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# The Palliative Care Program

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*A preliminary report of these data was presented at "Promoting Financial Excellence in End-of-Life Care: A Policy Directions Forum," September 9, 2002, Washington, DC, sponsored by The Robert Wood Johnson Foundation.*

## Background: Recognizing the Need for Palliative Care

The need to improve health care for Americans as they approach the end of their lives has gained increased attention during the past decade. The imminent influx of "baby boomers" into our elderly population has created an additional burden on our health care system: the need to develop new models for providing cost-effective, patient-centered palliative care at the end of life. Persons older than 65 years—a group that currently represents 12.6% of the US population—will nearly double by 2030 to account for 20.2% of the US population.<sup>1</sup> Each year, fewer than 5% of Medicare recipients die. Yet the cost of services in the last year of life for this small segment of enrollees represents 25% of total annual Medicare costs.<sup>2</sup> The mean Medicare cost of health care in the last year of life is approximately \$26,000—about six times the per capita health care cost for Medicare survivors.<sup>2</sup>

Unfortunately, current constraints imposed by Medicare regulations serve as enormous barriers to developing models of palliative care for terminally and chronically ill patients. These barriers and numerous barriers to providing hospice services (eg, patients refusing hospice services, physician uncertainty in determining life expectancy, patient unwillingness to forego curative care, negative connotations of hospice care) result in patients dying

either in acute care units or in intensive care units, sometimes after receiving medically futile care. In 1996, in the Kaiser Permanente (KP) Southern California TriCentral Service Area (KP TriCentral), 63% of patients who died in the intensive care unit and 54% of those who died in the medical/surgical unit had a primary or secondary diagnosis of one of three commonly fatal, incurable conditions: cancer, congestive heart failure (CHF), or chronic obstructive pulmonary disease (COPD).

The KP TriCentral leadership subsequently recognized the need to design a program that changed the focus from inpatient to home-based care for patients nearing the end of life. In contrast to traditional models of care—which emphasize curative treatment until death and offer little, if any, palliative care—the program would integrate palliative care into curative care earlier in the patient's disease process. Seriously ill patients needed services to enable them to better manage their own care at home and thus reduce their need for inpatient and emergency services. With this improved model of end-of-life care, we hypothesized that palliative care patients would be more satisfied with their health care and would use fewer medical services than would their counterparts receiving traditional end-of-life medical care.

## Developing a Palliative Care Program

The KP TriCentral Palliative Care (TCPC) Program began as a pilot study in 1997, and began receiving annual funding in 1998. The TCPC Program is an interdisciplinary, home-based program for patients at the end of life. The program offers these patients enhanced pain control, symptom management, and psychosocial support to improve quality of life and care while reducing the overall cost of care. By blending palliative care and curative measures, the TCPC Program provides gradual transition for patients with a 12-month survival prognosis and thus allows them to retain their primary care physician while receiving home visits from the palliative care team and physician.

Abundantly patient-centered, the TCPC Program's mission—consistent

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<b>Table 1. KP Southern California TriCentral Service Area Hospice and Palliative Care Program team members</b>
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<p><b>Team members:</b> Janet Allen, MSN, RN, Assistant Department Administrator, Hospice Willy Arban, RN, Triage Supervisor, Hospice and Palliative Care David Cherin, PhD, Senior Research Consultant, Partners In Care Tim Clark, RN, Palliative Care Susan Mattered, RN, MN, Assistant Department Administrator, Quality Management Karen Oman, LCSW, Palliative Care Luella Robison, RN, Clinical Nurse Supervisor, Palliative Care June Simmons, LCSW, CEO, Partners In Care Jill Volkman, RN, Intake Nurse, Palliative Care Santee Washington, RN, Clinical Nurse Supervisor, Palliative Care Gretel Whisnant, RN, Clinical Nurse Supervisor, Palliative Care</p>

with that of the KP Southern California Region—is to achieve the best possible quality of life for patients by relieving suffering, controlling symptoms, and restoring functional capacity while remaining sensitive to patients' personal, cultural, and religious values, beliefs, and practices. The program's interdisciplinary health care team (Table 1) encourages and empowers patients to actively participate and collaborate in designing, evaluating, and revising the patient's plan of care.

### Structure and Implementation of the TCPC Program

Focusing on patients at the end of their lives, the TCPC program is designed to serve the approximately 2300 TriCentral members each year who die from a chronic medical condition. Specific criteria for admission into the TCPC Program generally include homebound status, a diagnosis of life-threatening disease (primarily cancer, CHF, or COPD), and a prognosis of not more than approximately one year to live. Referrals originate from many sources, including physicians, discharge planners, home health nurses, and social workers.

Although modeled after KP's hospice program (which operates within Medicare guidelines), the TCPC Program features three important modifications to overcome current barriers to palliative care:

- Because estimating life expectancy is often difficult, referral guidelines are more relaxed for the TCPC Program than for hospice admission (which requires a prognosis of less than six months); patients are accepted into the TCPC Program if they have a prognosis of less than a year to live. Physicians are

asked to refer any patient to the TCPC Program if the physician “would not be surprised if this patient died in the next year.”

- Although the TCPC Program emphasizes improved pain control and symptom management, patients participating in the program need not forego curative care as they do in hospice programs.
- Patients participating in the program are assigned a palliative care physician, who coordinates care from a variety of health care practitioners (including the patients' primary care physician), thus preventing the service fragmentation that often occurs in health care systems.

In addition to these design improvements, the program features five core components, each of which contributes to enhanced quality of care and patient quality of life:

- An interdisciplinary team approach that focuses on the patient and family and in which care is provided by a core team consisting of a physician, nurse, and social worker with expertise in pain control, other symptom management, and psychosocial intervention.
- Home visits by all team members (including physicians) to provide medical care, support, and education as needed by patients and their caregivers.
- Ongoing care management to fill gaps in care and to ensure that the patient's medical, social, and spiritual needs are being met.
- Telephone support via a toll-free number as well as after-hours home visits available 24 hours per day, seven days per week, as needed by the patient.
- Advanced care planning that empowers patients and their families to make informed

decisions and choices about end-of-life care.

### Ongoing Program Quality Measures

A patient survey was administered to all patients participating in the TCPC Program to assess their satisfaction with the care they receive. The program's performance goal is for satisfaction levels among participating patients to be as high or higher than among other patients receiving home health care. Since inception of the TCPC Program, patients completing satisfaction surveys have consistently rated the program highly (4.5 to 4.7 on a scale of 1 to 5, where 5 = most satisfied).

All visiting team members assessed pain level during each contact with the patient and ensured that the mean pain rating remained at 3 or lower on a scale of 0 to 10, where 0 was lowest pain rating. This goal has been consistently met for 96% of patients participating in the TCPC Program.

The TCPC Program has continued to monitor service use for all patients. By analyzing utilization review reports, staff members routinely count 911 calls and unplanned inpatient admissions, try to explain these calls and admissions, and determine what, if anything, could have been done to prevent them. The program's performance benchmark is to reduce the total number of 911 calls and unplanned admissions to fewer than three per month per 100 patients enrolled in the TCPC Program. The TCPC team has reduced the number of these calls and unplanned admissions to a mean of two to four per month per 100 patients enrolled in the program.

### TCPC Program Evaluation Methods

The TCPC Program was evaluated

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by Partners In Care Foundation, an external nonprofit health research group, to determine whether the program met the complex physical, emotional, social, and spiritual needs of chronically ill patients at the end of their lives while improving the cost effectiveness of such care. This evaluation was conducted as both a quality assurance measure and as rigorous research investigation of a breakthrough service model. The Kaiser Permanente Southern California Human Subject Protection Committee approved the study.

### Study Design and Participants

A nonequivalent comparison group design was used in which the intervention group was compared with a group receiving usual care services. The intervention group consisted of patients enrolled in the TCPC Program; the comparison group consisted of KP home health patients who, like the intervention group, had a diagnosis of COPD, CHF, or cancer; two or more emergency department visits or hospital admissions in the past year; and limited life expectancy.

A total of 558 participants were enrolled in the study: 210 patients in the intervention group and 348 in the comparison group. The 73 eligible patients who declined to be interviewed were statistically equivalent in diagnosis, gender, age, ethnicity, and study group eligibility (ie, for intervention or comparison group) to study participants.

To ensure that the intervention and comparison groups were comparable, data analyses were conducted among a subgroup of patients: the 298 participants who died during the two years of the study (159 in the TCPC Program, 139 in the comparison group). By selecting participants who met this selection criterion, we could

compare similar groups of patients at the end of life. The place of death was also recorded for each patient.

### Data Collection

All data were collected between March 1999 and August 2000. Patients were interviewed by telephone seven days after enrollment in either the TCPC Program or the comparison group and every 60 days thereafter. These interviews were conducted by undergraduate and graduate-level research assistants who were blinded to group assignment. Data collected from the interviews included demographic data as well as patients' rating of their illness severity, quality of life, and satisfaction with services. The Reid-Gundlach Satisfaction with Services<sup>3</sup> instrument was used to measure patient satisfaction with services. The patient satisfaction survey yielded overall ratings for three categories: satisfaction with services, perception of service providers, and likelihood of recommending services to others in the future.

Service utilization data were collected from KP administrative databases. These data included number of emergency department visits, physician office visits, hospital days, skilled nursing facility days, home health and palliative visits, and hospice visits.

The cost effectiveness of the TCPC model was evaluated using staff costs only.

### Data Analysis

Analyses were conducted using the SPSS 10.1 statistical software package (SPSS Inc, Chicago, Illinois). Statistically significant between group differences in number of days of service and illness severity were controlled as covariates when service use data were analyzed. Multivariate analysis of co-

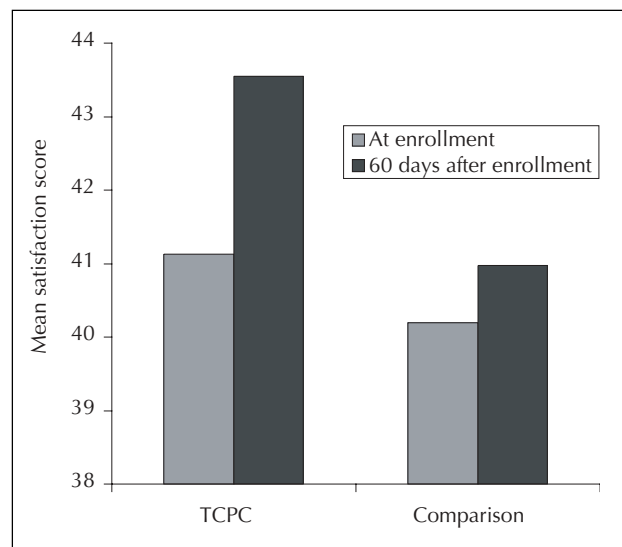


Figure 1. Graph shows change in mean satisfaction scores at enrollment and 60 days after enrollment among participants in the KP Southern California TriCentral Palliative Care (TCPC) Program (intervention group) and comparison group enrolled in a traditional home health program. Mean satisfaction score was significantly higher at 60 days after enrollment for the TCPC group only ( $p = .01$ ). Maximum satisfaction score reported was 48.

variance (MANCOVA) also controlled for Type I error associated with multiple tests. Post hoc Student t-tests were conducted on each dependent variable to determine group differences for each variable. Multiple regression was conducted to determine the portion of costs explained by study group, controlling for days of service, severity of illness, and diagnosis of CHF. Review of the data from the linear regression analysis showed violation of the linearity assumption; therefore, semilog transformation was conducted on the dependent variable (costs) using the LIMDEP 7.0 data analysis software package (Econometric Software, Inc, Plainview, New York). Alpha (threshold of statistical significance) was set at .05.

### Results of TCPC Program Evaluation High Patient Satisfaction

No statistically significant differ-

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ence in mean satisfaction scores was seen between intervention and comparison groups at baseline, although satisfaction at baseline was high for both groups (intervention group mean score = 41, comparison group mean score = 40). However, at 60 days after enrollment, the satisfaction score for the intervention group increased significantly from baseline ( $p = .01$ ), whereas scores for the comparison group remained unchanged (Figure 1).

Our data analysis of patients who died during the study enabled us to compare place of death for intervention and comparison groups (Figure 2); significantly more patients in the intervention group died at home (87%) than in the comparison group (57%) ( $p < .001$ ).

#### Effective Cost Management

The intervention group had fewer emergency department visits, inpatient days, skilled nursing days, and physician office visits than did the comparison group, although the intervention group had more home care visits than did the comparison

group (Figures 3a,b).

For the TCPC group, per-patient cost reduction was seen across diagnoses (range \$3514 to \$8293) but was significant for patients who had cancer ( $p = .001$ ) or COPD ( $p = .02$ ) (Figure 4). Per-patient costs for the intervention group averaged \$6580 less than for the comparison group, a significant reduction of 45% ( $p < .001$ ). Because our cost-effectiveness calculation did not include fixed costs (such as building maintenance), which are higher for acute care services compared with home-based services, the cost reduction results are extremely conservative.

#### Discussion

The results of this study indicate that enrollment in the TCPC palliative care model produced lower costs of care as well as higher patient satisfaction than did enrollment in usual health care services. These findings remained highly significant even after the data were controlled for days of service, severity of illness, and having a CHF diagnosis.

The primary innovations of the TCPC Program were development and implementation of a new model of health care in which services are provided to chronically and seriously ill Health Plan members over an extended period of time. Instead of patients experiencing an abrupt transition from curative care to palliative care—a situation that exists under Medicare guidelines in most care settings—the TCPC Program ensures continuity between traditional medical care and

hospice care through gradual transition from a curative focus to increasing palliative measures. In addition, the KP fiscal structure—currently limited by traditional Medicare financing—was reorganized to support development of an outpatient palliative care model. Because cost savings were realized in an inpatient setting, financial support was transferred from inpatient budgets to support the TCPC home-based program. These organizational and fiscal difficulties are encountered by most Health care systems; therefore, few similarly comprehensive models of care anywhere in the United States can compare with the KP model.

This study offers tremendous implications for health care. As noted in this study, the palliative care model reduced by 45% the cost of services received by patients at the end of life. Given the high cost of health care in the last year of life, this cost reduction represents tremendous savings.

In addition to being costly, acute care at the end of life is not always preferred by patients who are near death. The SUPPORT Investigators<sup>4</sup> found that although most patients studied desired to die at home, about 60% of deaths occurred in the hospital, and 18% occurred in nursing homes or hospice. In addition, many patients who receive acute care treatment at the end of life receive aggressive and futile forms of treatment.<sup>5</sup> Thus, the palliative care program provides an ethical alternative to traditional end-of-life care by allowing patients an opportunity both to die without pain and to remain in the comfort of their own home. The lower use of emergency care, hospital, skilled nursing facility, and physician office visits among members of the intervention group compared with the comparison

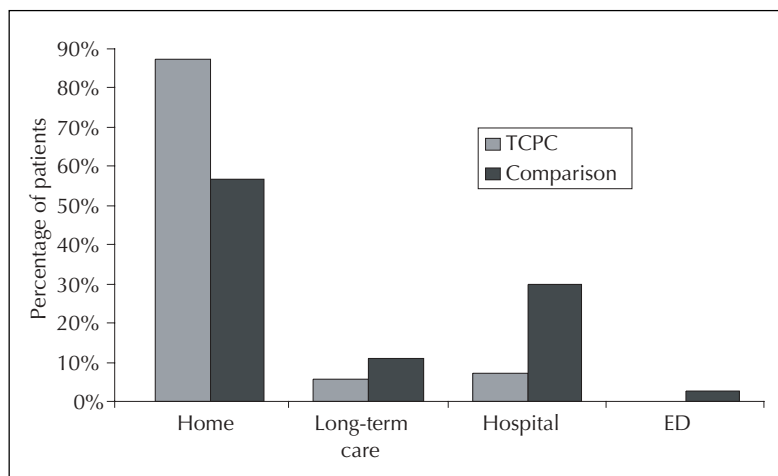


Figure 2. Graph shows place of death among members of intervention and comparison groups. More TCPC patients died at home ( $p < .001$ ) than those receiving usual care; no TCPC patients died in the emergency department.

group illustrates the TCPC Program's ability to effectively transfer end-of-life care from a high-cost, acute care setting to a lower-cost, home-based setting that allows patients to die in the comfort of their own home. The substantially higher satisfaction reported by patients in the intervention group at baseline and at each follow-up—as long as 60 days after study enrollment—supports a recommendation that care be transferred from a hospital setting to the home environment.

The study provided the conclusive evidence needed to increase the standard of care to seriously ill KP members by integrating the TCPC model into usual care within the KP Southern California TriCentral Service Area. An unexpected benefit of the study was heightened consciousness—and acquisition—of improved end-of-life skills by physicians and other health care professionals who do not directly provide palliative care services. In addition, the TCPC team members learned not only to work together as a group but also to develop the skills necessary to plan, implement, test, and improve the quality of end-of-life care. Team members continue to use these skills as they seek further avenues for enhancing the quality of care.

Our evaluation was limited by its research design; to further test this model and to strengthen the validity of the findings, randomized controlled studies are needed. In addition, the potential for generalizing this model to other sites and populations is limited because the study was conducted within a closed-system managed care organization and because the sample was drawn from the Southern California area only. Multisite studies are needed to test the ability to generalize this model to other organizational systems, populations, and communities.

### Future of Palliative Care

Interest in replicating this model has been expressed nationally. In June 2001, the KP Northwest Region implemented the TCPC model. Preliminary analysis has shown results consistent with the findings for the KP Southern California TriCentral Service Area (Andy Kyler, Louise H Clark, MD, personal communication, June, 2002).<sup>a</sup> In January 2002, the TCPC Program was awarded two-year funding from the Garfield Memorial Fund to test replicability of the TCPC Program at two other KP sites. Currently, the TCPC staff is working with health care teams at KP sites in Colorado and Hawaii to initiate the TCPC Program and to both refine and adapt it as needed for successful implementation at each site.

In April 2001, the Project on Death in America (conducted by the Open Society Institute, New York) named Dr Brumley and Ms Hillary to its Faculty Scholars Program. This program provides national recognition to outstanding faculty and clinicians who are working to improve end-of-life care. Dr Brumley and Ms Hillary have developed a comprehensive "toolkit" that includes all the support materials needed to implement the TCPC Program. To benefit the largest professional audience possible, the toolkit is available on the Web for general public access at: [www.growthhouse.org/palliative](http://www.growthhouse.org/palliative).

Dr Brumley led development of

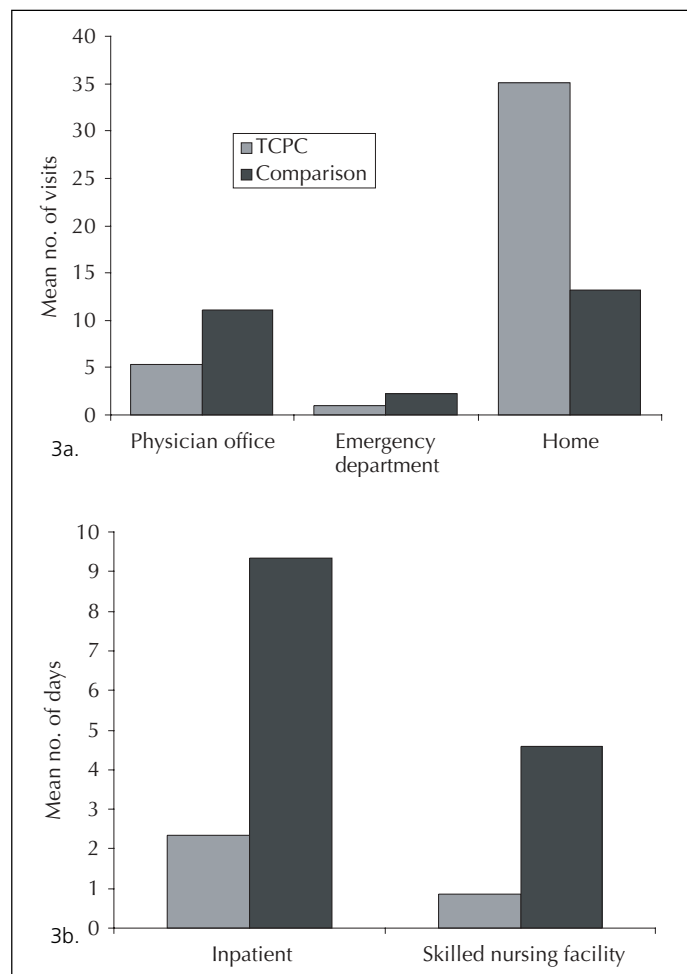


Figure 3a,b. Graphs show service utilization by patients in intervention and comparison groups, categorized by a) mean number of visits and b) mean number of days. Compared with the TCPC group, the comparison group had higher mean number of physician office visits ( $p = .001$ ), emergency department visits ( $p < .001$ ), inpatient days ( $p < .001$ ), and skilled nursing facility days ( $p < .000$ ) but lower mean number of home visits ( $p = .005$ ).

the TCPC Program and continues to serve as its director. Throughout, he has been assisted by Ms Hillary, who serves as nurse manager for the TCPC Program. The KP Southern California TriCentral Service Area leadership team has provided administrative and financial assistance to ensure ongoing operation and expansion of the TCPC Program. The TCPC team has been assisted throughout by the Partners In Care Foundation, an external non-profit agency providing research

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and evaluation expertise and consultation as well as leadership strongly influenced by social work.

Together, this multidisciplinary team contributed to success of the TCPC Program by integrating clinical, financial, service delivery, and research methods. These rigorous methods ensured ongoing success of the TCPC model and facilitated its replication within and beyond the KP system.

Presentations on the TCPC Program have been delivered at professional meetings and conferences internationally. Moreover, Dr Brumley has served as faculty member—and TCPC staff participated—in an Institute for Health Improvement national collaborative on

improving end-of-life care. The TCPC model has been shared with more than 200 health care teams and agencies throughout the United States. In addition, two articles<sup>6,7</sup> have been published in professional journals, and another<sup>8</sup> is in press.

Dr Brumley has testified in Washington, DC, before a congressional subcommittee examining end-of-life health care issues. The purpose of this invitational forum was to assemble key policymakers, government officials, and leaders in health care to discuss the national implications of recent demonstration projects in end-of-life care and to determine next steps toward improving access to services and quality of care for dying Americans and their families. ❖

*To be published in a revised version as: Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. J Palliat Med 2003 Oct;6(5). Reproduced by permission of the publishers, Mary Ann Liebert, Inc.*

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**Acknowledgments**

The program was funded by the Garfield Memorial Fund. Funding for support material was provided by the Project on Death in America, Open Society Institute, New York. David Cherin, PhD, provided the research design, overview of the study, and assistance with data analysis.

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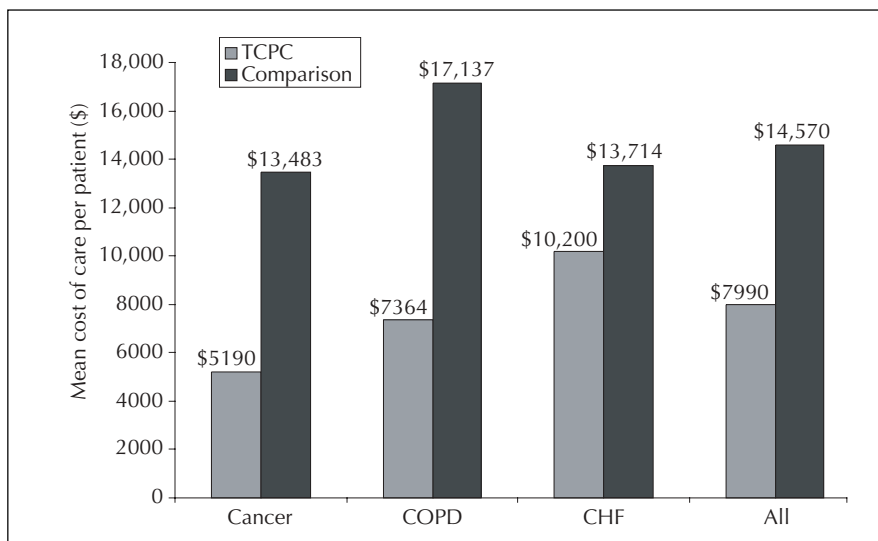


Figure 4. Mean per-patient cost of care, categorized by diagnosis, for patients in intervention and comparison groups. Compared with the TCPC group, the comparison group had higher costs of care for cancer ( $p = .001$ ), for COPD ( $p = .02$ ), and combined for cancer, COPD, and CHF ( $p < .001$ ).