A Taxonomy for Disease Management

A Scientific Statement From the American Heart Association

Disease Management Taxonomy Writing Group

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Background—Disease management has shown great promise as a means of reorganizing chronic care and optimizing patient outcomes. Nevertheless, disease management programs are widely heterogeneous and lack a shared definition of disease management, which limits our ability to compare and evaluate different programs. To address this problem, the American Heart Association’s Disease Management Taxonomy Writing Group developed a system of classification that can be used both to categorize and compare disease management programs and to inform efforts to identify specific factors associated with effectiveness.

Methods—The AHA Writing Group began with a conceptual model of disease management and its components and subsequently validated this model over a wide range of disease management programs. A systematic MEDLINE search was performed on the terms heart failure, diabetes, and depression, together with disease management, case management, and care management. The search encompassed articles published in English between 1987 and 2005. We then selected studies that incorporated (1) interventions designed to improve outcomes and/or reduce medical resource utilization in patients with heart failure, diabetes, or depression and (2) clearly defined protocols with at least 2 prespecified components traditionally associated with disease management. We analyzed the study protocols and used qualitative research methods to develop a disease management taxonomy with our conceptual model as the organizing framework.

Results—The final taxonomy includes the following 8 domains: (1) Patient population is characterized by risk status, demographic profile, and level of comorbidity. (2) Intervention recipient describes the primary targets of disease management intervention and includes patients and caregivers, physicians and allied healthcare providers, and healthcare delivery systems. (3) Intervention content delineates individual components, such as patient education, medication management, peer support, or some form of postacute care, that are included in disease management. (4) Delivery personnel describes the network of healthcare providers involved in the delivery of disease management interventions, including nurses, case managers, physicians, pharmacists, case workers, dietitians, physical therapists, psychologists, and information systems specialists. (5) Method of communication identifies a broad range of disease management delivery systems that may include in-person visitation, audiovisual information packets, and some form of electronic or telecommunication technology. (6) Intensity and complexity distinguish between the frequency and duration of exposure, as well as the mix of program components, with respect to the target for disease management. (7) Environment defines the context in which disease management interventions are typically delivered and includes inpatient or hospital-affiliated outpatient programs, community or home-based programs, or some combination of these factors. (8) Clinical outcomes include traditional, frequently assessed primary and secondary outcomes, as well as patient-centered measures, such as adherence to medication, self-management, and caregiver burden.

Conclusions—This statement presents a taxonomy for disease management that describes critical program attributes and allows for comparisons across interventions. Routine application of the taxonomy may facilitate better comparisons of...
structure, process, and outcome measures across a range of disease management programs and should promote uniformity in the design and conduct of studies that seek to validate disease management strategies. (Circulation. 2006; 114:1432-1445.)

Key Words: AHA Scientific Statements • disease management • chronic disease • delivery of health care • classification • heart failure

The past decade has witnessed increasing prevalence of chronic disease in the United States. This trend has contributed to skyrocketing healthcare costs and highlighted the fragmented nature of care available to chronically ill patients. Consequently, many public policy makers and organizations have embraced disease management as a means of reorganizing medical treatment for chronic illness, shifting the emphasis toward an integrated, patient-centered approach to care. The purported benefits of disease management include improved health outcomes, greater patient satisfaction, better quality of life, and reduced healthcare costs.

Despite the promise offered by disease management programs, questions remain about their potential for widespread application. Randomized trials of disease management have demonstrated improved outcomes for conditions such as heart failure, diabetes mellitus, and chronic kidney disease, but these studies generally have been conducted at single sites, and it is not known how successfully their results can be generalized to larger patient populations. In addition, many disease management programs are multidimensional, and the essential program elements that are associated with efficacy have yet to be established. These challenges are further complicated by a lack of standardization: The term disease management has entered into common usage without a shared, specific understanding of its meaning. Instead, multiple definitions of disease management and a variety of related models exist. Although disease management programs generally share core elements such as risk management and coordination of care, individual program components are highly variable. This variability presents difficulties in comparing and contrasting models, programs, outcomes, and effectiveness. The heterogeneity also impedes the development of policies that will provide incentives for the provision of disease management.

In response to these challenges, the American Heart Association (AHA) formed an interdisciplinary Disease Management Taxonomy Writing Group to develop a classification system for disease management. The work of the AHA Writing Group builds on the previous efforts of the AHA’s Expert Panel on Disease Management to establish core principles for the application of disease management to cardiovascular disease and stroke (Table 1). The taxonomy outlined in the present statement provides a conceptual framework that can be used both to compare the diverse range of disease management programs and to inform efforts to identify specific factors associated with effectiveness.

Background

The challenge in identifying a precise definition for disease management lies partially in its complex origins and historical evolution. Although the term disease management was first coined in the early 1990s, many of its components were used informally throughout much of the history of medical practice. Common attributes of disease management, such as formal and informal best practices and multidisciplinary care teams, had long been used to identify and treat patients. However, these techniques were inconsistently applied. In addition, throughout most of the 20th century in the United States, disease management components were implemented in a healthcare system characterized by fragmentation and poorly aligned reimbursement priorities. The shift toward a model of care organized around the principles of disease management, with an emphasis on coordinated care, evidence-based practice, and outcomes evaluation, has been a relatively recent phenomenon.

Managed care organizations were among the first to adopt disease management concepts, in part because of their structure for sharing economic risk. Because hospital costs represent a significant portion of patients’ overall healthcare resource utilization, disease management strategies to reduce hospitalization rates and length of stay offered attractive financial incentives to these organizations.

Other early disease management initiatives included pharmaceutical company programs developed in response to concerns

TABLE 1. Principles and Recommendations From the AHA’s Expert Panel on Disease Management

1. The main goal of disease management should be to improve the quality of care and patient outcomes.
2. Scientifically derived, peer-reviewed guidelines should be the basis of all disease management programs. These guidelines should be evidence based and consensus driven.
3. Disease management programs should help increase adherence to treatment plans based on the best available evidence.
4. Disease management programs should include consensus-driven performance measures.
5. All disease management efforts must include ongoing and scientifically based evaluations, including clinical outcomes.
6. Disease management programs should exist within an integrated and comprehensive system of care in which the patient–provider relationship is central.
7. To ensure optimal patient outcomes, disease management programs should address the complexities of medical comorbidities.
8. Disease management programs should be developed for all populations and should particularly address members of underserved or vulnerable populations.
9. Organizations involved in disease management should scrupulously address potential conflicts of interest.
that health maintenance organizations (HMOs) might decrease payments for drugs. Pharmaceutical companies began identifying patients with chronic illnesses, determining their level of risk, and offering educational services to promote medication adherence and behavior change. By bundling prescription drugs with these ancillary services, companies sought to add value to their products and to increase the likelihood that they would be included on HMO formularies.

It was not until the mid-1990s that disease management strategies were adopted by the healthcare industry on a wider scale, though still principally as a means of controlling costs. This widespread adoption coincided with a period of significant transition within the US healthcare delivery system: The promise of long-term cost savings offered by HMOs had begun to wane, and consumer dissatisfaction with managed care was high. At the same time, the chronic disease burden continued to drive healthcare spending and utilization rates.

In response to these conditions, disease management emerged in the healthcare marketplace as an attractive new model for controlling costs.

A body of medical literature evaluating disease management also began to emerge in the mid-1990s. In 1995, Rich et al published a landmark article that reported results of a prospective, randomized trial of a nurse-directed, multidisciplinary intervention on the rates of readmission within 90 days of hospital discharge, quality of life, and costs of care for high-risk patients ≥70 years of age who were hospitalized with heart failure. Readmissions for heart failure were reduced by 56%, and the program saved almost $500 for each person enrolled. The study provided strong validation for the concept of disease management and was soon followed by many other trials of disease management interventions. Phillips and colleagues, in a review of this literature, studied 18 trials and found that during a pooled mean observation period of 8 months, the risk of readmission was reduced by 25%.

Once the disease management trend took hold, it spread rapidly. Numerous healthcare companies—including HMOs, pharmaceutical manufacturers, pharmaceutical benefits managers, medical groups and hospitals—organized quickly to meet the demand for comprehensive initiatives that would improve chronic disease care while reducing expenditures. By 1999, some 200 disease management programs were in place for conditions such as congestive heart failure, diabetes, and asthma. These disease-specific programs shared certain common features, including an integrated approach to care, patient education, and the collection of outcomes data. Ultimately, though, the proliferation of disease management programs was characterized by variety rather than uniformity. Market forces encouraged companies to develop proprietary treatment algorithms and unique component packages in an effort to gain a competitive advantage. As a result, private sector disease management developed as a diverse field exhibiting a wide range of programmatic features.

Government interest in disease management also evolved during this period. Motivated in part by private sector developments, in the late 1990s Congress authorized several demonstration projects to evaluate disease management strategies under fee-for-service Medicare (see Table 2). President Clinton’s 1999 Medicare Modernization proposal named disease management as an important new tool for modernizing the Medicare program. As part of the 2003 Medicare Modernization Act, Congress authorized Medicare Health Support, which constitutes the largest randomized evaluation of disease management to date. Under this pilot program, approximately 160,000 Medicare beneficiaries with congestive heart failure and complex diabetes among their chronic conditions will be randomized to either an intervention or a control group; those assigned to the intervention group will be able to accept or decline participation. Eligible beneficiaries will be identified through a population-based approach that uses Medicare claims data. Patients in the intervention group will receive guidance to promote medication adherence, self-management, and access to covered healthcare services. Disease management interventions will be delivered by private healthcare organizations, which must guarantee effective management of comorbidities, reduced healthcare costs, improved quality of care, and improved provider and patient satisfaction. After 2 years, pending successful interim results, this pilot may be expanded nationally.

These initiatives represent a landmark effort to determine whether disease management programs can be effective in improving health and cost outcomes for selected subgroups of chronically ill Medicare beneficiaries. Collectively, the demonstration and pilot projects comprise the largest evaluation of disease management to date, and their outcomes will undoubtedly influence future public and private sector approaches to disease management.

States also have been permitted to develop disease management programs for their primary care case management and fee-for-service Medicaid populations; to date, 28 states have done so. These programs may be designed and operated by health plans or state Medicaid agencies, or they may be contracted out to disease management organizations. Because of this flexibility, state disease management programs vary widely in their scope and impact. Many are still at an early stage of development, so effectiveness cannot be evaluated.

### Disease Management Definitions and Related Models

Numerous definitions of disease management exist. They have evolved over time in response to the changing conditions...
outlined above, and they feature varying levels of specificity, ranging from the highly conceptual to the highly detailed. A sample of published definitions is provided in Tables 3 and 4 to illustrate the diversity of opinion that exists in the field. Each of these definitions shares a common theme—the transition from a traditional system of care, characterized by fragmentation and resource-intensive acute care, to a more integrated model—but their specific points of emphasis differ significantly. Epstein and Sherwood reference risk-based patient identification and outcomes measurement, whereas Zitter discusses organization of care and reimbursement practices. Faxon et al draw attention to quality of care, the use of science-based guidelines, the management of comorbid conditions, and the role of the physician. Given this degree of divergence, it is challenging to identify specific components that truly define a disease management program.

The Disease Management Association of America (DMAA), a nonprofit trade association representing stakeholders in the disease management industry, responded to this problem by publishing a comprehensive definition that has gained widespread acceptance in recent years (Table 4). However, the DMAA definition is not used universally, and many programs that fail to meet its standards are nonetheless described as disease management programs in the medical literature. It is also not clear that this definition can be supported empirically, as the optimal mix of ingredients for a successful disease management program is not yet known. For these reasons, the AHA Writing Group believes that a broad definition is necessary as research continues to define the key components associated with positive outcomes.

The development of alternative care management models, many of which are considered under the overarching heading of disease management, has further complicated the search for a standard definition. Terms such as disease management, disease management programs in the medical literature, and multidisciplinary care have been used interchangeably with disease management, but their unique characteristics are rarely enumerated. Because disease management programs have historically provided narrowly tailored medical solutions focused on one dominant health problem, several of these alternative models have arisen in an attempt to provide a more integrated approach to care, directing attention to the wide range of patient comorbidities. Boundaries between models have increasingly blurred, however, as disease management programs have started to evolve to encompass both comorbid conditions and a greater constellation of outpatient services. Below is a discussion of the most commonly referenced disease management–related models.

**Case management** is characterized by intensive post-discharge monitoring by a case manager (usually a nurse) who connects patients to community-based, nonmedical support services. (It is important to distinguish between case management services provided by nurses or physicians and those provided by nonlicensed personnel. Described both as case managers and care managers, this latter group typically provides functional assistance to patients who are incapacitated and facilitates communication among patients, caregivers, and providers. However, these individuals may not possess the training and expertise necessary to address the complex physiological issues associated with conditions such as heart failure or diabetes.) Case management programs provide individually tailored care plans for patients who are at high risk socially, financially, and medically. These plans frequently include education designed to reduce harmful behaviors and promote beneficial ones. Because many high-risk patients’ problems are social or functional in nature, coordinating access to community resources and social support services—such as respite care, home-delivered meals, and

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**TABLE 3. Selected Disease Management Definitions**

1. “[disease management] refers to the use of an explicit systematic population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes.”

2. “… disease management is generally defined as a comprehensive, integrated approach to care and reimbursement based on a disease’s natural course. The goal of disease management is to address the illness or condition with maximum effectiveness and efficiency regardless of treatment setting(s) or typical reimbursement patterns.”

3. “… disease management typically refers to multidisciplinary efforts to improve the quality and cost-effectiveness of care for selected patients suffering from chronic conditions. These programs involve interventions designed to improve adherence to scientific guidelines and treatment plans.”

**TABLE 4. DMAA Definition of Disease Management**

Disease management is a system of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant. Disease management:

- supports the physician or practitioner/patient relationship and plan of care;
- emphasizes prevention of exacerbations and complications through the use of evidence-based practice guidelines and patient empowerment strategies; and
- evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health.

Disease management components include:

- population identification processes;
- evidence-based practice guidelines;
- collaborative practice models to include physician and support-service providers;
- patient self-management education (may include primary prevention, behavior modification programs, and compliance/surveillance);
- process and outcomes measurement, evaluation, and management; and
- routine reporting/feedback loop (may include communication with patient, physician, health plan, and ancillary providers, and practice profiling).

Full-service disease management programs must include all 6 components. Programs consisting of fewer components are disease management support services.
transportation assistance—is integral to the case management approach. Family and caregivers are often engaged to provide social support, and the majority of patients’ interaction with the healthcare system is through case managers. Some case management programs—particularly those deployed in the Medicaid environment—create a more prominent “gatekeeping” role for the primary care provider. Traditionally, a physician, this individual is responsible for approving referrals and other non-primary-care service utilization in an effort to contain costs. Primary care case management usually operates as a blended fee-for-service/capitation model: All medical services are paid on a fee-for-service basis, but the primary care provider also receives an additional per capita management payment to cover administrative expenses. Physician case management may also involve nurse case coordinators who assume many of the standard case management duties described above.

**Coordinated care** involves the development and implementation of a therapeutic plan designed to integrate the efforts of medical and social service providers. Care coordination programs may designate a specific individual to manage provider collaboration, similar to the gatekeeping case management role discussed above. Traditionally, coordinated care initiatives have targeted the healthcare system in an attempt to reduce inappropriate utilization of resources, rather than explicitly aiming to improve health outcomes.

**Multidisciplinary care** mirrors the holistic approach of case management by adapting treatment plans to the medical, psychosocial, and financial needs of each patient. It differs, however, by involving a greater range of medical and social support personnel. Multidisciplinary disease management typically draws on the expertise of physicians (including the primary care provider), nurses, pharmacists, dietitians, social workers, and others to facilitate the transition from inpatient acute care to long-term, outpatient management of chronic illness. Some multidisciplinary disease management programs have incorporated a “health coaching” approach, in which health professionals promote patient empowerment to achieve behavior modification and treatment compliance. Other multidisciplinary programs have also sought to improve patient access to home health care, hospice care, and palliative care.

The **chronic care model (CCM)** is the most comprehensive of the disease management–related models included here. Originally developed by Wagner et al., the CCM is founded on an understanding and appreciation of the overlapping domains in which health care occurs. These domains include (1) the entire community, (2) the healthcare system, and (3) the provider organization. The CCM further identifies 6 essential elements within these domains that are necessary to ensure optimal chronic care: (1) community resources and policies, (2) healthcare organization, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems. These elements are intended to provide a practical guide for restructuring the management of chronic care, incorporating sufficient flexibility to allow customization for different treatment settings. In contrast to models such as case management or multidisciplinary care, the CCM does not focus on the roles of specific personnel.

Instead, it aims to coordinate activities within primary care systems to improve organizational and health outcomes.

### A Taxonomy for Disease Management

The AHA’s Disease Management Taxonomy Writing Group supports the effort to establish a comprehensive, theory-based definition of disease management. However, the group also recognizes that many, if not the majority, of existing disease management interventions fail to meet the full range of criteria required under the comprehensive approach advocated by DMAA. By adopting an empirical approach based on published reports of disease management, we aimed to develop a taxonomy that could account for this diversity. Consequently, although aspects of the DMAA definition and the AHA taxonomy are in agreement, our different methodologies also produced divergent results. For example, the DMAA requires full-service disease management programs to incorporate routine reporting and feedback, which roughly corresponds with our “Method of Communication” domain. However, the AHA taxonomy expands this category to describe different options for communication format (one on one, in a group setting, or electronically mediated), medium (face to face, by telephone, or through the Internet), and function (symptom monitoring, patient education, or pharmacological management). Moreover, no evidence suggests that all features of any one definition need be satisfied for the intervention to be effective. Among the studies reviewed for the present statement, positive outcomes were associated with simple, single-intervention designs as well as with highly complex programs. Thus, the need remains for a broad-based taxonomy that can adequately classify all types of disease management programs, from the most comprehensive to those that are more selective in what they offer. Such a taxonomy would facilitate the description and comparison of different programs.

The taxonomy that follows is designed to meet this need through both descriptive and prescriptive analysis. It is based on a conceptual model developed by the AHA Writing Group that was refined through a review of published reports of disease management strategies for heart failure, depression, and diabetes. A complete listing of these published reports is available as an online Data Supplement. The conditions of heart failure, depression, and diabetes were chosen because of their lengthy history as targets for disease management intervention and because of the relative abundance of published studies evaluating those interventions. Beyond this focus, however, the taxonomy is intended to be applicable to disease management programs across myriad chronic disease states and to both current and future models. The AHA Writing Group strongly encourages researchers and publishers to report the results of disease management trials according to the taxonomic framework described here. Although detailed reporting requirements may vary by study design or disease state, at a minimum, every article on disease management should include information addressing the 8 domains (and respective subdomains) of the taxonomy.

### Methods

The AHA Writing Group began by establishing a conceptual model that categorized common disease management components into categories of increasing specificity. The initial model
consisted of 4 domains, selected because of their broad relevance to disease management programs: target population, intervention design, method of communication, and intensity. This model was then refined through an iterative process of comparison with a wide range of disease management protocols drawn from the academic literature. Published reports of disease management programs were deconstructed, and an inductive analytical approach was used to identify additional categories of program components. After further discussion, we conceptualized these categories into an expanded disease management taxonomy, with our original model of disease management components used as the organizing framework.

Search Strategy
To identify study protocols for evaluation, a MEDLINE literature search was performed on the terms heart failure, diabetes, and depression in tandem with disease management, case management, and care management. The initial search was limited to articles published in English between January 1995 and January 2005. However, further screening of the reference list of each article yielded several additional relevant publications, some of which fell outside of the original date range. The reference screening process was continued until no new articles were identified, resulting in a final date range of December 1987 to April 2005.

Articles were selected according to the following criteria: (1) They described interventions designed to improve outcomes and/or reduce medical resource utilization in patients with heart failure, diabetes, or depression; and (2) they used clearly defined protocols incorporating at least 2 prespecified components traditionally associated with disease management (such as patient education, involvement of nonphysician personnel, or intensive follow-up). Because study outcomes were not formally evaluated or statistically compared, the review was able to accommodate a heterogeneous mix of interventions and study designs. Indeed, these broad inclusion criteria were deliberately established to encourage the assessment of a wide range of interventions to best capture the full spectrum of disease management–related activities.

Taxonomy
On the basis of our conceptual model and subsequent refinement, the Writing Group developed a taxonomy that includes the following 8 domains: (1) patient population, (2) intervention recipient, (3) intervention content, (4) delivery personnel, (5) method of communication, (6) intensity and complexity, (7) environment, and (8) clinical outcomes. Within each of these domains, additional levels of detail, or subdomains, were identified. For example, intervention design can be more precisely specified according to subdomains such as patient education, medication management, and peer support care. A graphic representation of the taxonomic structure is found in the Figure, and the taxonomy is used to compare 2 heart failure disease management programs in Table 5.

Because the taxonomy was refined through comparison with reports from the academic literature, its content and structure reflect the attributes of programs described in those reports. However, the taxonomy was constructed to accommodate future developments in the field. The domains and subdomains outlined below represent a framework for the content that reports of disease management should include, as well as the level of detail with which that content should be described. This framework incorporates sufficient flexibility to accommodate the evolving nature of disease management and novel approaches that may be developed in the future.

1. Patient Population
To classify disease management interventions, or to compare disease management programs, it is critical that their target...
patient populations be clearly defined. Although narrowly
tailed selection criteria may facilitate the conduct of re-
search, this approach fundamentally limits our ability to
understand the impact of disease management in the broader
population of chronically ill patients. The following subdo-
mins should be addressed in a patient population definition.

### Risk Status

The patient populations included in the review differed widely in their levels of risk. In disease management inter-
ventions for heart failure, this included variability in such
important factors as age, degree of left ventricular dysfunc-
tion, and NYHA class. Among diabetes programs, patients
differed in their diabetes type, degree of glycemic control,
and the presence of complications. The impact of disease
management can vary widely depending on the fit between
the intervention and the risk status of the patient population.
High-risk groups—such as older patients, patients with a
history of prior hospitalizations, and patients with significant
comorbidities—may experience fewer hospitalizations in re-
sponse to disease management. Failure to account for the risk
status of the target population can therefore lead to inappro-

### Medical Comorbidities

All studies included in the review identified a primary
condition targeted by the disease management inter-
vention. However, few of the reports explicitly discussed the
management of comorbid conditions in addition to the
primary diagnosis. The remainder either excluded
patients with comorbidities from participation or noted
their presence without taking steps to manage those
conditions. A large proportion of patients with chronic
illness suffer from medical comorbidities, and some of the

greatest challenges in caring for these patients involve the
complex interactions of different disease states. As disease
management evolves to meet the full range of medical
needs experienced by chronically ill patients, programs

### TABLE 5. Comparison of 2 Disease Management Programs

<table>
<thead>
<tr>
<th>Taxonomic Domain</th>
<th>Disease Management Program A&lt;sup&gt;43&lt;/sup&gt;</th>
<th>Disease Management Program B&lt;sup&gt;42&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention recipient</td>
<td>Patients</td>
<td>Patients</td>
</tr>
<tr>
<td>Patient population</td>
<td>Diagnosis of heart failure or cardiomyopathy</td>
<td>Diagnosis of severe heart failure; eligible for elective heart transplantation</td>
</tr>
<tr>
<td></td>
<td>Mean age: 80.3 years</td>
<td>Mean age: 52 years</td>
</tr>
<tr>
<td></td>
<td>NYHA class III or IV</td>
<td>NYHA class III or IV</td>
</tr>
<tr>
<td></td>
<td>Patients were excluded if any of the following applied:</td>
<td>Mean left ventricular ejection fraction: 0.21</td>
</tr>
<tr>
<td></td>
<td>● need for permanent nursing home care,</td>
<td>Mean VO&lt;sub&gt;2max&lt;/sub&gt;: 11.0</td>
</tr>
<tr>
<td></td>
<td>● serious or life-threatening illness, or</td>
<td></td>
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<tr>
<td></td>
<td>● communication problem.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unspecified demographic and psychosocial information was collected.</td>
<td></td>
</tr>
<tr>
<td>Intervention content</td>
<td>Patient meeting with study nurses</td>
<td>Detailed baseline evaluation</td>
</tr>
<tr>
<td></td>
<td>Development of individual patient care plans</td>
<td>Medication therapy optimized for each patient</td>
</tr>
<tr>
<td></td>
<td>Treatment based on established guidelines</td>
<td>Treatment based on established guidelines</td>
</tr>
<tr>
<td></td>
<td>Patient education on weight monitoring, medication adherence,</td>
<td>Patient/caregiver education on diet, exercise, self-monitoring, and</td>
</tr>
<tr>
<td></td>
<td>symptom recognition, and diet</td>
<td>symptom recognition</td>
</tr>
<tr>
<td></td>
<td>Regular updates to patients’ primary care providers or home</td>
<td></td>
</tr>
<tr>
<td></td>
<td>health staff</td>
<td></td>
</tr>
<tr>
<td>Delivery personnel</td>
<td>Specialty-trained research nurses</td>
<td>Heart failure clinical nurse specialist</td>
</tr>
<tr>
<td></td>
<td>Home health nurses (for select patients)</td>
<td>Study cardiologists</td>
</tr>
<tr>
<td></td>
<td>Physicians</td>
<td>Referring physician</td>
</tr>
<tr>
<td>Method of communication</td>
<td>Face to face: individual</td>
<td>Face to face: individual</td>
</tr>
<tr>
<td></td>
<td>Telephone: in person</td>
<td>Face to face: group</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Telephone: in person</td>
</tr>
<tr>
<td>Intensity and complexity</td>
<td>Patients were followed up for 6 months.</td>
<td>Patients were followed up for 6 months.</td>
</tr>
<tr>
<td></td>
<td>Frequency of contact was variable because patients were</td>
<td>Patient contact occurred:</td>
</tr>
<tr>
<td></td>
<td>responsible for initiating contact with study nurses.</td>
<td>● within 3 days of hospital discharge,</td>
</tr>
<tr>
<td></td>
<td>At a minimum, all patients were contacted at baseline, week 1,</td>
<td>● weekly until criteria for clinical stability were met,</td>
</tr>
<tr>
<td></td>
<td>and monthly thereafter.</td>
<td>● 2 to 3 days after any major medication change, and</td>
</tr>
<tr>
<td></td>
<td>Program featured a high level of complexity.</td>
<td>● at routine intervals between weeks 2 and 8.</td>
</tr>
<tr>
<td>Environment</td>
<td>Hospital based, outpatient</td>
<td>Hospital based, outpatient</td>
</tr>
<tr>
<td>Clinical outcomes</td>
<td>Percentage of patients who did not visit the study nurse</td>
<td>Patient functional status</td>
</tr>
<tr>
<td></td>
<td>Change in NYHA class</td>
<td>No. of hospital readmissions</td>
</tr>
<tr>
<td></td>
<td>No. of hospital readmissions</td>
<td>Estimated hospital costs</td>
</tr>
<tr>
<td></td>
<td>If readmitted, length of hospital stay</td>
<td></td>
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</table>

V<sub>2max</sub> indicates peak exercise oxygen consumption.
and interventions may similarly evolve to address comorbidities more comprehensively.

**Nonclinical Characteristics**

In addition to defining the clinical parameters of the target population, researchers must consider other nonclinical characteristics when describing a disease management intervention. A number of studies in the review identified potentially significant patient characteristics such as education level, annual income, literacy, and marriage status. Riegel and LePetri have noted that the specific role played by these factors is unclear; it may vary with the nature of the disease management intervention. Patients with higher levels of education and greater self-efficacy may be more responsive to self-management strategies while exhibiting no difference in their response to medication management. A more systematic attempt to document and report nonclinical characteristics of the target population will improve the comparability of study results and may facilitate elucidation of the specific mechanisms underlying improved outcomes.

2. **Intervention Recipient**

The patient population that is expected to benefit from disease management (see Patient Population above) should be differentiated from the individuals who are targeted by the intervention. In most studies these 2 groups overlapped: Heart failure patients who received education about diet, exercise, and weight monitoring were also intended to receive direct benefit as a result. However, the literature also describes disease management interventions designed to benefit patients indirectly by influencing provider behavior. Under this alternative strategy, healthcare providers receive instruction (often developed from evidence-based guidelines) about optimal care for the target population, are given feedback on the results of care received by their patients, or alter the organization of care processes. In our review, the provider education approach was used less frequently in the heart failure studies reviewed but was common in disease management programs for depression and diabetes.

3. **Intervention Content**

Intervention content is another key domain in describing any disease management program. Disease management interventions range widely from a single educational session to remote electronic monitoring to comprehensive programs involving multidisciplinary care teams. This variety reflects the perspective of those providing the intervention (e.g., physician, nurse, or pharmacist), issues specific to the patient population, and the goals of the funding organization. Specifically, the content of a disease management program led by a clinical pharmacist will probably address pharmacological therapy, whereas that led by a nurse may emphasize patient education to improve self-care. A disease management program for heart failure would likely aim to reduce hospitalization costs, whereas the program for a patient with diabetes might emphasize glucose control. The content of a program funded by a hospital may address ways to shorten hospital stays, but an intervention paid for by an HMO would want to limit readmissions. These different perspectives contribute significantly to the variety found among disease management programs.

Patient education is the cornerstone of all disease management programs, and the majority of those reviewed incorporated patient education on topics such as the consequences of illness in daily life. For heart failure patients, this included recognition of warning signs of deterioration; advice on diet, fluid, and sodium management; and the importance of daily weighing. Diabetic patients received education about weight and caloric intake control, blood glucose self-monitoring, and foot measurement and care. Educational interventions also addressed behavioral strategies to improve patient compliance with prescribed diet, exercise, and medication regimens. A smaller number reinforced educational messages with ancillary materials, such as brochures or videos.

Peer support was one component that was regularly present in disease management programs for depression but has been used less frequently as part of cardiac disease management. In disease management for depression, peer support was provided by trained individuals, linked with study subjects of similar age and sex, who had experienced an episode of major depression. These individuals were expected to make telephone or in-person contact with the patient for at least 6 months; during these encounters, peer supporters were supposed to model and share their successful coping skills, provide emotional support, and encourage self-monitoring and continued medical treatment.

Though less structured than the peer support intervention described above, disease management programs for diabetic patients routinely educated participants in a group setting. Groups ranged in size from 4 to 28 patients, and their educational content was similar to that offered in studies that used one-on-one sessions. Group education sessions were reinforced by encouraging patients to interact between sessions and by follow-up nurse contact.

4. **Delivery Personnel**

The type of delivery personnel is another key domain. Programs with similar patient populations and intervention content may vary substantially in the qualifications of the individuals who deliver the content, which may in turn influence program effectiveness.

The programs reviewed generally emphasized a multidisciplinary approach to care; however, the specific disciplines represented, as well as the number of personnel involved, varied significantly across programs. It has been noted elsewhere that the optimal mix of program delivery personnel is not yet known: Small teams may be as likely to improve outcomes as large ones, and alternative models (involving personnel such as health educators) have yet to be thoroughly explored. The following list therefore includes a range of delivery personnel commonly represented in disease management programs, but we do not claim the list to be exhaustive.

Nurses

Nursing staff were integral to nearly all of the disease management strategies included in the review. Their duties were broad in scope, consisting of patient education, inpatient and outpatient evaluations, and making treatment or patient...
support recommendations to physicians. Among these, the most common theme was reliance on nurse expertise to provide patient education and frequent follow-up to relay clinically relevant findings to the patient’s physician, thereby effecting more intensive management of the disease. In some studies, nurses also made home visits to optimize medication management, identify early signs of deterioration, and intensify medical follow-up as needed.\textsuperscript{65–67}

**Case Managers**
A subset of studies also cast nurses in the role of case manager. The precise duties associated with this title were not always clearly articulated, though it generally connoted a more supervisory role in patient care. Case managers assessed patients in person and via telephone; monitored and participated in education sessions for patients and caregivers; relayed information to patients about symptoms and medication side effects; collected information about medication use, symptoms, and vital signs; discussed patients’ status with treating physicians; and coordinated care with ancillary patient services, such as physical therapy or social work consultations. Some qualified case managers independently managed patients’ medication.

**Physicians**
Physician involvement tended to be greatest during the early stages of disease management intervention. Specialist physicians (cardiologists, psychiatrists, or endocrinologists) routinely conducted an initial consultation with each patient, involving a comprehensive assessment of the patient’s status, with follow-up review as required. This was followed by the establishment of individualized treatment plans, with particular attention to the optimization of medication. Ongoing evaluation of patients’ progress was performed by a combination of different personnel, including specialist physicians, nurses, and primary care physicians. Despite their inclusion in many of the interventions, however, the role of the primary care physician was variable and often ill defined. In some cases, they were encouraged to conduct regular patient monitoring and to modify the treatment plan as needed; in others, they were merely kept apprised of their patients’ status.

**Pharmacists**
A small number of studies\textsuperscript{68,66,68–71} evaluated the addition of a pharmacist to the care team. In these studies, the pharmacist reviewed patient histories and medication regimens and provided recommendations to physicians to optimize drug therapy. The pharmacist also communicated directly with patients, discussing medication changes, emphasizing the importance of adherence, and conducting telephone follow-up.

**Social Workers**
Social workers participated in both heart failure and depression interventions to help coordinate social services. This included assessment of patients’ living arrangements, economic status, cognitive abilities, and existing sources of social support. Social workers also helped connect patients to legal resources, meal delivery services, therapy, and live-in caregivers.\textsuperscript{72} In one study of depression, a psychiatric social worker screened volunteers who had expressed interest in providing structured peer support for subjects.\textsuperscript{73}

**Dietitians**
Multidisciplinary heart failure disease management programs routinely included dietitians who provided individualized dietary assessment and instruction. Dietitians were also a regular feature in diabetes disease management because of the importance of weight and blood glucose control for diabetic patients.

**Physical Therapists**
Patients were offered a physical therapy assessment in both heart failure and diabetes studies, and physical therapists designed personalized exercise programs to improve patients’ strength and endurance.

**Psychologists**
Although many depression disease management studies augmented physician services with nursing support, a smaller number also included psychologists among the members of the care team.\textsuperscript{74,75} Psychologists were not specifically identified in any of the heart failure or diabetes studies reviewed.

**Information Systems Specialists**
A subset of disease management programs used electronic devices or automated telephone messages to deliver content to patients.\textsuperscript{41,76,77,79–81} In addition to monitoring clinical information such as blood pressure, weight, and blood glucose, these programs offered programmed education in areas such as medication adherence and behavior change.

5. **Method of Communication**
The methods used to deliver disease management interventions are increasingly important to consider, particularly as information technology has become a more prominent feature in many disease management programs. In most studies, care providers communicated directly with patients through face-to-face interaction. However, a significant number either replaced or augmented face-to-face contact with a mediated form of communication. Remote electronic monitoring systems were used in a subset of heart failure studies\textsuperscript{41,76,77,79,80} to record measurements of patients’ weight, blood pressure, heart rate, and oxygen saturation. These systems required the installation of electronic equipment in patients’ homes to transmit data to a central location via telephone or the Internet. Telephone monitoring was more common than remote electronic monitoring in heart failure, diabetes, and depression interventions. Disease management interventions that closely monitored symptoms and vital signs also tended to emphasize intensive management of patients’ pharmacological therapy.

Telephone contact also provided an opportunity for care providers to reinforce educational content, offer encouragement, and respond to patient questions. In one study of diabetes, an automated telephone care program was used as the primary method of patient education, with additional telephone reinforcement by a nurse educator.\textsuperscript{81}

Only one study\textsuperscript{82} specified the use of the Internet as a means of transmitting educational information to patients; however, the use of advanced technology is expected to increase.

6. **Intensity and Complexity**
Disease management programs differ both in the intensity with which interventions are delivered and in their structural complexity.
A recent systematic review of disease management interventions for depression found that patient outcomes were improved by complex strategies incorporating clinician education, nurse case management, and greater interaction between primary and secondary care. However, the same review also identified improved outcomes associated with simpler, less expensive interventions such as telephone medication counseling. If a basic program is able to deliver the same benefits as a more costly one, it is more likely to be implemented on a wider scale. It is therefore critical that disease management interventions are reported and analyzed not only in terms of their individual components, but also in terms of the relationship between these components and the intensity with which they are delivered.

**Duration**

The duration of patient participation in the disease management interventions reviewed varied significantly. Most programs typically involved structured intervention (some combination of education, medication management, and counseling) for no more than a 6-month period. A few provided less intensive telephone follow-up ranging from 3 months to 2 years.

**Frequency/Periodicity**

For hospital-based programs, patient–provider interaction occurred most frequently during the inpatient phase. However, outpatient interventions could also be intensive and time consuming. Ledwidge et al. required heart failure patients to complete 3 scheduled clinic visits and 10 separate clinic-led consultations during the 3 months immediately after discharge. Home-based interventions and telephone support programs involved significantly less face-to-face contact. Stewart and Horowitz found evidence of reduced hospital readmissions for heart failure patients after only 1 home visit by a cardiac nurse with reinforcement by a community pharmacist, and Krumholz et al. required only 1 in-person education session. Structured telephone contact tended to take place weekly during the immediate postdischarge period, with the frequency decreasing over time.

**Complexity**

The individual components of disease management contribute to overall program structure, such that disease management programs can also be characterized by their complexity. On the basis of their mix of individual components, programs were quite heterogeneous in this respect. Highly complex programs maximized the application of many different disease management components, involved a wide variety of delivery personnel, and were more likely to tailor the application to the individual needs of each patient. For example, Naylor et al. evaluated a highly complex hospital discharge protocol administered by advanced practice nurses in conjunction with patients’ physicians, caregivers, and other home-based service providers. Program components included individualized discharge planning; assessment of functional, cognitive, and emotional health; extensive self-management education; and regularly scheduled home visits and telephone contact. By contrast, the least complex programs were characterized by far fewer disease management components, with fewer disciplines represented among delivery personnel and a more uniform approach to patients. A simple home-based telemonitoring intervention studied by Cor-disco and colleagues involved only electronic transmission of patients’ weight and symptoms, with daily review by a nurse. Finally, programs of intermediate complexity could be recognized by the incorporation of some, but not all, of the intervention components and delivery personnel described in the preceding sections of the taxonomy. Krumholz and colleagues investigated a program of intermediate complexity in which heart failure patients received a nurse-led hour-long education session shortly after discharge, followed by telephone-based reinforcement for 1 year. Although the program did not provide individualized care plans, nurses could encourage physician contact during the telemonitoring phase if patients’ status deteriorated.

Finding a reliable coding system for complexity may be challenging, but any adequate description of a disease management program should provide a description of the operational aspects of the program. Program complexity may significantly affect clinical outcomes, intervention costs, and overall costs of care; however, few analyses have examined the association between program complexity and these factors. This is an area for further exploration, as it is important to identify the types of disease management program structure that optimize chronic care at the level of individual patients or targeted patient communities.

**7. Environment**

The environment in which disease management interventions are delivered also has the potential to affect both patient and financial outcomes, though it is not yet clear which environmental factors are associated with success. The majority of studies included in the review implemented disease management interventions in the outpatient setting, incorporating a mix of hospital-based clinic visits and telephone contact. In some cases (particularly those involving patients with more advanced progression of disease or limited mobility), disease management interventions were delivered in patients’ homes, either electronically or by program staff (see Method of Communication above). Other programs specifically targeted the hospital-to-home transition, reinforcing inpatient education and medication management with subsequent outpatient contact and monitoring.

Program environment also varied with the disease being targeted. Heart failure programs were significantly more likely to incorporate an inpatient component because of the high hospitalization rate for patients with heart failure. Alternatively, disease management interventions for depression and diabetes were more often administered from primary care clinics. In addition to the physical location of a disease management program, organizational factors may have a significant environmental impact. Organizations responsible for funding and executing disease management programs range widely, including government agencies, health insurers, physician groups, hospitals, and private disease management companies. It is not yet known whether these different organizational environments, and the different financial motivations that accompany them, impact the cost or efficacy of disease management programs.

**8. Clinical Outcomes**

A description of a disease management program should also include a clear description of its goals—that is, the outcomes it is designed
to influence. Although interventions to improve patient and/or caregiver knowledge, self-care behavior, medication adherence, and overall quality of life were common components of disease management programs, outcomes specific to these interventions were not assessed or reported with consistency in the heart failure literature reviewed. Instead, patient mortality and hospital readmission rates were often the primary outcomes assessed and reported with consistency. This trend reflects a design bias in favor of programs targeting costs. Reductions in readmission rates tended to reduce their costs while producing economic loss for hospitals charged with implementing disease management programs. For payers, there may be little enthusiasm for implementing disease management if it results in economic loss to the system. Few other interventions in medicine are required to be cost saving. However, a shift in the domains of program evaluation toward patient-centered outcomes such as quality of life, changes in caregiver burden, and overall societal costs may facilitate a change in perspective by hospital systems through increased demands by patients for these beneficial programs and a change in reimbursement priorities by private and public payers.

Non–hospital-based programs for depression and diabetes tended to report on a wider range of outcomes. For depression, these included medication adherence, frequency of mental health visits, satisfaction with treatment, symptoms of depression, and general mental and physical functioning. Diabetes disease management programs generally reported change in glycosylated hemoglobin value as the primary outcome measure, though secondary outcome variables, including weight, blood pressure, lipid profile, eye and foot examinations, diabetes knowledge, and health-related quality of life were also reported with regularity.

Conclusion

Conceptually, disease management should include key elements such as a coordinated system of care, delivery system support, support for patient self-care, identification of at-risk populations, a continual feedback loop between patients and care providers, measures of clinical and other outcomes, and the goal of improving overall health. In practice, however, disease management programs contain myriad different elements and vary significantly in their comprehensiveness. The taxonomy outlined in this statement is intended to advance the field by providing a system to classify these diverse elements and programs. It does not attempt to certify which particular programs or components qualify as disease management, but rather establishes a framework for understanding the programs that exist. The taxonomy represents a first step toward establishing a common language for evaluation of disease management and should ultimately facilitate more rapid identification of effective program components.

Disclosures

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<th>Other Research Support</th>
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A Taxonomy for Disease Management: A Scientific Statement From the American Heart Association Disease Management Taxonomy Writing Group

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_Circulation_. 2006;114:1432-1445; originally published online September 4, 2006; doi: 10.1161/CIRCULATIONAHA.106.177322

_Circulation_ is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 0009-7322. Online ISSN: 1524-4539

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