Original Article

Clinical Impact of a Home-Based Palliative Care Program: A Hospice-Private Payer Partnership

Christopher W. Kerr, MD, PhD, John C. Tangeman, MD, FACP, Carole B. Rudra, PhD, MPH, Pei C. Grant, PhD, Debra L. Luczkiewicz, MD, Kathleen M. Mylotte, MD, William D. Riemer, Melanie J. Marien, MS, PA-C, and Amin M. Serehali, MA

The Center for Hospice & Palliative Care (C.W.K., J.C.T., P.C.G., D.L.L., W.D.R., M.J.M.), Cheektowaga; Rudra Research (C.B.R.), Buffalo; and Independent Health (K.M.M., A.M.S.), Buffalo, New York, USA

Abstract

Context. Outpatient programs have been traditionally offered in the U.S. under programs such as the Medicare Hospice Benefit. Recommendations now emphasize a blended model in which palliative care is offered concurrently with curative approaches at the onset of serious or life-limiting disease. The efficacy of nonhospice outpatient palliative care programs is not well understood.

Objectives. The aim of the study was to evaluate the clinical impact of a home-based palliative care program, Home Connections, implemented as a partnership between a not-for-profit hospice and two private insurers.

Methods. This was a prospective, observational, database study of 499 Home Connections participants enrolled between July 1, 2008, and May 31, 2013. Measured outcomes were advance directive completion, site of death, symptom severity over time, program satisfaction, and hospice referral and average length of stay.

Results. Seventy-one percent of participants completed actionable advance directives after enrollment, and the site of death was home for 47% of those who died during or after participation in the program. Six of eight symptom domains (anxiety, appetite, dyspnea, well-being, depression, and nausea) showed improvement. Patients, caregivers, and physicians gave high program satisfaction scores (93%–96%). Home Connections participants who subsequently enrolled in hospice care had a longer average length of stay of 77.9 days compared with all other hospice referrals (average length of stay 56.5 days).

Conclusion. A home-based palliative care program was developed between two local commercial payers and a not-for-profit hospice. Not only did this program improve symptom management, advance directive completion, and satisfaction, but it also facilitated the transition of patients into hospice care,

Address correspondence to: Pei C. Grant, PhD, Center for Hospice & Palliative Care, 225 Como Park Boulevard, Cheektowaga, NY 14227, USA. E-mail: pgrant@palliativecare.org

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Key Words
Palliative care, outpatient care, home-based palliative care, end-of-life care

Introduction

Substantial evidence supports the benefits of inpatient and outpatient palliative care under programs such as the Medicare Hospice Benefit, which is generally available to individuals aged 65 years and older in the U.S. Positive outcomes include reduced symptom burden, improved quality of life, increased patient and family satisfaction, appreciable cost avoidance, and reduction in hospitalizations.[1–7] Thus, the number of hospital-based palliative care programs has grown rapidly. In 2010, 81% of U.S. hospitals with 300 or more beds reported offering inpatient palliative care services.[8] Recommendations now emphasize a blended care model in which palliative care is offered concurrently with curative approaches at the onset of serious or life-limiting illness.[9–14]

Gaps remain in the application of and evidence for palliative care across the continuum, specifically in the outpatient setting, where most patients experience illness and receive care. The advancement of outpatient palliative care, particularly home-based models, has been limited in part by economic realities, specifically insufficient fee-for-service revenue and an absence of financial benefit or incentive for cost avoidance. The emergence of managed care has altered the alignment of economic and clinical outcomes, favoring a broader application of palliative care across settings. Four randomized outpatient palliative care interventions have demonstrated improved symptom control, patient satisfaction, and quality of life, along with reduced health care utilization and costs.[15–21] These home care studies occurred within a closed staff model insurance company, or vertical care system, where the complete spectrum of care, including financial services, is provided by a single health care organization. It is unclear whether these results will extend to horizontal care models, in which health care delivery is provided by many different and often unconnected organizations, and coordination of care is much more difficult.

Although palliative care under the Hospice Benefit has demonstrated positive clinical outcomes, there remain numerous barriers to timely access including challenges in prognostication and discussing death.[22–24] According to one report, the national median length of stay for hospice patients was only 19 days, which may hamper adequate symptom management and support before death.[25]

The present study describes the outcome of a collaborative model between a not-for-profit hospice and two private insurance companies to provide home-based palliative care upstream and outside of the Hospice Benefit. Although the current fee-for-service environment limits the provision of home-based palliative care by a provider such as hospice, there are potential savings via cost avoidance for the health care system and payer. Unlike hospice, home-based palliative care requires neither a limited prognosis nor patients to forgo or not be appropriate for aggressive and curative treatments. The impact of this model on advance directive completion, site of death, symptom severity, and satisfaction is reported. Disposition including entry into hospice and hospice length of stay are also noted.

Methods

Program Description: Home Connections

The Center for Hospice & Palliative Care (Cheektowaga, New York) established Home Connections (HC), a home-based palliative care program, in 2008. HC serves Erie County, New York, and is available to adult patients, 18 years or older, with advanced chronic illness. HC serves patients upstream from the Hospice Medicare Benefit, so patients may still be receiving aggressive or cure-focused treatments and do not necessarily have an expected prognosis of six months or less.

The HC team includes a palliative care-trained registered nurse (RN) coordinator, social worker (MSW), trained volunteers,

and a palliative care physician (MD). Physicians participate in weekly interdisciplinary team meetings to discuss the plan of care and goals for each patient seen the previous week. Social worker involvement in the plan of care is reviewed by the RN coordinator at the time of comprehensive admission and discussed during team meetings. An innovative aspect of the program is the payment model in which two local private insurance payers support the program via a per member/per month fee. Referrals come from physicians, hospice/palliative care agencies, local insurers, or the community (self, family, and friends). Services include pain and symptom management directed by the palliative care physician, patient education, supportive discussions about health care decision making and goals, social work visits to facilitate access to community support services, respite care through volunteers, and 24/7 on-call palliative care nurse support. When clinically appropriate, HC also helps patients transition to hospice care, if desired. Patients also may stop receiving HC services when they become clinically stable and return to self-care or if they require a higher level of care and transition to a more supervised environment such as a hospital, assisted living facility, or nursing home.

Study Population

A prospective, observational, database study of HC program participants enrolled between June 1, 2008, and May 31, 2013, was conducted. Thirty-nine of 685 participants enrolled in the program more than once; only their initial enrollment periods were used in this analysis. Participants who were still enrolled in the HC program at the time of analysis (186 of 685 participants) were excluded. This study received ethical approval from the University at Buffalo Institutional Review Board.

Measures

Administrative and clinical data were gathered retrospectively using Center for Hospice & Palliative Care's standardized data collection instrument (Suncoast Solutions© EMR). Duration of enrollment in weeks, total number of encounters, and encounters per week were measured. *Encounters* included face-to-face visits and telephone calls. Encounters excluded program work that did not directly involve participants, for example, consultations between providers. The proportion of participants who completed the following *advance directives* was measured: the New York State Medical Orders for Life-Sustaining Treatment, health care proxy, and indication of the code status (i.e., do-not-resuscitate order). *Discharge disposition* among participants discharged alive was categorized as home/self-care, hospice care, hospital, or other health care facility (assisted living facility or nursing home). Data with respect to known *location of death* among participants who died during or after enrollment were collected from the database. Location of death was categorized as home, hospital/hospice inpatient unit, or assisted living facility/nursing home. *Symptoms* were routinely assessed by nurses during participant encounters using the Edmonton Symptom Assessment System (ESAS).[26,27] Symptoms are scaled from zero (none or best possible) to 10 (worst possible) and included anxiety, appetite, dyspnea, depression, nausea, pain, weakness, and well-being. Telephone surveys were used to measure patient, caregiver, and physician satisfaction with the HC program. Surveys were administered every 90 days for patients during their program stay, whereas caregivers were surveyed every 180 days. Physicians were surveyed on discharge of patients from the HC program.

Statistical Analysis

Frequency and distributions of participant characteristics at enrollment are reported. Medians and intraquartile ranges of continuous outcomes overall and according to those characteristics are reported. Using the *K*-sample median equality test, differences in enrollment duration across categories of participant characteristics were tested. When analyzing categorical outcomes, percent distributions of participant characteristics within outcome categories were determined. Differences in distributions across categories were tested using the Chi-squared or Fisher's exact test.

It was hypothesized a priori that symptoms would improve during participation in the HC program. Participants were categorized by symptom scores at enrollment, in which scores of 0–2 were defined as "good," 3–6

"moderate," and 7–10 "poor." Each ESAS score was calculated within each week of enrollment, with Week 0 comprising Days 0–6, Week 1 comprising Days 7–13, and so forth. Some participants had multiple scores per week; some participants did not have scores in every week as visits were provided on an as-needed basis. Each mean ESAS score was plotted according to the week from enrollment within the categories defined by that score at enrollment. Linear regression was used to estimate the mean (95% confidence interval) change over time in symptom scores. Models were fit separately for good and moderate/poor scores at enrollment because of symptom improvement would not be expected among patients with a low symptom burden at enrollment. Hypothesizing that these symptoms reach thresholds, models were fit within 0–10, 11–20, and 21–30 weeks of enrollment separately. Scores measured after 30 weeks of enrollment were excluded because of sparse data.

Results

Patient Characteristics

From July 2008 to May 2013, a total of 685 patients were admitted to HC. Four hundred ninety-nine were included in the analysis, with 186 excluded because they were still enrolled at the end of the study period (Table 1). Participants were more likely to be women (57%), elderly (69% aged 70 years or older), and white (89%). The Palliative Performance Scale[28] was assessed at the time of enrollment and ranged from 30% ambulation (totally bedbound) to 80% ambulation (full activity with effort). Life-limiting diagnoses were most commonly neoplasm (51%), circulatory system disorders (17%), respiratory

Table 1
Frequency and Percent Distributions of Home Connections Participants, Median (IQR) Duration of Enrollment, and Percent Completion of Advance Directives, Overall and According to Selected Characteristics at Enrollment

Characteristic	No. (%)	Median (IQR) Wks of Enrollment	Advanced Directive Completion (%)
Overall	499 (100)	14 (5–29)	88.2
Age in years[a]			
21–59	64 (12.8)	17 (5–33)	83.3
60–69	93 (18.6)	18 (5–26)	89.2
70–79	148 (29.7)	13 (5–28)	84.1
80–89	149 (29.9)	14 (7–30)	90.9
90–101	45 (9.0)	11 (4–41)	94.7
Gender			
Female	284 (56.9)	16 (6–32)	89.0
Male	215 (43.1)	11 (5–29)	87.0
Race[a,b]			
White	446 (89.4)	13 (5–29)	89.3
Black	48 (9.6)	22 (12–33)	77.1
Other	5 (1.0)	22 (13–34)	87.5
Marital status			
Married	257 (51.5)	16 (5–30)	85.8
Widowed	155 (31.1)	13 (5–29)	92.2
Other	87 (17.4)	15 (5–28)	86.9
Source of referral[a]			
Self/family/friend	49 (9.8)	11 (5–20)	89.2
Physician	151 (30.3)	20 (7–35)	87.6
Hospice/palliative care	147 (29.5)	12 (4–29)	93.4
Local insurer	125 (25.1)	12 (5–27)	82.5
Health care facility	27 (5.4)	20 (8–35)	97.0
Primary diagnosis			
Neoplasm	255 (51.1)	11 (4–25)	86.4
Circulatory system disorder	87 (17.4)	17 (7–41)	87.5
Respiratory disease	54 (10.8)	15 (6–31)	85.2
Mental disorder	40 (8.0)	11 (5–32)	95.2
Other	63 (12.6)	16 (8–42)	92.7

IQR = intraquartile range; Wks = weeks.
Advance directives include New York State Medical Orders for Life-Sustaining Treatment, health care proxy, and do-not-resuscitate.
[a]Advance directive completion, Chi-squared or Fisher's exact test, $P < 0.05$.
[b]Enrollment in weeks, *K*-sample median equality test, $P < 0.05$.

diseases (11%), and mental disorders, for example, dementia (8%). Physicians (30%), the hospice/palliative care agency (30%), and a local insurer (25%) were the most common referral sources. Patients referred from hospice were primarily people who had stabilized or improved and no longer met hospice enrollment criteria.

Enrollment

The median (intraquartile range) duration of enrollment was 14 weeks (4–29 weeks) (Table 1). Enrollment typically involved 10 (5–17) direct encounters, with an average of 0.7 (0.5–1.4) encounters per week (data not shown). Older participants had significantly shorter enrollment duration than younger participants. Enrollment duration was also significantly shorter among white compared with nonwhite participants, although the total number of encounters was higher, resulting in similar frequencies of encounters across racial groups. Participants referred by physicians or facilities had significantly longer enrollment and greater total number of encounters compared with those referred by nonphysicians (self, family, or friend) or a local insurer (Table 1).

Advance Directive Completion

About 88% of participants had one or more completed advance directives, with 71% of those without advance directives before enrollment subsequently completing them. Health care proxy was most common (77%), followed by selection of do-not-resuscitate status (48%) and New York State Medical Orders for Life-Sustaining Treatment (23%, data not shown). Completion of directives was significantly more likely among older participants, nonblack participants, and those referred by health care facilities and hospice programs.

Discharge Disposition, Entry Into Hospice, and Average Length of Stay

Seventeen participants died while still enrolled in the HC program and 45 had unknown discharge disposition because of change in the patient status such as relocation or change in insurance coverage. Of the remaining 437 participants, 44% (n = 194) were discharged to hospice care, 31% to home or self-care (n = 137), and 24% to a hospital or other facility (hospital, n = 47; other facility, n = 59). Black participants were significantly more likely to be discharged to home/self-care than white participants. Older participants were significantly more likely to be discharged to hospice and nonhospital facilities than younger participants. Married participants and those with cancer were more likely to be discharged to hospice (Supplementary Table 1, available at jpsmjournal.com). Those who transitioned to hospice care were enrolled longer (average length of stay = 77.9 days, median 31 days) compared with those who entered hospice care without an HC referral (average length of stay = 56.5 days, median 16 days).

Site of Death

About half (n = 243) of participants died during or after HC participation, with about half of those (46.5%; n = 113) dying at home. The remainder of deaths occurred in facilities such as hospitals (11.5%; n = 28), nursing homes (8.6%; n = 21), assisted living facilities (2.9%; n = 7), and hospice inpatient unit (30.4%; n = 74). Location of death was not significantly related to any of the examined characteristics at enrollment (data not shown).

Symptom Severity Over Time

Many symptoms were well controlled at enrollment: 79%–95% of participants reported good scores for anxiety, depression, dyspnea, nausea, and pain. Good well-being and appetite scores were less common (45% and 50%, respectively). Only 16% of participants reported good weakness scores at enrollment (Supplementary Table 2, available at jpsmjournal.com).

Figure 1 shows symptom score trajectories according to score at enrollment. Anxiety, appetite, dyspnea, and well-being appeared to improve over time among those who enrolled with initial poor or moderate scores. They also appeared to remain relatively constant among those with good scores at baseline. Depression and nausea also appeared to improve over time among those with poor symptoms at onset; however, sample sizes were small. Weakness and pain scores appeared roughly constant over time, regardless of the score at baseline.

Table 2 quantifies mean change in symptoms over time among participants with moderate or poor symptom control at enrollment.

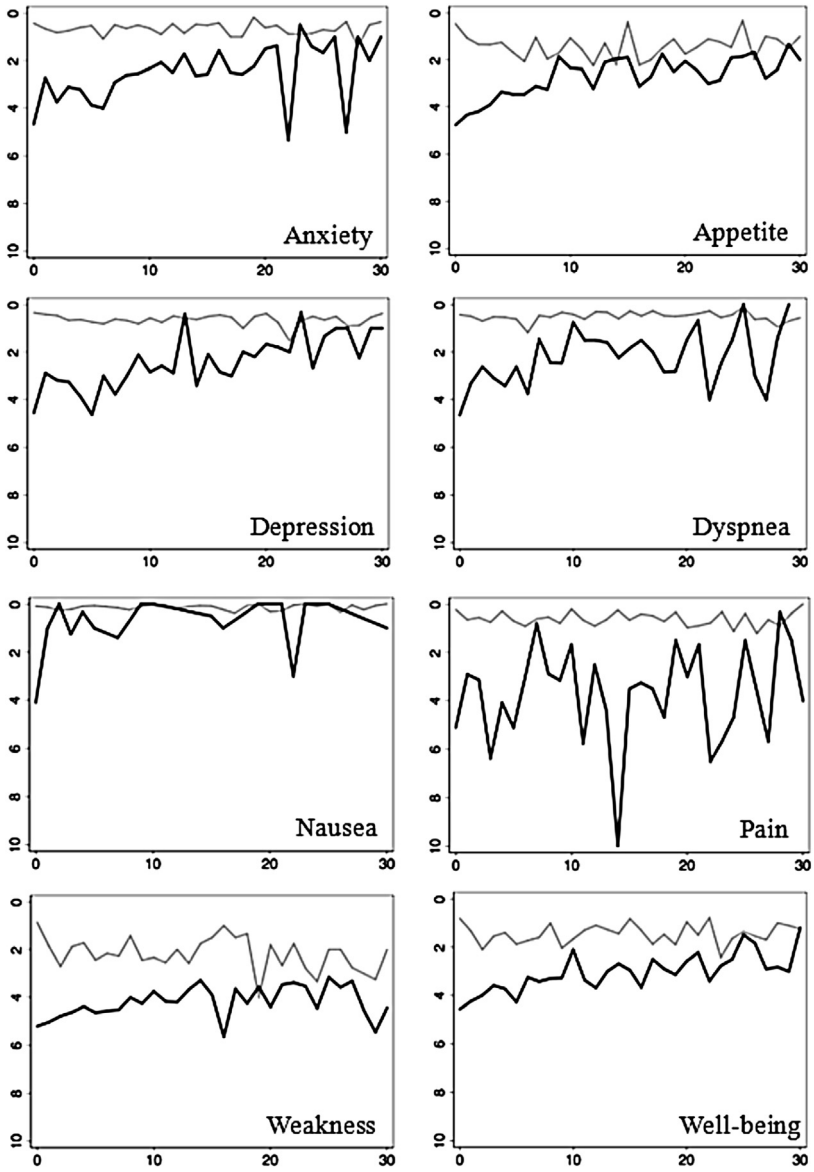

Fig. 1. Mean ESAS item scores (*y*-axis) as a function of the week of enrollment (*x*-axis) within groups categorized by the score at enrollment: good scores (0−2) on onset are represented by the gray line and moderate (4−6) and/or poor (7−10) scores at onset are represented by a black solid line ($n = 428$). ESAS = Edmonton Symptom Assessment System.

Changes were calculated within three periods: 0−10, 11−20, and 21−30 weeks after enrollment. Mean scores for all symptoms declined (i.e., improved) by 0.12−0.32 points/week during the first 10 weeks of enrollment. All declines except those for depression and pain were statistically significant. After the 10th week of enrollment, scores remained stable, on average. Changes ranged from −0.27 to 0.14 points/week; none were statistically significant. Symptoms among those with good scores at onset did not significantly change over time, with two exceptions; appetite and depression scores increased (i.e., worsened) significantly during the first 10 weeks of enrollment (0.11 and 0.04 points/week, both $P = 0.02$) but remained stable thereafter (data not shown).

Patient, Caregiver, and Physician Satisfaction

Patients, caregivers, and physicians were consistently satisfied with the program

Table 2
Mean (95% CI) Changes per Week in ESAS Item Scores Within 0–10, 11–20, and 21–30 Weeks After Enrollment Among Those With Moderate-to-Poor Scores (3–10) at Enrollment[a]

	0–10 Weeks	11–12 Weeks	21–30 Weeks
Anxiety	0.17 (−0.31, −0.03)	−0.01 (−0.13, 0.10)	−0.16 (−0.56, 0.24)
Appetite	−0.24 (−0.30, −0.19)	−0.04 (−0.17, 0.09)	−0.09 (−0.23, 0.04)
Depression	−0.13 (−0.28, 0.02)	−0.04 (−0.27, 0.18)	−0.06 (−0.26, 0.15)
Dyspnea	−0.27 (−0.42, −0.11)	0.11 (−0.01, 0.23)	−0.10 (−0.59, 0.40)
Nausea	−0.32 (−0.64, −0.01)	−0.18 (−2.18, 1.83)	0.04 (−0.48, 0.56)
Pain	−0.25 (−0.52, 0.03)	−0.27 (−0.85, 0.32)	−0.10 (−0.71, 0.52)
Weakness	−0.12 (−0.16, −0.09)	0.02 (−0.15, 0.19)	0.14 (−0.02, 0.31)
Well-being	−0.17 (−0.24, −0.10)	−0.06 (−0.16, 0.04)	−0.07 (−0.25, 0.12)

CI = confidence interval; ESAS = Edmonton Symptom Assessment System.
Number of observations per analysis ≥80.
[a]Number of participants per analysis ranged from 19 for nausea to 347 for weakness.

throughout the study period. Within these groups, 95% of patients and 93% of caregiver respondents reported high satisfaction (score of 4 or 5), and 96% of physicians said the quality of services was excellent or good (Fig. 2).

Discussion

Palliative care programs have experienced rapid growth since 2000, primarily via inpatient consultation services, with most large U.S. hospitals now offering inpatient palliative care.[1–7] Outpatient palliative care has traditionally been offered primarily under the Hospice Medicare Benefit, which is appropriate for patients with an expected prognosis of six months or less who choose to forgo or who are not appropriate for aggressive or curative treatments.[8] As reviewed recently, a growing body of evidence supports outpatient palliative care programs outside of the Hospice Medicare Benefit to provide palliative services throughout the care continuum.[29] This review calls for expansion of innovative care models to support outpatient palliative care.

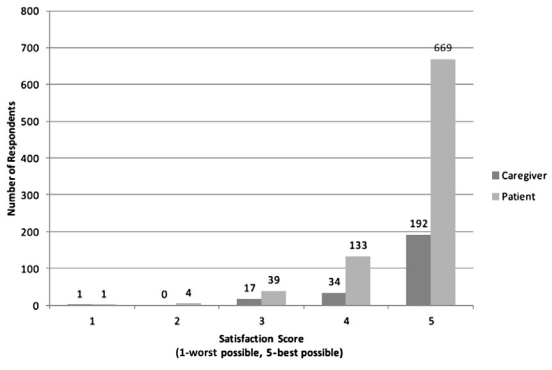

Fig. 2. Patient and caregiver satisfaction scores. Patients and caregivers were asked "How would you rate the overall service and care provided to you? Please consider all aspects of service and care from the time of our first contact with you through today. Rate service on scale where 1 = worst possible and 5 = best possible."

In the present study, community-based outpatient palliative care was financially supported by two commercial insurance companies. Enrollment in home-based palliative care appeared to contribute to an increased rate of actionable advance directive completion, increased likelihood of dying at home, and improvements in multiple symptoms. Hospice referral rates were higher and lengths of stay longer than those observed among patients who had not first been enrolled in the palliative care program.

A 2008 report to Congress from the Department of Health and Human Services estimated that only 18%–36% of adults, and 50% with advanced illness, had completed advance directives.[30] In our study, 71% of patients completed actionable advance directives, with discussions generally occurring at home, with family involvement, rather than during a disease exacerbation. This is important since completion of advance directives is expected to reduce end-of-life costs and help prevent burdensome, unwanted interventions.[31]

Although most Americans wish to die at home (approximately 70%[32,33]), only a third did so in 2009.[34] In the present study, nearly half (46.5%) of patients who were current or

former participants in the HC program died at home, undoubtedly enhancing quality of death and saving costs. Of the patients included in this study, only 11.5% died in a hospital, compared with nearly 25% of deaths in the U.S. in 2009.[34] Compared with patients dying in hospitals, patients dying at home exhibit better quality of life, physical comfort, and psychological well-being.[35] Death in hospitals, particularly intensive care units, also adversely impacts the grief process experienced by family members, with increased rates of preloss grief, post-traumatic stress disorder, anxiety, and depression.[35]

Studies have shown that outpatient palliative care programs, where available, can reduce symptom burden.[15,16,29,36] In this study, six of eight symptom domains showed improvement, typically stabilizing within 10 weeks of enrollment. Consistent with other results,[15,16] our program also received high caregiver, physician, and patient satisfaction scores, with 93%–96% reporting high satisfaction.

In addition, 39% of patients in our study ultimately chose to receive hospice care with lengths of stay approximately one month longer than local patients referred from other sources. With the national median length of stay for hospice patients only 19 days,[37] many patients and their families are not enrolled long enough to take full advantage of the benefits provided by hospice programs. Although both palliative care and hospice address physical and emotional symptoms and provide psychosocial support, hospice provides a much broader range of services as patients approach the end of life along with bereavement support for families for a year or more after their loved one's death. Furthermore, earlier hospice enrollment provides potential financial benefits for commercial payers as well.

American health care has typically offered attempts at aggressive curative care until death is imminent, thus artificially prolonging the dying process.[25] In addition, traditional reimbursement models have rewarded service volume, rather than services that offer value and desired outcomes and minimize burdensome futile care. Palliative care may represent an important offering as new models of health care delivery emerge. In many markets, hospice programs are the major or only provider of palliative care in the home, albeit under the restrictions of the Hospice Medicare Benefit or similarly structured insurance benefits. In the present study, HC was developed as a partnership between local commercial payers and a hospice provider, thus allowing fluid movement of patients into hospice care when desired and, as an unexpected finding, a means to continue palliative care follow-up for patients discharged from hospice care when unexpected stabilization occurred.

Limitations

The primary limitations of this study were the retrospective design and absence of a comparison group. Although national estimates of advance directive completion and location of death provide implicit comparison measures, these outcomes may differ within the local population who would have been eligible for palliative care but did not receive it. It is possible that symptoms would have remained stable or improved in the absence of palliative care, although other studies suggest this is unlikely.[1–5,15,16,29,36] Furthermore, although six of the eight symptoms showed statistically significant improvement in ESAS scores over time, it is possible that small statistically significant changes in ESAS scores may not translate to meaningful clinical changes. The results reported in this study may also not generalize to patients and health care systems in other settings as participants were members of two local insurance company health plans. However, these two companies provide insurance for 61% of the local adult population (M. J. M. and A. M. S., e-mail communication, December 2013). The study population was as or more diverse than those previously examined with regard to diagnosis and age.[15–18] However, most participants were white, limiting generalizability to other racial groups. This is of particular concern given the observed racial differences in advance directive completion, enrollment duration, and discharge disposition. Despite these limitations, our findings provide evidence for the positive impact of a home-based palliative care program implemented as a partnership between a community hospice provider and two local private insurance companies.

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Supplementary Table 1

Percent Distributions of Selected Characteristics at Enrollment According to Discharge Disposition Among 437 Patients Discharged Alive From Palliative Care[a]

Characteristic	Home/Self-Care ($n = 137$)	Hospice ($n = 194$)	Hospital ($n = 47$)	Other Facility ($n = 59$)
Age in yrs[a]				
21–59	13.1	13.9	12.8	6.8
60–69	24.8	17.5	14.9	15.3
70–79	28.5	32.0	31.9	23.7
80–89	29.9	25.3	38.3	39.0
90–101	3.6	11.3	2.1	15.3
Gender				
Female	61.3	54.6	48.9	62.7
Male	38.7	45.4	51.1	37.3
Race[a]				
White	83.9	93.8	95.7	91.5
Black	14.6	5.7	5.3	6.8
Other	1.5	0.5	0.0	1.7
Marital status[a]				
Married	44.5	57.2	51.1	39.0
Widowed	29.9	27.8	34.0	45.8
Other	25.6	15.0	14.9	15.3
Source of referral				
Self/family/friend	11.7	10.8	4.3	6.8
Physician	36.5	28.4	42.6	23.7
Hospice/palliative care	23.4	31.4	29.8	33.9
Local insurer	21.9	23.2	21.3	30.5
Health care facility	6.6	6.2	2.1	5.1
Primary diagnosis[a]				
Neoplasm	43.1	64.4	48.9	30.5
Circulatory system disorder	20.4	11.3	27.7	20.3
Respiratory disease	8.8	11.9	12.8	8.5
Mental disorder	7.3	4.1	6.4	22.0
Other	20.4	8.3	4.3	18.6

[a]Seventeen patients who died while enrolled in the Home Connections program and 45 patients with unknown discharge disposition are excluded.

Supplementary Table 2

Frequency (%) Distributions of ESAS Item Scores at Enrollment ($n = 428$)[a]

ESAS Item	Good (0–2)	Moderate (3–6)	Poor (7–10)
Anxiety	327 (79.4)	73 (17.5)	17 (4.1)
Appetite	207 (49.6)	166 (39.8)	44 (10.6)
Depression	335 (80.3)	72 (17.3)	10 (2.4)
Dyspnea	339 (81.3)	66 (15.8)	12 (2.9)
Nausea	398 (95.4)	15 (3.6)	4 (1.0)
Pain	357 (85.4)	45 (10.8)	16 (3.8)
Weakness	66 (16.0)	267 (64.6)	80 (19.4)
Well-being	185 (44.5)	202 (48.6)	29 (7.0)

[a]Seventy-one participants without ESAS item assessments in the first week of participation are excluded. Row totals may not add to 428 because some participants had missing items.