Original Article

Targeted Investment Improves Access to Hospice and Palliative Care

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Abstract

Context. Availability of hospice and palliative care is increasing, despite lack of a clear national strategy for developing and evaluating their penetration into and impact on the target population.

Objectives. To determine whether targeted investment (i.e., strategic grants made by one charitable foundation) in hospice and palliative care in one U.S. state (North Carolina [NC]) led to improved access to end-of-life care services as indicated by hospice utilization.

Methods. Access was measured by the death service ratio (DSR), defined as the proportion of people who died and were served by hospice for at least one day before death. Calculation of the DSR is based on counts of patients accessing hospice by county in a given year (numerator) and U.S. Census projected population data for that county (denominator). Multilevel modeling was the primary analytic strategy used to generate two models: 1) comparison of the DSR in counties with vs. without philanthropic funding and 2) relationship between years since receipt of a philanthropic grant and DSR.

Results. In NC, the average DSR increased from 20.7% in 2003 to 35.8% in 2009 (55% increase). In 2009, 82 of 100 NC counties had a DSR below the U.S. average (41.6%). In Model 1, significant associations were found between county population and DSR ($P = 0.03$) and between receipt of philanthropic funding and DSR ($P = 0.01$); on average, funded counties had a DSR that was 2.63 percentage points higher than unfunded counties.

Conclusion. Receipt of philanthropic funding appeared to be associated with improved access to palliative care and hospice services in NC. J Pain Symptom Manage 2013;46:629–639. © *2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Hospice, palliative care, death service ratio, access

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Introduction

Focused on optimizing quality of life for patients with advanced illnesses, palliative care provides comprehensive management for physical and psychosocial symptoms and aids patients and caregivers in health care decision making.[1] Although appropriate at any phase of disease, palliative care often focuses on the needs of patients with serious life-limiting illnesses who are nearing the end of life, when symptoms are hard to control and existential suffering increases.

Despite evidence showing that palliative care improves quality of life[2] and reduces spending,[3–5] the U.S. has lacked a clear national agenda for developing palliative care models, expanding service delivery, and establishing financing mechanisms. Instead, palliative care has developed ad hoc.

Hospice, a subset of palliative care, has been shaped in the U.S. by reimbursement legislation. Since 1983, the Medicare program has included a hospice benefit. Eligibility requires 1) a life expectancy of six months or less and 2) goals of care that focus on comfort and symptom management rather than cure. Medicare coverage of hospice prompted a steady increase in the number of hospice providers and in the proportion of Medicare decedents who use hospice. The number of hospice programs in the U.S. rose from 1545 in 1985 to 5150 in 2010.[6] Similarly, the number of hospital-based palliative care and hospice programs increased from 632 (15% of hospitals) in 2000 to 1568 (63% of hospitals) in 2010.[7] Factors driving the increase in service availability included high family satisfaction with hospice care;[8–10] reduction in total costs of care with palliative care utilization;[11–13] increasing visibility through national associations' promotion and education; grass-roots efforts (e.g., to promote advance care planning); recognition of Palliative Medicine as a subspecialty by the Accreditation Council for Graduate Medical Education, American Board of Medical Specialties, Centers for Medicare and Medicaid Services, and other national entities; and increased investment in hospice inpatient units and palliative care programs.

Current hospice and palliative care delivery models fall into four general categories: hospital-based palliative care, community-based palliative care, community-based hospice, and inpatient hospice (Fig. 1). Patients may receive care in one of these settings only or may move through settings; a typical progression is from community-based palliative care services to inpatient hospice as illness advances, functional status declines, and clinical needs increase. Representing a loosely

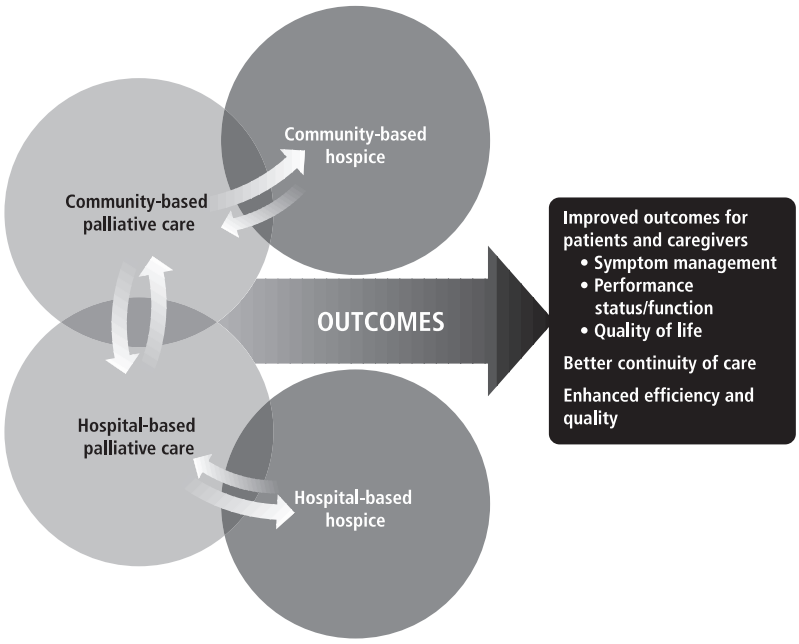

Fig. 1. Four models of palliative and hospice care.

associated mix of organizations and care venues rather than an intentionally designed, seamless continuum, these four delivery models have developed separately and are differently financed. Currently, hospices remain primarily community-based organizations, whereas palliative care providers are mainly organized within inpatient services in non-profit hospitals. There is limited availability of either inpatient hospice or community-based palliative care.[14]

This article examines a simple question with powerful policy implications: do targeted investments in hospice and palliative care contribute to access to and use of these services? We use the term "targeted investment" to indicate that funds were distributed in a way intended to generate a specific outcome. To address this question, we evaluated the effect of private philanthropic funding for the development of hospice and palliative care programs in North Carolina (NC) on access to these services. We used hospice utilization as a summary indicator for access to end-of-life care.

The Duke Endowment, a 501(c)(3) nonprofit charitable foundation, has awarded more than $9.3 million since 2000 to help build inpatient and residential hospice facilities and to develop palliative care programs in the southeastern U.S. More than $5.4 million in Duke Endowment grants have been awarded to existing organizations in NC in support of community-based hospice and palliative care to help stimulate the development of a hospice and palliative care network and to improve the availability of services in local communities. Duke Endowment grants exceeding $3.9 million have helped grantees leverage the funds needed to build residential hospice centers, doubling the number of hospice beds in the region.

This article focuses on the impact of The Duke Endowment's targeted investment on access to hospice and palliative care services; investment was broadly defined as philanthropic funds intended to support development of and access to hospice and palliative care. Our objective was to use the proportion of decedents served by hospice before death as the measure of access[15] to compare counties receiving a targeted philanthropic investment from The Duke Endowment against counties not receiving Endowment funds. Additional purposes were to generate information that may assist in planning for subsequent investment (e.g., investment targeted at reducing between-county disparities in access to hospice and palliative care), establish a baseline against which to monitor the impact of subsequent investments in hospice and palliative care, and create a replicable method for evaluating the impact of investments in hospice and palliative care service delivery, including federal or state investments.

Methods

Outcome and Assumptions

Access to hospice services was measured by the death service ratio (DSR), defined as the proportion of people who died and were served by a hospice provider for at least one day before their death divided by all deaths in the targeted area or population.[15] Calculation of DSR included all decedents in NC regardless of their age or insurance status. Analyses rested on the following assumptions: 1) an increase in the DSR indicates an increase in access to hospice; 2) a person who died in a particular county used hospice services in that county; and 3) Duke Endowment investment in a hospice or palliative care program in a particular county would impact hospice access in that county, with little contamination across county lines.

Data Sources

The DSR was calculated by the Carolinas Center for Hospice and End of Life Care, an association representing more than 100 hospice providers in North and South Carolina. In routinely reporting the DSR, the Carolinas Center uses counts of patients accessing hospice by county each year (numerator) and U.S. Census projected population deaths for that county and year (denominator). Geographic information systems software (ESRI, Redlands, CA) uses U.S. Census projections to determine population at the county level; population data were verified through geodemographic clusters for the U.S. (CLARITAS, Inc., New York, NY).

Data on funding provided by The Duke Endowment was obtained directly from the Endowment. The Duke Endowment annually

reports its grant-making; this information is publicly available. Funding type and amount of grants (U.S. dollars) were mapped to the NC counties in which the funds were distributed.

Statistical Analysis

Maps of NC that depict Duke Endowment funding and DSR by county were generated with ESRI Business Map Pro Mapping Software 5.1 (ESRI, Richardson, TX).

Multilevel modeling was used as the primary analytic strategy to test the hypothesis that Duke Endowment funding of hospice and palliative care programs increased access to hospice care at the end of life (i.e., increased DSR). Multilevel models were selected as particularly appropriate for analyses of longitudinal data with correlated repeated measures. Analyses were conducted in SPSS 18.0 (SPSS Inc., Chicago, IL).

Two models were employed: Model 1 compared the DSR in counties with Duke Endowment funding vs. the DSR in counties without Duke Endowment funding. Model 2 examined the relationship between years since receipt of Duke Endowment funding and DSR. In both models, time was coded so that the intercept reflected the level of DSR (i.e., the dependent variable) in 2003, the first year with available DSR data for all counties. Models included fixed effects for initial status (intercept), time (i.e., year), and county population. Population was included as a time-varying covariate. Receipt of Duke Endowment funding (coded as 0 = did not receive funding, 1 = received funding) was included in the model as a time-varying covariate; thus, a county could be coded as funded or unfunded by The Duke Endowment in each year. Because each model included random effects for the intercept and time, variation could be identified across counties as well as across time. An unstructured covariance structure allowed the random terms (slope, intercept) to be correlated. The possibility of a nonlinear pattern of change over time was tested using higher-order polynomial terms (e.g., quadratic term) but was rejected because, according to the likelihood ratio test, the fit of the quadratic model was not significantly better than a linear model (alpha = 0.05). Thus, the linear model was retained.

Project Funding and Management of Conflict of Interest

This project was a partnership between Four Seasons (Flat Rock, NC) and Duke University Medical Center (Durham, NC). Incorporated in 1979, Four Seasons is a full-service, nonprofit hospice and palliative care organization serving approximately 70% of deaths in Henderson County, NC. The Duke Endowment has provided funding to support inpatient hospice and outpatient palliative care services at Four Seasons. In 2005, The Duke Endowment funded development of the inpatient palliative care service at Duke University Medical Center. Additionally, The Duke Endowment provides substantial annual philanthropic support to Duke University and Duke University Medical Center. Until 2010, The Duke Endowment funded the development of a statewide palliative care quality monitoring database coordinated by two authors of this manuscript (A. P. A. and J. B.). One author (D. H. T.) oversees an undergraduate student scholarship program, the Benjamin Duke Scholars, which is funded by The Duke Endowment. The Duke Endowment did not contribute to this analysis, its interpretation, or a decision to publish, except to provide information about the grants they funded.

To manage conflict of interest, an additional Duke researcher was recruited to this project (R. S.) to assist with data acquisition and analysis; R. S. did not receive any funding from The Duke Endowment. The analysis was restricted to global assessment of hospice and palliative care service funding as it related to the DSR at the county level, with information obtained from an outside organization (Carolinas Center for Hospice and End of Life Care). Finally, two external peer reviewers (C. R., J. K.) were asked to independently review the manuscript for balance and potential bias; they are listed in the Acknowledgments but not as authors, to avoid the possibility that co-authorship might influence their review.

Results

Targeted Investment and Increased Use of Hospice Care

During the study period (2003–2009), 28 of the 100 NC counties received funding from

The Duke Endowment to support development of community-based hospice and palliative care. Multiple grants of varying sizes were awarded to existing organizations to help stimulate the development of a hospice and palliative care network and to improve the availability of services in local communities; details are provided in Table 1. Comparisons between unfunded and funded counties are presented as estimated marginal means in Table 2.

In 2009, the average DSR in NC was 35.8% (range 5.4%–63.7%); this figure represents a 55% increase over the 2003 average DSR of 20.7% (range 0%–41.3%). Eighty-two of the 100 counties in NC had a DSR below the 2009 U.S. average of 41.6%; the average DSR of these 82 counties was 28.2% (range 5.4%–41.0%). The DSR in 67 of the 100 NC counties fell below the 2009 state average of 35.8%; in these 67 counties, the average DSR was 25.7% (range 5.4%–35.7%). The 10 NC counties with the highest DSR in 2009 had an average DSR of 51.8% (range 47.4%–63.7%), whereas the lowest 25 counties had an average DSR of 18.9% (range 5.4%–24.0%). Visual inspection of Duke Endowment grants mapped onto NC counties suggests that the counties with the highest DSR are locations of philanthropic investment and that locations of lowest DSR are areas without investment (Fig. 2).

Relationship Between Targeted Investment and DSR

In Model 1, DSR in counties that received Duke Endowment funding was compared with DSR in counties that did not receive Duke Endowment funding. In NC, the DSR generally increased over time from 2003 to 2009 (B = 1.79; SE = 0.14; t = 12.65; $P < 0.001$) (Fig. 3). There was a significant association between county population and DSR (B = 0.000014; SE = 0.000006; t = 2.17; $P = 0.03$), suggesting that for every 100,000 person increase in county population, DSR increased by 1.4 percentage points. There was a significant association between receipt of Duke Endowment funding and DSR (B = 2.63; SE = 1.04; $t = 2.54$; $P = 0.01$), indicating that, on average, funded counties had a DSR that was 2.63 percentage points higher than unfunded counties.

Model 2 examined the relationship between DSR and the number of years since receiving Duke Endowment funding. Again, results showed that the DSR increased over time generally in NC from 2003 to 2009 (B = 1.70; SE = 0.15; t = 11.05; $P < 0.001$), and the DSR increased as county population increased (B = 0.000025; SE = 0.000009; t = 2.61; $P = 0.01$). In 2003 (i.e., at the intercept), there was a significant association between number of years since receiving Duke Endowment funding and DSR (B = 1.76; SE = 0.32; $t = 5.47$; $P < 0.001$). For each year of Duke Endowment funding, the 2003 DSR increased by 1.76 percentage points. There was also a significant interaction between time and years since Duke Endowment funding (B = 0.10; SE = 0.04; t = 2.51; $P = 0.01$), indicating that the rate of change in the DSR from 2003 to 2009 increased with number of years since receiving Duke Endowment funding. This indicates that the impact of funding persists and increases, so that over time the impact of Duke Endowment funding is magnified (when DSR is considered as the outcome). Finally, there was a significant interaction between county population and number of years since receiving Duke Endowment funding (B = −0.000006; SE = 0.0000018; t = −2.99; $P = 0.004$), indicating that there was a greater increase in the DSR associated with number of years since receiving Duke Endowment funding in counties with smaller populations.

Discussion

This study sought to determine whether targeted philanthropic investment helps increase access to hospice care. Access was measured by a percentage termed DSR, which was calculated as the proportion of all decedents (denominator) to those who were served by hospice at least one day before death (numerator). NC counties receiving philanthropic grants from a single charitable funder (The Duke Endowment) were compared with counties not receiving grants from this funder. Results from 2003 to 2009 indicate that receipt of a philanthropic grant did improve access. The DSR increased in those counties receiving funds from The Duke Endowment; these increases were in addition to increases generally

Table 1

North Carolina Counties Receiving Palliative Care Grants From The Duke Endowment

County	Population (2010)	Population Change, From 2000 to 2010 (%)	Median Household Income (2009)[a]	Funding Awarded	Number of Grants	Grant Year(s)
Buncombe	238,318	15.5	**$40,979**	$200,000	2	2003–2004; 1996–1998
Burke	90,912	2.0	**$36,177**	$25,000	1	1999–2000
Cabarrus	178,011	35.8	$52,988	$150,000	1	2003–2005
Caldwell	83,029	7.3	**$35,489**	$100,000	1	2002–2003
Catawba	154,358	8.9	**$42,100**	$250,000	5	2006–2006; 2005–2006; 2000–2001; 1999–2000; 1998–1999
Cleveland	98,078	1.9	**$38,304**	$250,000	3	2005–2005; 2004–2005; 2003–2004
Davidson	162,878	10.6	**$43,420**	$150,000	1	2007–2008
Duplin	58,505	19.2	**$31,026**	$150,000	1	2007–2008
Durham	267,587	19.8	**$48,770**	$395,500	3	2006–2006; 2005–2006; 2004–2005
Forsythe	350,670	14.6	**$45,769**	$765,000	6	2007–2010; 2003–2004; 2002–2002; 2001–2002; 2000–2001; 1997–1998
Gaston	206,086	8.3	**$40,940**	$150,000	1	2005–2007
Guilford	488,406	16.9	**$44,386**	$592,589	8	2007–2008; 2006–2007; 2005–2006; 2001–2002; 2000–2001; 1999–2000; 1998–1999; 1997–1998
Henderson	106,740	19.7	**$44,408**	$902,810	7	2007–2009; 2007–2008; 2006–2007; 2006–2006; 2005–2006; 2003–2004; 1997–1998
Iredell	159,437	30.0	**$47,979**	$150,000	1	2004–2005
Johnston	168,878	38.5	**$49,501**	$150,000	1	2009–2010
Mecklenburg	919,628	32.2	$53,158	$150,000	1	2006–2007
New Hanover	202,667	26.4	**$44,719**	$545,000	6	2002–2005; 2004–2004; 2003–2004; 2001–2002; 2000–2001; 1999–2000
Orange	133,801	13.2	$51,944	$212,302	3	2003–2004; 2002–2002; 2001–2002
Pitt	168,148	25.7	**$36,339**	$149,883	2	2007–2008; 2004–2005
Richmond	46,639	0.2	**$30,449**	$100,000	1	2000–2001
Robeson	168,148	25.7	**$36,339**	$150,000	1	2006–2007
Rockingham	93,643	1.9	**$36,104**	$150,000	1	2007–2008
Rutherford	67,810	7.8	**$34,016**	$250,000	3	2004–2004; 2003–2004; 2002–2004
Scotland	36,157	0.4	**$31,974**	$100,000	1	2002–2004
Surry	73,673	3.4	**$34,397**	$150,000	1	2007–2008
Wake	900,993	43.5	$63,770	$710,647	4	2008–2009; 2006–2009; 2001–2002; 2000–2001
Counties receiving grants ($n = 27$)	5,623,200	15.9	**$40,572**			
Counties not receiving grants ($n = 73$)	3,912,283	12.3	**$39,099**			

[a]Bold indicates median household income below the U.S. median of $50,221.

Table 2
Mean Death Service Ratio for All North Carolina Counties by Year and Funding Status

Funding	Year	Death Service Ratio Mean (SE)[a]	95% CI
No Duke Endowment funding	2003	18.3 (0.9)	16.4–20.1
	2008	26.7 (1.2)	24.3–29.2
Duke Endowment funding	2003	26.3 (1.5)	23.4–29.2
	2008	39.7 (2.0)	35.7–43.6

[a]Estimated marginal means, controlling for population using a population value of 87,734.

occurring in the DSR during the study period. Impact of Duke Endowment funding persisted across time and was most prominent in counties with smaller populations.

This study provides proof of concept for DSR as a feasible and instructive measure of access to hospice care. We wanted to test this analytic method and provide baseline information that could be useful as more investment in, and proliferation of, palliative care occurs. Despite the limitations, the DSR might be considered a means of verifying access to end-of-life care. For this demonstration, NC allowed for a unique "natural experiment" because of 1) the presence of a philanthropic organization that has strategically funded hospice and palliative care programs in NC and 2) prior investment, provided by the same philanthropic organization, for the development of data collection, data access, geospatial analysis, data management, and analytic capacity in this area.

The results of this study could help to inform strategic planning on a state or regional basis and policy intended to improve access to hospice and palliative care nationally. The DSR proved to be a workable measure of access; the analysis was feasible and yielded information that could assist with the planning of subsequent investments in hospice and palliative care (e.g., investment targeted at reducing disparities in the DSR across counties). Although presented as pilot findings, our results do establish a baseline against which to measure the impact of subsequent investments, whether by The Duke Endowment, other philanthropic funders, or state or federal agencies.

In spite of The Duke Endowment's success in expanding access to hospice through focused grant-making, our analysis found persistent disparities in access across NC counties. Possible reasons include difficulty delivering services in rural areas where patients are more geographically dispersed, higher rates of diseases warranting palliative care in certain areas, socioeconomic factors inhibiting individuals from seeking hospice and palliative care, lack of providers in certain areas (particularly rural ones), and cultural factors (e.g., local attitudes toward dying). Here, the confirmation that investment can improve a targeted outcome shows how results might be used to inform policy—when analysis of the DSR identifies an access gap, such as rural or racial/ethnic disparities, investment can be targeted so as to address the gap.

To improve outcomes in the most underserved counties, a funding approach that aims to maximize local (i.e., county-level) return on investment may be more effective than one seeking to maximize aggregate statewide return on investment. A county-by-county approach to each county's specific needs might entail the following steps: determine which counties have a low DSR and high Medicare decedent costs; review death records, looking for trends in disease categories and correspondingly high costs; analyze each county's DSR by race/ethnicity and age to uncover potential disparities and unmet needs; in targeted counties, identify hospice and palliative care organizations that are willing to partner with the funding agency and quantify their organizational strength (e.g., financial stability, presence of full-time medical director); strategize with these organizations regarding ways to lower costs and increase the DSR (e.g., through local disease management programs); finally, analyze data to determine the impact of grant size and timing of investment on outcomes, so as to intelligently guide future investments. Strategic planning should take into account reasons for low performance, paying attention to modifiable vs. currently unalterable factors.

Counties receiving Duke Endowment funding had higher DSRs at baseline (Table 2), suggesting that these counties, in aggregate, had

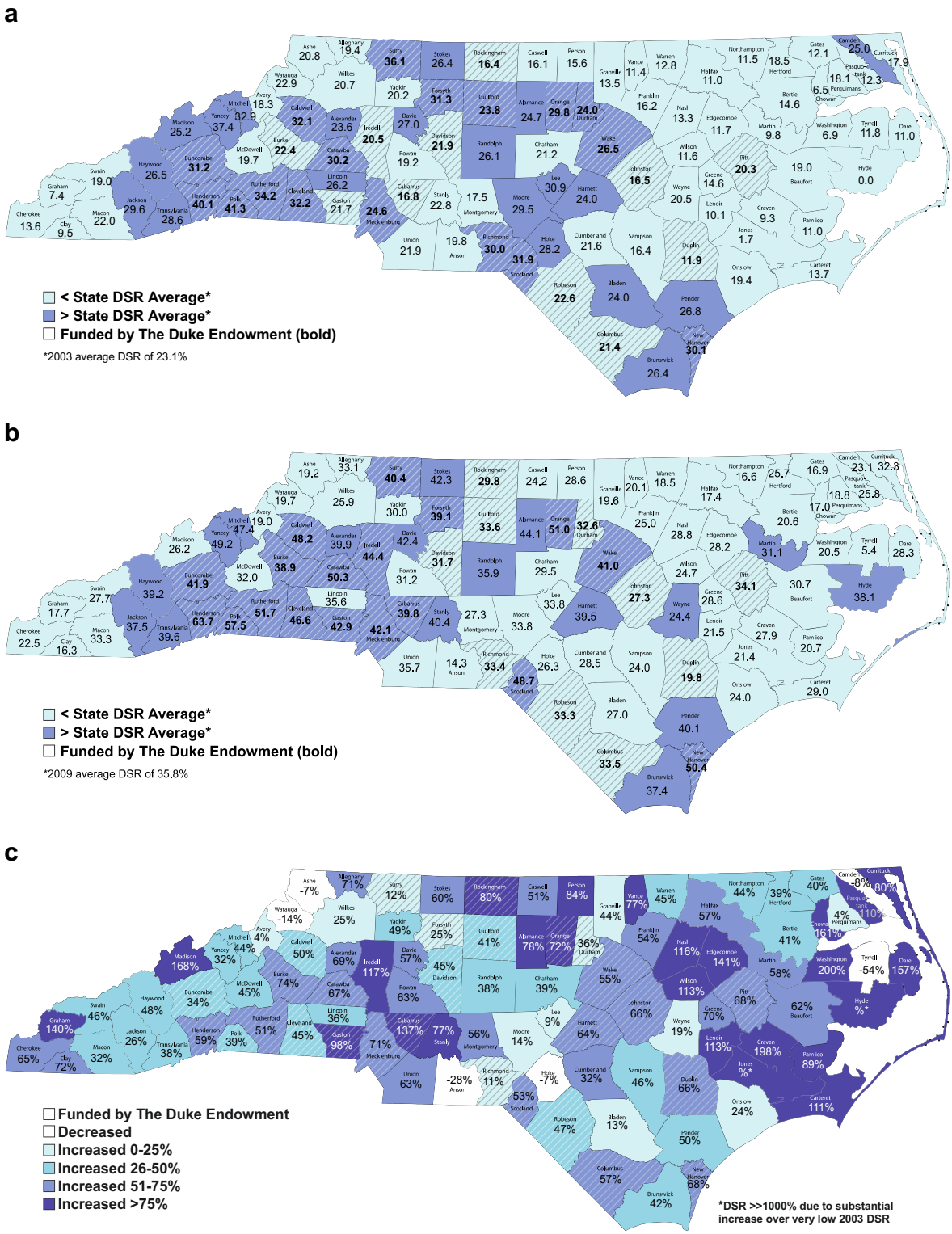

Fig. 2. Change in DSR across North Carolina counties, 2003–2008, and relationship to The Duke Endowment (TDE) funding. a) Association of philanthropic investment with DSR, 2003. b) Association of philanthropic investment with DSR, 2009. c) Association of philanthropic investment with change in DSR, 2003–2009. DSR = death service ratio.

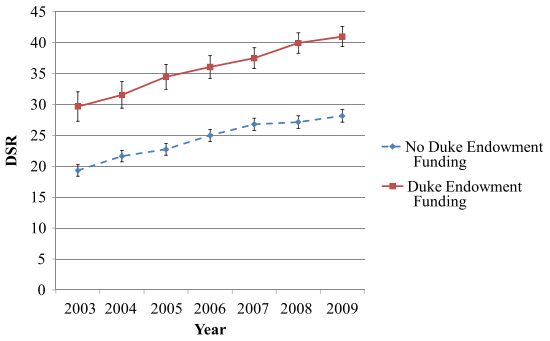

Fig. 3. Mean DSR for all counties by year and funding status. DSR = death service ratio.

greater hospice availability and more robust hospice referral patterns in 2003. Regions with the most sophisticated approaches to end-of-life care and savvy hospice programs may have been the ones that applied for and received philanthropic funding from the Endowment; this is an important limitation to this study. Conversely, the communities that are the most underserved may lack the infrastructure necessary to initiate the process of seeking philanthropic funds and, therefore, the availability of funding may be more of an indicator of a particular county's level of interest in palliative care rather than the funding itself. As a first step, a comprehensive strategy for strengthening models of palliative care and hospice and for supporting the development of community-based organizations using these models may be needed. As a result of resource scarcity at the points of greatest need, federal or state participation in this process is likely required.

This focused exploratory study has several acknowledged limitations and should be viewed as a proof of concept. First, total number of hospice deaths and DSR are surrogates for access; they merely quantify the number and proportion of individuals who access hospice services before death regardless of when care was accessed before death. As a measure of access, the DSR is imperfect. For example, it cannot discern whether hospice services are available, but individuals choose not to access them. An increase in the DSR was assumed to indicate an increase in access to hospice, but other potential reasons for increased DSR were not explored. We also assumed that most patients accessing community- and hospital-based palliative care would ultimately access hospice services, although this assumption was not tested. Reasons for lack of access to hospice were not identified or addressed. The demonstrated increases in access were modest and were evaluated by a single summary measure, the DSR. Better outcome measures are needed; as measures of access, DSR and total number of hospice deaths do not elucidate critical outcomes such as the quality of care or quality of death.[16] The DSR increases as total county population increases, and we do not know what this potential confounder means. These measures cannot differentiate where along the care continuum patients accessed care, that is, whether patients accessed palliative care and then segued to hospice, accessed hospice only, or accessed palliative care but chose not to proceed to hospice; neither do they tell us when hospice actually began in relation to death. Analyses assumed county-based catchment, that is, a hospice patient who died in a particular county was assumed to have used hospice services in that county. Likewise, analyses tested the hypothesis that Duke Endowment investment in a hospice or palliative care program in a particular county would lead to hospice uptake in that county, with little contamination across county lines. Breakdown of data by county is driven by the availability of data; county breakdown only roughly estimates the pattern of service delivery. In reality, hospice service areas may cross county lines; individuals living in one county may access care in another county; and competition for populations beyond their county borders may skew the geographic distribution of DSR. Nonetheless, the general patterns emerging from this study have face validity and appear consistent with the fact that most hospice programs in NC are organized on a county basis. Any clear link between the exposure (Duke Endowment investment) and outcome (DSR), how these investments were used within each county, and other possible county or population-based confounders or covariates remain topics for further study. Finally, it is possible that change in the DSR in certain counties occurred because of philanthropic gifts from sources other than The Duke Endowment.

Expansion of this study's approach, using a model that incorporates a broader set of baseline characteristics of the regions of

interest and outcome measures in addition to DSR, could improve our ability to assess changes in outcomes such as access to care and disparities in hospice and palliative care. Although philanthropic efforts can play a role in the development of such models, governmental support (such as through the Centers for Medicare and Medicaid Services) will likely be necessary to 1) develop a robust methodology for evaluating the impact of funding different models of hospice and palliative care and 2) achieve maximum improvement in access to care, symptom relief, and cost savings for investments made in hospice and palliative care.

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