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Outcome Evaluation of a Randomized Trial of the PhoenixCare Intervention: Program of Case Management and Coordinated Care for the Seriously Chronically Ill

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ABSTRACT

***Objective*: To document outcomes of a randomized trial of the PhoenixCare demonstration program of palliative care and coordinated care/case management for seriously chronically ill individuals who simultaneously received active treatment from managed care organizations (MCOs).**

***Design*: Patients, continuously enrolled between July 1999, and March 2001, were randomly assigned to the PhoenixCare program or a control group receiving usual MCO care.**

***Setting*: Hospice of the Valley, Phoenix, Arizona.**

***Participants*: Participants were 192 patients with chronic obstructive pulmonary disease (COPD) or chronic heart failure (CHF), who had an estimated 2-year life expectancy.**

***Intervention:* Intensive home-based case management provided by registered nurse case-managers, in coordination with patients' existing source of medical care, comprised the intervention. Program foci included disease and symptom management, patient self-management of illness and knowledge of illness-related resources, preparation for end-of life, physical and mental functioning, and utilization of medical services.**

***Outcome measures*: Outcomes, assessed every 3 months by telephone interview, included measures related to all program foci; the SF-36™ was used to evaluate physical and mental functioning; emergency department visits exemplified medical service utilization.**

***Results:* Compared to controls, PhoenixCare patients exhibited significantly better outcomes on self-management of illness, awareness of illness-related resources, and legal preparation for end of life. They reported lower symptom distress, greater vitality, better physical functioning and higher self-rated health than randomized controls. Emergency department utilization was equivalent across groups. Patients with COPD showed stronger responsiveness to the intervention.**

***Conclusion*: A novel model of patient care that combined greatly enhanced palliative care-focused case management with ongoing MCO-based treatment was associated with improved functioning of chronically severely ill patients in the last years of life.**

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INTRODUCTION

BOTH THE QUALITY and cost of health care at end-of-life are matters of great concern to the health care delivery system.[1–3] Patients with serious advanced illness experience undertreatment of symptoms while they receive aggressive life-prolonging treatments that are both physically burdensome and costly.[4] By design of Medicare funding for the hospice benefit, these patients gain access to palliative care focused on alleviation of symptoms, support for caregivers/families, and preparation for end of life only after they have relinquished disease-modifying or curative treatment. Palliative care funding through Medicare is available only for the final 6 months of life. Yet many patients and families may face unmet clinical needs for a longer period of time than the hospice benefit allows.[4]

To address these issues of quality and cost of care The Robert Wood Johnson Foundation funded 22 demonstration projects in 1999 through a national initiative, Promoting Excellence at End-of-Life Care. The initiative sought to support novel care delivery models that "extend(ed) palliative care upstream in the course of illness, concurrent with ongoing life-extending care"[2] (p. 311) with the aim of identifying successful models and approaches. Among the 22 projects was the PhoenixCare program, a demonstration program of palliative care and coordinated care/case management services designed specifically for seriously chronically ill individuals who were simultaneously receiving active disease treatment through managed care plans. The demonstration project was funded to Hospice of the Valley, Phoenix, Arizona, one of the largest community-based hospice providers in the country.

This paper provides the outcome evaluation of a randomized trial to assess the impact of the PhoenixCare program. From the perspective of outcome evaluation, randomized trials to evaluate community models of enhanced case management and palliative care for individuals are rare. Programs have been documented with case studies,[5,6] demonstration projects showing effects in treated groups in the absence of untreated comparison groups[7] or in nonequivalent control group designs.[8–10] Meier et al.,[11] describe the implementation of a randomized trial of an intervention to integrate formal palliative care with case management.

OVERVIEW AND RATIONALE OF THE PHOENIXCARE PROGRAM

Overview

PhoenixCare was a freestanding program of home-based palliative care case management developed specifically for The Robert Wood Johnson initiative.[12] Distinct from the hospice model, it was designed to reach patients receiving treatment from one of multiple managed care organizations (MCOs). Participants were home-residing, were diagnosed with congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD), and had a life expectancy of up to 2 years from time of enrollment (rather than the 6-month window of Medicare hospice). The goal of the PhoenixCare program was to expand the scope of patient care and to improve patient quality of life relative to a comparable group of managed care patients not receiving the additional PhoenixCare intervention services. PhoenixCare delivered home-based services focused on disease and symptom management, patient and caregiver education on disease management, and social and psychological support.[12] Registered nurse case managers delivered the primary PhoenixCare services and assumed a leadership role in coordinating PhoenixCare services with the patient's primary care physician, with any case managers provided by the patient's MCO, and with community agencies. Patients' health care was funded by Arizona's alternative to Medicaid, by Medicare + Choice (Medicare Risk contracts), or by commercial health insurance plans.

Rationale

The rationale for the PhoenixCare approach to integration of palliative care with treatment delivery through MCOs was fivefold in nature. First, at the time of study design, Arizona had the greatest proportion of its health care delivered by MCOs.[12] Second, in 1998, the year before the grant initiative, the federal government initiated the managed care Medicare model (Medicare + Choice) as an alternative to fee-for-service; the model rapidly proliferated. A substantial portion of chronically ill patients whom PhoenixCare aimed to reach were Medicare or Medicaid eligible. Third, most individuals with life-limiting illnesses reside at home rather than in care facilities.[11] Home-based palliative care for individuals

who were seriously ill but neither institutionalized nor imminently dying would reach the largest population needing palliation. Fourth, the ability to link a single effective program of palliative care to a multiplicity of MCOs was expected to yield efficiency in providing palliative care services while treatment continued. Fifth, it appeared that the MCOs would provide a natural referral stream of clients to the study. In summary, partnering with MCOs was expected to create the combination of treatment and palliation that might best serve a large population of patients with life-limiting illnesses who were still actively living. It was theorized that the PhoenixCare intervention would lead to better physical and mental functioning, at less or no more cost to the health care system. Lockhart et al.[12] provide an in-depth description of the PhoenixCare program content, its delivery, patient recruitment, provider and patient reaction, and the generalizability of the PhoenixCare model to broad medical contexts.

FOUR PROGRAM FOCI AND HYPOTHESES

The PhoenixCare intervention was organized around four foci.

Focus 1. Self-management of illness and knowledge of resources

First, the PhoenixCare program aimed to increase patient self-management of illness and knowledge of health-related resources by providing information and education to patients and caregivers.

Focus 2. Preparation for end of life

Second, the PhoenixCare program aimed to improve patients' preparedness for end of life by promoting the acquisition of appropriate legal documents and discussion of legal documents with significant others.

Focus 3. Physical and mental functioning

Third, the PhoenixCare program aimed to enhance the physical and mental functioning of clients through intensive case management by PhoenixCare staff, as well as patient education for self-management of illness.

Focus 4. Utilization of medical services

Fourth, the PhoenixCare program aimed to shift from utilization of high cost emergency medical services and inpatient acute hospitalization to proactive management of disease in outpatient settings, through intensive management and patient education on self-management of disease.

It was hypothesized that the PhoenixCare participants, compared to controls, would achieve better self-management, preparation for end of life, and physical and mental functioning (Foci 1 through 3), with lower utilization of costly emergency and inpatient services, specifically fewer emergency department visits and reduced length of stay (LOS) in hospitals (Focus 4).

METHOD

Participants

By design, all participants were residing at home and were members of one of seven MCOs in the Phoenix, Arizona, metropolitan area that agreed to partner with the PhoenixCare demonstration project. Enrollment occurred during the period July 1, 1999 through March 31, 2001. Patients could be referred by community agencies, hospitals, the MCOs, physicians, family/friends, or by self-referral. Over the course of the enrollment period, 965 individuals were referred for evaluation of eligibility for participation, 365 met eligibility criteria, and 240 agreed to participate.

Of the 240 individuals, 192 were diagnosed with either COPD ($n = 62$) or CHF ($n = 130$) and served as participants in the outcome evaluation. The remaining 48 patients had metastatic cancer; they were originally included but were eliminated because of structural changes in the institution housing the project. All participants met specific criteria designed to enroll patients who might live for up to 2 years beyond enrollment, based on expert judgment that drew on available prognostic data.[13–18]

All participants were required to be 18 years of age or older. Patients with CHF were required to be diagnosed with either class IIIB heart failure (i.e., symptoms with any activity) or class IV heart failure (i.e., symptoms at rest). Patients with COPD were required to have oxygen saturations of less than 88% on room air, or baseline pO_2 less than 55 on room air, and to be on continuous oxy-

gen. Across the two diseases, all patients were required to exhibit marked limitation of physical functioning, in that any activity resulted in fatigue, palpitation, dyspnea, or angina. All patients were required to have exhibited recent exacerbation of their conditions as evidenced by treatment in an emergency department, urgent care facility, or hospital within the 3 months prior to enrollment. For purposes of data collection by telephone interview, patients were required to have a telephone in the home, and to either speak English or have a translator present in the home. Participation in PhoenixCare was completely voluntary. Patients were not paid; nor did they or their MCO pay for any services provided by the program. Patients did not relinquish any health care services for which they were otherwise eligible.

Procedures

Eligibility evaluation, randomization to condition, and initial data collection. Randomization was carried out within diagnosis, in blocks of 30 patients (15 PhoenixCare, 15 control) by a member of the project administration staff. Sealed envelopes, color-coded by diagnosis and containing the assignment to condition, were shuffled and assigned to participants in order of shuffling.

A PhoenixCare staff Enroller completed an initial eligibility evaluation interview and intake session. In this initial session, eligible patients were informed (1) that there were two intervention conditions, PhoenixCare and control, (2) that assignment to condition was random, and (3) that all study participants in both conditions would receive telephone interviews every three months. Patients who agreed to participate gave written informed consent and completed the initial interview that constituted the baseline (time 0) data point. Finally, the Enroller, blinded to condition, opened the sealed envelope that identified the patient's study condition. All study procedures were approved by the Institutional Review Board of Good Samaritan Regional Medical Center, a collaborating organization.

Measurement points. Every 3 months all participants received a 30- to 45-minute telephone interview administered by a professional interviewing firm; interviewers were blind to condition and diagnosis. Up to 5 callbacks were attempted. Patients not interviewed were retained for future interviews. During the interview, proxy respondents could read or translate for patients. Proxy responses were not accepted, because they do not represent patients' self-perceived health well.[19,20]

Tracing procedures. PhoenixCare staff contacted control participants monthly to verify managed care enrollment, required for eligibility, document changes in address and in living situation, and to verify continued participation. Registered nurse case managers updated this information on an ongoing basis for PhoenixCare intervention participants.

PhoenixCare intervention. PhoenixCare palliative intervention services were added to treatment services provided by the MCOs to constitute the PhoenixCare intervention. The complete PhoenixCare intervention is described in Lockhart et al.[12] Registered nurse case managers, each with a caseload of 30–35 patients, provided service. A medical director, social worker, and pastoral counselor provided support to case managers, who coordinated "care planning with PhoenixCare team members, primary care physician, health plan case manager (if there were one), patient/family, and community agencies."[12] (pp. 1003–1004). Three distinct care protocols addressed phases of service delivery: (1) admission and initial case management of medically unstable patients, (2) management of stable patients following stabilization, and (3) support of unstable patients experiencing an exacerbation episode. All three protocols provided disease and symptom management, educational services, and support services. At admission, the disease and symptom protocol included assessing current health status, identifying immediate symptom management needs, establishing communication with the MCO contact and attending physician, developing an emergency response plan and coordinating this plan with attending physician. Educational services included development of advance care plans, providing education to patient and family about the disease, about patient self-monitoring and self-management of disease. Support services included assessing psychological and spiritual needs, assisting with access to community resources that might provide custodial care, transportation, and help with finances. During periods of patient stability, the three classes of services continued as needed, with

evaluation of compliance with medication regimes, assessment of new symptoms, reinforcement of educational activities including advance care planning, and ongoing monitoring of need for support services. During illness exacerbation episodes, the registered nurse case managers took an active role in assessing medical status and implementing a symptom control intervention, and in communicating with the attending physician and MCO contact concerning the exacerbation episode. They also provided education concerning new symptoms or conditions and use of new medications, developed new patient goals, supported patient decision making, assessed psychological, spiritual, and emotional needs of the patient and family, and made counseling referrals when required.

Control condition. Usual care provided by the MCOs, including medication and technical treatment, constituted the control condition. The focus of MCO case management was medical and disease oriented, including medication and lab monitoring, weight/blood pressure and blood glucose monitoring, and implementation of prior authorization mechanisms. Services were delivered via telephone by all seven MCOs and, in addition, through occasional home visits in five MCOs. Other support services included disease and symptom education, nutrition and psychological counseling, transportation and coordination of medical service. Each MCO provided its own individual case management to some portion of their clients.

Measures

Four broad classes of measures, summarized in detail in Table 1, informed the four foci of the intervention.

Intake interview and every-three–month follow-up interview (Focus 1–3). Questions addressing the first three program foci were integrated into a single l12-item questionnaire, of which 56 items, summarized in Table 1, formed the basis of the

Table 1. Outcome Measures by Focus of Intervention (k = number of items)

Focus 1: Patient self-management of illness and knowledge of resources (every 3-month interview)
1. Resources: resources to help with illness, including community resources, family and friends, individuals to help with medical problems (k = 3 items)
2. Illness self-management: information to manage illness at home, in emergency (k = 2 items)
3. Patient experienced an event in 4 weeks immediately preceding the interview for which he/she felt unprepared (k = 1 item)

Focus 2: Preparation for end of life (every 3-month interview)
1. Possession of appropriate legal documents, living will or advance directives, medical power of attorney (k = 2)
2. Discussion of legal documents with physician, with family and friends (k = 2)

Focus 3: Physical and mental functioning (every 3-month interview)
1. Patient able to initiate or resume an enjoyable activity in the 4 weeks immediately preceding the interview (k = 1)
2. Symptom control, taken from Memorial Symptom Assessment Scale[21] as integrated into the Surrogate Integrated Care System Afterdeath Interview.[22] Patient identifies most troublesome symptom within the four weeks just prior to the interview and then rates the frequency, severity, and distress associated with the symptom. Up to three symptoms are considered with separate rating of frequency, severity, distress for each symptom (k = 9 items)
3. Medical Outcomes Study Short-Form-36 Health Survey (SF-36™, Ware et al.[23]) which assesses "health-related quality-of-life outcomes, namely, those known to be most directly affected by disease and treatment" (op.cit, p.2:3). Eight subscales include Physical Functioning, General Health, Vitality, Social Functioning, Role-Physical, Bodily Pain, Role-Emotional, Mental Health. Scale scores are derived as weighted sums of items following Ware et al.[19] and then are converted to 100 point scales (k = 8 scale scores).

Focus 4: Medical system utilization (medical utilization data furnished by MCOs)
1. Number of emergency department visits in six months prior to study enrollment
2. Number of stand alone emergency department visits (not followed immediately by hospitalization) during study
3. Hospitalizations, length of stay

Additional measures of study participation
1. Number of months in program
2. Reasons for withdrawal from study

present evaluation. Two existing scales were integrated into the questionnaire. First, we incorporated the symptom control items from the Memorial Symptom Assessment Scale,[21] which previously had been integrated into the Surrogate Integrated Care System Afterdeath Interview.[22] Second, we assessed functional status and well-being with the SF-36™ Health Survey[23] that characterizes "health-related quality of life outcomes, namely, those known to be most directly affected by disease and treatment"[23] (p. 2:3). The SF-36™ is sensitive to chronic conditions that PhoenixCare targeted. A population of patients enrolled in Medicare + Choice exhibited declining scores on the SF-36™ in response to chronic conditions.[24] The remaining items of the questionnaire were developed specifically for this evaluation.

Utilization of medical services: Claims information records (Focus 4). MCOs furnished utilization data on each participating patient for the duration of his/her enrollment in the study, as well as for the 6 months prior to enrollment (or all the time that the patient had been enrolled in the MCO up to 6 months prior to enrollment in the study).[a] We considered emergency department visits as stand-alone events and LOS in the hospital. For our enumeration of emergency department visits, we considered only those emergency department visits that did not result in an immediate hospitalization. Emergency department visits resulting in hospitalizations were not counted. In determining which emergency department visits to count, we established that if a patient's condition was so severe and medically compromised that a hospitalization was required subsequent to an emergency department treatment, then that patient could not have managed his/her own symptoms adequately with the PhoenixCare individualized treatment plan at home. We derived two emergency department counts: (1) number of emergency department visits in the 6 months prior to entry into PhoenixCare, to characterize normative emergency department use pattern by the patient, and (2) total number of emergency department visits during PhoenixCare enrollment. Multiple medical claims were possible for a single emergency department visit; we thus counted only one emergency department visit per 24-hour period. We had originally intended to characterize hospitalizations as discrete events, to compute the LOS for each hospitalization, and then to compute the cumulative LOS across hospitalizations over the same time period as for emergency department visits. Inadequately reported hospital claims data did not permit calculation of length of stay. In a notable number of instances, admission date/discharge date pairs could not be unambiguously established from streams of MCO claims data; such pairs are required for each hospitalization episode for computation of the LOS of that hospitalization.[b] Beyond this, an extensive line-by-line review of medical claims data by the PhoenixCare Medical Director and Project Director revealed that hospitalizations could not be sorted into those directly related to the PhoenixCare target diagnoses (CHF, COPD) versus those related to other ancillary conditions, because all hospitalizations were identified by the primary diagnosis regardless of the treatment provided.

Statistical analysis

We refer to the intake interview as time 0, the first 3-month follow-up interview as time 3, the next, as time 6, etc. All analyses of intervention outcomes examined effects as a function of experimental condition (PhoenixCare, control), diagnosis (CHF, COPD), and their interaction. In these analyses, we controlled for any pretest differences by including the corresponding time 0 score as a covariate. We report both the overall effect of the intervention and any differential pattern of intervention effects within diagnoses. The number of patients available for analysis dropped from 192 at intake (time 0) to 112 at time 3, 92 at time 6. Our analytic strategies included as many cases as possible for the analysis of each aspect of the intervention. We examined outcomes at

[a]A fifth class of measures assessed program implementation, characterizing the extent, timing, and type of service provided to patients throughout the intervention. This last stream of data supported the evaluation of program implementation, reported in Lockhart et al.[12]

[b]We devoted extensive effort to rendering the streams of claims data from the MCOs amenable to computation of LOS. There was no consistent method for reporting of claims data across MCOs. In our attempt to capture admission/discharge pairs, we found some measurements so anomalous from the perspective of medical utilization that we ultimately judged that the claims data could not be used to compute LOS (e.g., pairs of admissions and discharges that were separated by a year and would have led to computation of 365-day hospitalizations.)

time 3 for all cases with time 3 data and outcomes at time 6 for all participants with time 6 measures. We used analysis of covariance (ANCOVA) for analysis of continuous variables; logistic regression, for binary variables; and Poisson regression,[25] for counts of number of emergency department visits.

Growth curve modeling of functional status over time. We expected that changes in functional status, as measured on the SF-36™, might accrue gradually over time, even beyond the first 6 months of the intervention. We thus applied growth curve modeling in the multilevel framework[26] to each of the eight scales of the SF-36™ to test hypotheses concerning the impact of the PhoenixCare intervention and to characterize whether groups improved, remained level, or declined over time. For each SF-36™ scale, we fit a linear trajectory to all available data from each individual. Each individual's trajectory was characterized by its intercept and slope. Intercepts and slopes then became dependent variables for analysis as a function of condition, diagnosis, and the condition by diagnosis interaction. The average intercept of the individuals in a particular group (e.g., patients with COPD in the PhoenixCare group) measures the overall level of functioning of the group at one point in time. Differences in intercepts across groups represent differences in level of functioning. By moving the intercept across the time scale in a series of analyses,[27] we could detect the point in time, if any, at which differences in levels of functioning between groups emerged. The average slope in a group characterizes the overall trend (decline, stability, improvement) for physical and mental health over time. Differences in slopes across groups indicate that groups are changing differentially over time. Each trajectory began at the time 3 data point; trajectories continued through the full complement of data for each case. The Initial Interview point (time 0) was used as a covariate to control for any differences between groups in their intercepts at the outset of the intervention.

Treatment effect size estimates. We report a standardized effect size estimate for each observed difference between the PhoenixCare and control conditions (i.e., the number of standard deviations of difference between the groups). We use Hedges' g = [(PhoenixCare mean-Control mean)/pooled standard deviation] for continuous outcomes and Hedges' h = [(PhoenixCare estimated proportion—Control estimated proportion)/pooled standard deviation] for binary outcomes.[28] We chose standardized effect size estimates for two reasons. First, with the exception of SF-36™, there are no norms on which to compare differences on our scales. Second, these effect size estimates are used in meta-analyses of treatment outcome research.[29] Effect sizes of 0.2, 0.5, and 0.8 are considered small, moderate, and large, respectively[30]; these effect sizes have been supported in analyses of treatment outcomes.[29]

Pretest equivalence. To evaluate the success of randomization, we compared PhoenixCare and control at time 0 on all outcome measures. We used one-factor analysis of variance (ANOVA) for continuous outcome measures and χ^2 tests of independence for binary outcome measures.

Attrition analysis. We used the Jurs and Glass[31] procedure to examine attrition. For each dependent variable listed in Table 1, initial data (time 0) were examined in a two-factor analysis of condition (PhoenixCare versus control) by retention (retained, attrited). A main effect of retention reflects difference between participants who remained in versus left the study. An interaction between condition and retention signals differential attrition across conditions. Our statistical power to detect a small interaction accounting for 4% of variance at $\alpha = 0.05$ ranged between 0.79 and 0.84 depending on variance accounted for by main effects.[30]

RESULTS

Participant characteristics and outcome of randomization

Participant characteristics. Of the 192 patients enrolled, 101 (or 53%) were randomized to the PhoenixCare intervention; the remaining 91 (47%) served as controls. Immediately after intake and before the outset of treatment, 1 intervention and 1 control case dissenrolled. Analyses of outcomes are based on these 190 cases. There were 67 CHF and 33 COPD PhoenixCare participants, and 62 CHF and 28 COPD controls. Participants were on average 68.5 years of age; 64% were female; 82% were Caucasian; 42% had greater than

Table 2. Demographics Characteristics of Study Participants

	Intervention n = *100*	*Control* n = *90*
Age in years		
Mean	68 years	70 years
SD	14	13
Percent female	58%	70%
Percent Caucasian	80%	84%
Percent married	40%	48%
Education		
Percent > HS degree	44%	41%
Percent HS degree	42%	35%
Percent < HS degree	14%	24%
Percent having someone to help with illness	87%	88%

SD, standard deviation of age, in years.

a high school degree; 44% were married; 87% reported having someone to help them with their illness. Table 2 summarizes demographic characteristics by experimental condition (PhoenixCare, control).

Pretest equivalence. PhoenixCare and control participants did not differ significantly (at $p \leq 0.10$) on any outcome measures related to Focus 1, Focus 2, or Focus 4 (i.e., emergency department visits in the 6 months prior to enrollment.) With regard to Focus 3, PhoenixCare participants tended to have higher scores on the SF-36™ Social Functioning Scale, $F(1,189) = 3.45$, $p = 0.07$, $g = 0.27$, and on the SF-36™ Mental Health Scale, $F(1,190) = 3.35$, $p = 0.07$, $g = 0.26$.

Delivery of the PhoenixCare intervention and control case management services

PhoenixCare intervention. The PhoenixCare intervention remained constant in design over the course of the study. Delivery of service by registered nurse case managers combined home visits and telephone calls. Patients averaged 44 contacts over the course of the intervention. Average monthly frequency of these services per patient (visits plus calls) were 6.3, 4.9, 3.9, 3.9, 3.4, 3.3, in the first 6 months of participation, of which 3.9, 2.2, 1.8, 1.5, 1.4, and 1.4 contacts were home visits. These services were stable beyond the first 6 months. Visits included seeing patients at home and accompanying patients to the physician's office to discuss patient progress and treatment options. The number of registered nurse contacts per month did not differ by diagnosis or by whether the participant lived alone or with someone else. The PhoenixCare social worker contacted 45% of patients; this subset of patients received an average of 6 contacts from the social worker.

Control case management services. PhoenixCare staff monitored the provision of MCO case management services through quarterly interviews with MCO directors of case management. In all, MCOs assigned their own case managers to 62% of all control participants and to 51% of PhoenixCare patients, $\chi^2(1) = 2.36$, $p = 0.12$. Over the course of the study, the MCOs greatly narrowed criteria for enrollment into case management and diminished the services provided, in response to financial pressures. Home visits and other support services were terminated by all MCOs; phone monitoring was maintained by only two MCOs throughout the study. Only medical and disease management was maintained throughout the study by all MCOs, albeit to an increasingly narrow range of patients. Three MCOs began to reinstate some services in the last quarter of the study, when actual enrollment into the PhoenixCare study was sparse.

Retention, and reasons for attrition, and attrition effects by condition

Retention. Potential length of stay in the program depended on enrollment date; participants enrolled from July 1, 1999 through March 31, 2001, but all data collection terminated on September 30, 2001. Of the 101 PhoenixCare participants, 62%, 55%, and 43% provided time 3, time 6, and time 9 interviews, respectively. Of the 91 control participants, corresponding percentages were 54%, 38%, and 33% at time 3, 6, and 9, respectively.

Reasons for attrition. At the end of data collection 44% of the PhoenixCare participants and 25% of control patients were still participating. Before time 3, 6% of all PhoenixCare and 8% of all control participants had died; 8% versus 9%, respectively, had entered hospice; and 1% versus 1% had entered skilled nursing facilities (SNFs). Corresponding percentages across the whole study for PhoenixCare versus controls, respectively, were 16% versus 13%, death; 12% versus 13%, hospice; 1% versus 3%, SNF. In all 6% of Phoenix-

Care and 11% of controls declined to continue participation; another 10% and 14%, respectively, disqualified by leaving their MCO. In sum, PhoenixCare and control participants appeared to have left the study at equal rates for medical causes (death, hospice, SNF), but controls left more often for other reasons.

Attrition effects. Participants who were retained had better physical and mental functioning (Focus 3) than those who left, because attrition included transfer to a skilled nursing facility, to a hospice, or death. Specifically, those retained at time 3 reported better General Health on the SF-36™ during the 3-month preenrollment period, $F(1,188) = 12.26$, $p < 0.001$, $g = 0.51$; the same result held for those retained versus lost at time 6, $F(1,188) = 12.03$, $p < 0.001$, $g = 0.50$. Those retained at time 6 reported significantly lower bodily pain during preenrollment, $F(1,187) = 7.93$, $p < 0.01$, $g = 0.41$, and also were more likely to have resumed a pleasant activity during preenrollment, $\chi^2(1) = 13.09$, $p < 0.001$, OR = 3.25, [CI: 1.72, 6.16], with 48% and 23% among retained and attrited participants, respectively, $h = 0.57$. With regard to end-of-life preparation (Focus 2) those retained were less likely to have discussed illness and death related legal documents with a physician during preenrollment, $\chi^2(1) = 4.95$, $p < 0.05$, OR = 0.51, [CI: 0.28, 0.92] , with 37% and 54% among retained and attrited participants, respectively, $h = 0.34$.

Only one condition by retention interaction was detected that signaled differential attrition, that for having been given sufficient information and education to manage illness at home, $F(1,183) = 3.93$, $p < 0.05$. Among those retained, PhoenixCare patients had received less information than had controls during pre-enrollment, $F(1,87) = 3.225$, $p < 0.08$; $g = 0.39$. The reverse was true for those who attrited, $F(1,96) = 1.071$, $p > 0.20$; $g = 0.21$.

Focus 1: Outcomes for self-management of illness and knowledge of resources

Table 3 summarizes the means on the five individual items measuring management of illness and awareness of resources at time 0 and at times 3 and 6, adjusted for time 0. In all 10 comparisons of PhoenixCare versus control outcomes (5 items at time 3 and at time 6), the PhoenixCare mean exceeded the control mean. As shown in ANCOVA, at time 3, PhoenixCare patients reported having received more education concerning community resources than controls, $F(1,107) = 5.80$, $p < 0.05$, $g = 0.45$. At 6 months PhoenixCare patients also exceeded controls in reporting that they had information about whom to speak concerning medical problems, $F(1,78) = 5.12$, $p < 0.05$, $g = 0.50$, and had sufficient information to handle illness emergencies, $F(1,86) = 8.19$, $p < 0.05$, $g = 0.59$.

After 3 months in the program, PhoenixCare participants were less likely than controls to have had an experience for which they were unprepared (see Table 3). In logistic regression of time 3 outcomes, the Condition by Diagnosis interaction, $p < 0.05$, OR = 6.07, [CI: 1.01, 36.53] reflected that COPD PhoenixCare patients were much less likely to have had such an experience than were COPD controls, $p < 0.05$, OR = 0.23, [CI: 0.05, 0.97], 32% and 58% in PhoenixCare and control respectively, $h = 0.73$. At time 6, a condition main effect, $p < 0.05$, OR = 3.22, [CI: 1.10, 9.44] reflected less preparedness overall of patients in the PhoenixCare condition, 42% and 21% in PhoenixCare and control respectively, $h = -0.45$.

In summary, the PhoenixCare participants reported a sense of having greater information for self-management of illness, a greater appreciation of resources available to help with their illness. In the early months of intervention only, they reported better preparedness for daily experiences, an effect that reversed at time 6.

Focus 2: preparation for end of life

The percentages of affirmative responses to the four binary indicators (yes/no) reflecting preparation for end of life are given in Table 4 (Focus 2) as a function of condition and time. In logistic regression of time 3 outcomes, PhoenixCare participants showed a higher rate of having a living will or advance directive than did controls, $p < 0.05$, OR = 4.47, [CI: 1.10, 18.18], with 71% compliance in PhoenixCare, 65% in control, $h = 0.67$. This represented a substantial gain for PhoenixCare patients (from 52% to 71%; see Table 4). No further effects of condition emerged.

Focus 3: physical and mental functioning

Participation in enjoyable activities. By the time 3 measurement point, patients in PhoenixCare re-

Table 3. Outcomes for Self-Management of Illness, Knowledge of Resources for Management, and Preparedness (Focus 1) at Initial Interview, Time 3 (Three Months Following Treatment Entry) and at Time 6 (Six Months Following Treatment Entry)

	Initial interview (unadjusted means)		*Means adjusted for initial status*[a]			
			Time 3[b]		*Time 6*[c]	
Item	*PhoenixCare*	*Control*	*PhoenixCare*	*Control*	*PhoenixCare*	*Control*
Focus 1: Self-management of illness and knowledge of resources						
Focus 1: Self-management of illness						
Participant has received sufficient information to manage illness at home	3.29	3.32	3.73	3.55	3.75	3.70
Participant has received sufficient information to handle illness emergency	3.51	3.52	3.72	3.52	3.90[d]	3.51[d]
Focus 1: Resources						
Participant has received education about community resources	1.80	1.76	2.57[d]	2.02[d]	2.14	1.74
Participant has received information about how family and friends can assist	1.29	1.42	2.24	1.98	1.97	1.94
Participant has received information about who to talk to about a medical problem	1.57	1.76	2.72	2.45	2.63[d]	2.19[d]
Focus 1: Preparedness (percent affirmative response)						
Participant had an experience which they were unprepared for in the last 4 weeks	47%	47%	32%[e]	40%[e]	42%[f]	21%[f]

Note: All items are on 4-point scales, where 1 = mostly false and 4 = mostly true.
[a]Means reported are adjusted means from an analysis of covariance with response to the item at the initial time 0 interview as the covariate.
[b]Three-month data include all cases with data at time 3.
[c]Six-month data include all cases with data at time 6.
[d]Corresponding adjusted means for PhoenixCare versus control differ significantly ($p < 0.05$).
[e]Proportions for PhoenixCare versus control differ significantly ($p < 0.05$).
[f]Proportions for PhoenixCare versus control differ significantly ($p < 0.05$).

ported having been able to initiate or resume an activity they enjoyed (see Table 4, Focus 3). As shown in logistic regression of time 3 outcomes, the condition by diagnosis interaction reached significance, $\chi^2(1) = 6.84$, $p < 0.01$, OR = 8.5, [CI: 1.69, 39.28]. In COPD, fully 63% of PhoenixCare patients responded "yes" as opposed to only 16% of controls, z = 3.38, $p < 0.01$, $h = 1.00$. This difference was not retained at time 6 for patients with COPD. There was no effect at either time point for patients with CHF.

Symptom control. At each interview participants identified, in open-ended fashion, up to three troublesome symptoms; symptoms identified could vary across time points. In all, 78%, 90%, and 92% of patients reported at least one symptom at time 0, 3, and 6, respectively.[c] At time 0, the symptom mentioned as most troubling with the greatest frequency was difficulty breathing (by 64% of all participants); pain and fatigue were also frequently mentioned. Mean ratings of the frequency, severity, and distress associated with the most troublesome symptom are given in Table 5. In a series of ANOVAs of time 0 symp-

[c]The non-reporting of symptoms at time 0 by 22% of patients was attributable to difficulties in initial intake interview administration by one case manager. Whether or not she had administered any particular interview that contained this difficulty in administration was unrelated to diagnosis (CHF, COPD) or to condition (PhoenixCare, control). Therefore, the lack of response weakened statistical power but did not affect conclusions about differences between conditions, the focus of the analyses.

TABLE 4. OUTCOMES FOR PREPARATION FOR END OF LIFE (FOCUS 2) AND RESUMPTION OF ACTIVITIES (FOCUS 3)

	Percent affirmative response					
	Initial interview		*Time 3*[a]		*Time 6*[b]	
	PhoenixCare	*Control*	*PhoenixCare*	*Control*	*PhoenixCare*	*Control*
Focus 2: Preparation for end of life						
Participant has living will or advance directive for medical treatment desired	52%	61%	71%[c]	65%[c]	70%	73%
Participant has documents such as medical power of attorney	56	63	66	69	68	76
Participant has discussed legal documents with physician responsible for care	40	48	48	59	34	62
Participant has discussed legal documents with family and friends	62	71	78	90	82	94
Focus 3: Physical and mental functioning						
Participant has been able to begin or resume an enjoyable activity in the last 4 weeks	34%	36%	49%[d]	37%[d]	45%	42%

Note: All items have a binary (yes, no) response. Number responding: Initial interview, $n = 189$; 3-month interview, $n = 111$; 6-month interview, $n = 90$.

[a]Patients who remained in the program for 3 months.

[b]Patients who remained in the program for 6 months.

[c]Adjusted proportions for PhoenixCare versus control differ significantly ($p < 0.05$).

[d]Adjusted proportions for PhoenixCare versus control differ significantly ($p < 0.05$).

tom frequency, severity, and distress ratings as a function of condition and diagnosis, conditions were equivalent at outset. In a parallel series of ANOVAs of Time 3 data,[d] only symptom distress showed an effect, specifically in the form of an interaction between condition and diagnosis, $F(1,99) = 4.89$, $p < 0.05$. PhoenixCare patients with COPD reported lower symptom distress than did COPD controls ($p < 0.05$), $g = 0.81$. The interaction effect held at time 6, $F(1,82) = 6.19$, $p < 0.05$, and reflected that PhoenixCare patients with COPD again tended to have lower (but not significant) distress ratings than did COPD controls, $F(1,22) = 1.97$, $p = 0.07$, $g = 0.58$. However, for clients with CHF, the reverse was true, with PhoenixCare participants reporting higher distress, $F(1,60) = 5.26$, $p < 0.05$, $g = 0.60$.

Trajectories of physical and mental functioning on the SF-36™. The eight subscales of the SF-36™ provided the main characterization of functioning over time. Table 6 gives the mean transformed scores on a 100-point scale at initial measurement (time 0) for all participants in the PhoenixCare study; high scores reflect better functioning. These mean scores are far below those of comparably aged participants in the Medical Outcomes Study (MOS), who were diagnosed with CHF and COPD.[23] The average score across the eight 100-point scales for PhoenixCare participants was 29. This reflects exceptionally low functioning compared to average scores of 55 and 56, respectively, for CHF and COPD patients in the MOS.

Table 6 summarizes the growth analyses. The slope of each of the four groups (condition × diagnosis) is reported. For the intercept, the measurement point (month), if any, at which differences among groups emerged is reported, along with a brief description of the difference.

Condition effects. As shown in Table 6, effects of the PhoenixCare intervention emerged on three scales: (1) Physical Functioning, a measure of activities of daily living, (2) General Health, a self-assessment of current health and expectation of future health, and (3) Vitality, a measure of level of energy. On Physical Functioning, PhoenixCare

[d]For the ANOVAs of symptom frequency, severity, and distress at time 3 and time 6, we did not covary out time 0 scores, since patients often reported different symptoms at time 0, time 3 and time 6. However, there were no differences in these ratings as a function of Condition and Diagnosis at time 0 that would have led to bias in outcomes, if ignored, at time 3 and 6.

Table 5. Mean Frequency, Severity, and Distress Ratings of the Most Troublesome Symptom (Focus 3)

	Mean frequency at each point in time[a]		
	Time 0	*Time 3*	*Time 6*
CHF			
PhoenixCare	2.83	2.90	2.87
Control	2.90	2.68	3.00
COPD			
PhoenixCare	3.08	3.35	3.08
Control	3.23	3.35	2.90
	Mean severity at each point in time[b]		
	Time 0	*Time 3*	*Time 6*
CHF			
PhoenixCare	2.35	2.18	2.20
Control	2.24	2.18	2.13
COPD			
PhoenixCare	2.54	2.35	2.08
Control	2.50	2.29	2.20
	Mean distress at each point in time[c]		
	Time 0	*Time 3*	*Time 6*
CHF			
PhoenixCare	4.19	3.72	4.03[d]
Control	3.81	3.32	3.30[d]
COPD			
PhoenixCare	4.38	3.41[d]	2.85[e]
Control	4.35	4.29[d]	3.80[e]

Note: Number of respondents is $n = 146$ for time 0, $n = 101$ for time 3, and $n = 85$ for time 6.

[a]Frequency measured on a 4-point scale: 1 = occasionally; 2 = some of the time; 3 = most of the time; 4 = all of the time.

[b]Severity measured on a 3-point scale: 1 = not at all severe; 2 = moderately severe; 3 = extremely severe.

[c]Distress measured on a 5-point scale: 1 = not at all; 2 = a little bit; 3 = somewhat; 4 = quite a bit; 5 = very much.

[d]$p < 0.05$ for difference between means.

[e]$p = 0.07$ for difference between means.

patients in both diagnoses remained the same over time (CHF) or improved (COPD) over time (as reflected in their slopes), while control patients declined over time, $z = 2.50$, $p < 0.05$ for the difference in average slope as a function of Condition. At the 9-month point, the PhoenixCare patients' physical functioning exceeded that of controls, as shown by the intercept difference, $z = 2.16$, $p < 0.05$, $g = 0.41$. Similarly, on the General Health Scale, the average slope for PhoenixCare was higher than for controls, $z = 2.16$, $p < 0.05$, and the PhoenixCare intercept exceeded that of controls at 9 months, $z = 2.51$, $p < 0.05$, $g = 0.47$. On the Vitality scale at the 3-month time point the interaction between condition and diagnosis was significant, $z = 2.52$, $p < 0.05$. Specifically, there was an intercept difference for COPD, with PhoenixCare having higher Vitality scores than controls, $z = 2.36$, $p < 0.05$, $g = 0.76$; no difference between conditions was observed for CHF.

In summary, the PhoenixCare intervention was associated with maintained or improved Physical Functioning and General Health, such that PhoenixCare patients exceeded controls by 9 months. PhoenixCare patients with COPD exhibited enhanced Vitality relative to controls.

Focus 4: medical utilization

In the 6 months prior to the outset of the PhoenixCare intervention, PhoenixCare participants averaged 0.12 emergency department visits per month (SD = 0.18). Control participants averaged 0.11 emergency department visits per month (SD = 0.20). This level of utilization remained essentially unchanged during the intervention, with averages of 0.11 (SD = 0.34) and 0.10 (SD = 0.31) visits per month for PhoenixCare and control participants, respectively.

In an overdispersed Poisson regression model[25] we predicted number of emergency department visits during enrollment from condition, diagnosis, and their interaction, controlling for total number of days in the program and number of preenrollment emergency department visits; there were no significant effects of condition. Neither were there any effects of condition on emergency department utilization for a subgroup of participants we identified as being at high risk for emergency department utilization.

Final statistical adjustment

Among all tests of pretest equivalence, PhoenixCare participants tended to exceed controls ($p < 0.10$) on two SF-36™ scales, Social Functioning and Mental Health. We repeated all analyses, statistically controlling these differences. All effects we have reported were maintained.

DISCUSSION

Summary of results

Evaluation outcomes supported an association between participation in PhoenixCare and posi-

TABLE 6. GROWTH MODELING ANALYSIS OF SF-36™ TRAJECTORIES OF PHYSICAL AND MENTAL FUNCTIONING OVER TIME (FOCUS 3)

		Slopes[a]				*Intercept differences*[b]	
	Time 0	*PhxCare*		*Control*			
SF-36™ Scale	*Scale mean*	*CHF*	*COPD*	*CHF*	*COPD*	*Month*[c]	*Description of finding*
Physical functioning[d]	13.0	0.18	1.00	−1.39	−0.95	9	PhxCare Clients > Control (COPD & CHF)
General health[e]	17.4	0.16	0.54	−0.17	−1.67	9	PhxCare Clients > Control (COPD & CHF)
Vitality	18.8	0.02	0.09	−0.91	0.61	3	PhxCare Clients > Control (COPD only)
Social functioning	33.9	−0.80	1.09	−2.15	3.72	3	CHF > COPD
Role-physical	12.7	−0.51	0.57	1.60	−0.14	—	
Bodily pain[f]	48.5	−0.57	2.98	−0.09	−0.45	—	
Role emotional	31.3	0.00	1.77	−0.24	3.08	—	
Mental health	53.6	−0.69	−0.37	−1.77	−0.10	—	

Note: All scores on the SF-36™ are transformed scores according to Ware *et al*.[19], (p. 6.17) that range from 0 to 100, as calculated by the formula: Transformed score = {[actual raw score-lowest possible score]/highest possible raw score} × 100.

[a]Slopes of average linear trajectory within a group, averaged across slopes of individual linear trajectories of individual within the group.

[b]Intercept difference reflects difference in overall elevation of trajectories across groups at a particular time (month).

[c]Month is month since enrollment in program; 3 months is at Time 3, and 9 months is at Time 9.

[d]Overall control slope is declining while overall PhoenixCare slope is rising ($p < 0.05$)

[e]Control slope is declining while PhoenixCare functioning remains stable ($p < 0.05$)

[f]High scores on the bodily pain scale represent freedom from pain, (i.e., lower experience of pain).

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.

tive outcomes. In support of Focus 1, Self-Management of Illness, PhoenixCare patients reported having received more information about both management of illness and about resources than did controls. In addition, after the first three months (time 3) PhoenixCare patients reported being less likely to have experienced health related events for which they were unprepared (though this effect reversed at time 6). In support of Focus 2, Legal Preparation for End-of-Life, PhoenixCare patients were more likely to have a living will or advance directive by time 3. With regard to Focus 3, Physical and Mental functioning, more PhoenixCare COPD patients than controls had returned to an enjoyable activity by time 3. PhoenixCare COPD patients also reported lower symptom distress time 3 (although the opposite was observed for PhoenixCare patients with CHF at time 6). On the SF-36™ scales, PhoenixCare patients with COPD reported greater vitality (level of energy versus fatigue) than COPD controls by time 3. Control patients declined in both Physical Functioning and General Health while PhoenixCare patients did not. At 9 months after treatment onset superior Physical Functioning and General Health emerged among PhoenixCare above control participants. Across program foci there were more positive effects associated with PhoenixCare for patients with COPD. Successful management of the symptoms of COPD has long been associated with adaptive psychological functioning and emotional stability of the patient.[32,33] All the effect sizes associated with the PhoenixCare intervention are moderate to large.

For Focus 4, Utilization of Emergency Medical Services, there was no reduction in standalone emergency department visits associated with PhoenixCare. Study participants apparently experienced extreme exacerbations of their conditions that could not be handled at home. The illness level of participants cannot be overestimated. On the SF-36™ Physica1 Functioning scale, which measures activities of daily living, the mean scale score was 13 for PhoenixCare participants, a remarkably low level of functioning, as compared to mean scale scores of 48 and 57 for patients with CHF and patients with COPD, respectively, in the MOS.[19]

Limitations of PhoenixCare design and evaluation

We experienced difficulties with recruitment of eligible participants, yielding fewer cases than planned.[12] The prognostication criteria we employed to predict life expectancy, while based on

the best available data, were limited. We sought participants expected to live for 2 years. One third of all participants died or transferred to hospice in the first 3 months, resulting in diminished statistical power to detect effects associated with the PhoenixCare intervention. Statistical power to detect moderate effect size differences between PhoenixCare and control participants fell from 0.93 to 0.74 to 0.64 at time 0, 3, and 6, respectively. We may have failed to detect small, yet meaningful, outcomes.

The quality of medical claims data put severe limitations on our ability to explore shifts in utilization. Hospitalization claims could not be meaningfully explored, as previously explained. Moreover, we were unable to characterize potential shifts to less costly aspects of care (e.g., office visits) because these services were not documented by all plans.

We experienced from 0% to 2% missing data on individual items, evenly distributed across conditions. If this minimal nonresponse to individual items reflected greater patient illness, then our data would be very slightly biased toward healthier overall responding.

We carried out multiple statistical tests, increasing the probability of collective type I error. Yet, the pattern of results is favorable to PhoenixCare. Of 14 effects reported, 12 favored PhoenixCare. If there were no difference between conditions in the population, the probability of observing this pattern of results by chance alone would be less than or equal to 0.004.

With regard to generality of findings, our results in general apply to those participants whom we retained for at least three months. Results for physical functioning pertain to those retained for nine months. Retained individuals had better health than those lost to the study. Our analysis of differential attrition across the PhoenixCare and control conditions suggests that the outcomes associated with PhoenixCare are not caused by differential health status across conditions.

Case management in treatment versus palliation

As characterized by Meier et al.[11] case management programs delivered by MCOs for those with life-threatening illnesses "typically focus primarily on service coordination, to a lesser extent on medical evaluation and decision making, and only rarely incorporate standard palliative care assessment and interventions. . . . " (p. 120). In contrast, palliative care services include establishing treatment goals in concert with patient and caregivers; pain and symptom relief; psychological support, and coordination of care.[4] The PhoenixCare staff, particularly the registered nurse case managers, engaged in all these palliative care activities. These registered nurse case managers also advocated for care to be delivered by the MCOs, and assumed a leadership role in coordination of care with MCO case managers (where they existed), physicians, family, and community organizations. Because PhoenixCare participants were approaching death but at the same time were actively living and pursuing treatment, PhoenixCare registered nurse case managers had both their own role in palliation and an administrative role in bringing together palliation and treatment services.

Mechanism of action of PhoenixCare

The potential mechanisms by which the PhoenixCare intervention was associated with beneficial outcomes bear exploration.[e] One possibility is that the PhoenixCare intervention provided an excess of usual care. PhoenixCare staff, particularly the registered nurse case managers, delivered specific palliative services focused on education and patient empowerment, services designed to complement, not duplicate, MCO-based treatment. A second possibility is that the PhoenixCare staff were exceptionally skilled at service delivery. PhoenixCare staff were selected to have experience in both chronic disease management and end-of-life care. They received specialized training in how to deliver the intensive PhoenixCare palliative care protocol. We attribute any positive impacts associated with PhoenixCare to delivery of the PhoenixCare palliation protocol, including advocacy for treatment, by experienced registered nurse case managers. We believe that the staff training and the PhoenixCare program can be exported to other settings.

Alternative models of home-based palliative care

The PhoenixCare program delivered home-based palliative care to individuals expected to

[e]We thank an anonymous reviewer for suggestions as to potential mechanisms that stimulate this discussion, as well as the discussion of limitations of the study.

live for 2 years who were still actively pursuing treatment through one of seven different MCOs. PhoenixCare provided palliative care as an add-on to the treatment services, including treatment-oriented case management, provided by the MCOs. In contrast, Meier et al.[11] furnished home-based palliative care by training case management nurses to add palliative case management to treatment oriented case management they usually provided; an outcome evaluation of this program is forthcoming. Alternative models of palliation funded through The Robert Wood Johnson initiative[3] included integrating hospice into a hospital setting and adding palliative care services in outpatient treatment settings. We designed our PhoenixCare model specifically to test whether a stand-alone organization especially devoted to delivery of high-quality home-based palliative care could partner with a variety of health care plans. We chose individualized case management in order to reach an essentially homebound population of seriously ill individuals.

CONCLUSION

Patients with severe illnesses who were still actively pursuing treatment appeared to benefit from the palliative services provided by the PhoenixCare intervention. Our findings lend support to the concept of palliation as integral to treatment for severe life limiting disease.[4]

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