerman, MD, The Cleveland Clinic, Cleveland, OH Gregg C. Fonarow, MD, Ahmanson-UCLA Cardiomyopathy Center,

Marie Galvao, MSN, ANP-C, Montefiore Medical Center, Bronx, NY J. Thomas Heywood, MD, FACC, Loma Linda University Medical Center, Loma Linda, CA

Thierry H. LeJemtel, MD, Albert Einstein Hospital, Bronx, NY Lynne Warner Stevenson, MD, Brigham and Women's Hospital, Boston, MA Clyde W. Yancy, MD, FACC, University of Texas, Southwestern Medical Center Medical Center, Dallas, TX

medical social workers, physical therapists; case managers; hospital administration; and other health care personnel. Interactive educational programs, which highlight data on heart failure treatment gaps, evidence-based care, and hospital best practices, are provided on an ongoing basis. These take the form of teleconferences, webcasts, national and regional ADHERE investigator meetings, and newsletters. The characteristics of hospitals that succeed with improving treatment rates over time are well

Los Angeles, CA

described, and ADHERE hospitals are encouraged to adopt strategies that have proven effective in improving cardiovascular care.15 The impact of the ADHERE Hospital Toolkit on improving treatment will be tracked over time and this data will be used to guide future versions of the tool kit and other strategies to improve care of patients hospitalized with heart failure.

Conclusions

As the largest registry of its type, ADHERE is providing premier data

Main Points

- If early heart failure care and time-to-treatment are to be improved, quality improvement efforts will need to involve the ED.
- The Acute Decompensated Heart Failure National Registry, or ADHERE™, was developed as a large, observational, national, multicenter study of characteristics, patterns of care, and outcomes of patients hospitalized with ADHF, in order to better define and improve care of these patients.
- Starting diuretics and vasoactive therapy in the emergency department appears to decrease the time-to-treatment.
- These studies strongly indicate that implementing comprehensive heart failure management programs with lifesaving medications prescribed before hospital discharge can be instrumental in significantly increasing the use of evidence-based therapy for heart failure and in reducing hospital readmission and mortality.
- The combined findings of ADHERE demonstrate the need for quality care improvements and interventions.

on clinical and demographic characteristics of patients, heart failure management patterns, and patient outcomes in a nationally representative sample of hospitalized ADHF patients. These data indicate that there are substantial, multifaceted opportunities to improve the efficiency and quality of care for patients hospitalized with ADHF. The ADHERE Hospital Toolkit has been designed to proactively help healthcare providers and hospitals rapidly improve care for these patients. Continued participation in the Registry allows hospitals to assess changes in care and outcomes over time, in order to facilitate their performance improvement efforts. By helping to identify gaps in care as well as the best practices for patients with this syndrome, ADHERE is setting the stage for quality improvement efforts for heart failure at the national level, and ultimately holds promise for improving public health.

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