



Online article and related content
current as of April 5, 2010.

Shifting Place of Death Among Children With Complex Chronic Conditions in the United States, 1989-2003

Chris Feudtner; James A. Feinstein; Marlon Satchell; et al.

JAMA. 2007;297(24):2725-2732 (doi:10.1001/jama.297.24.2725)

<http://jama.ama-assn.org/cgi/content/full/297/24/2725>

Correction

[Contact me if this article is corrected.](#)

Citations

[This article has been cited 16 times.](#)
[Contact me when this article is cited.](#)

Topic collections

Patient-Physician Relationship/ Care; End-of-life Care/ Palliative Medicine;
Pediatrics; Pediatrics, Other
[Contact me when new articles are published in these topic areas.](#)

Subscribe

<http://jama.com/subscribe>

Permissions

permissions@ama-assn.org
<http://pubs.ama-assn.org/misc/permissions.dtl>

Email Alerts

<http://jamaarchives.com/alerts>

Reprints/E-prints

reprints@ama-assn.org

Shifting Place of Death Among Children With Complex Chronic Conditions in the United States, 1989-2003

Chris Feudtner, MD, PhD, MPH

James A. Feinstein, MD

Marlon Satchell, MPH

Huaqing Zhao, MS

Tammy I. Kang, MD

THE PLACE OF DEATH OF AN INFANT, child, or adolescent who has lived with a medically complex chronic condition (hospital, home, or elsewhere) may be shifting over time. If so, what factors influence the place where these children die?

A growing body of evidence suggests that for pediatric patients who die of terminal illnesses, the location at the time of death has important implications. In addition to many pediatric palliative care clinicians attesting that “home is almost always the preference of the child, who can be in familiar surroundings,”¹ when care is provided in the home setting, parental satisfaction with care appears to be greater,² and subsequent adaptation and outcomes for parents and siblings may be improved.^{3,4} Additionally, the delivery of end-of-life care at home may also reflect the nature of preceding medical communication and decision making. In studies of children who died of cancer, earlier parental understanding regarding the child’s prognosis of no realistic chance for cure has been associated with a greater likelihood of death occurring at home.^{5,6}

Three interrelated developments make questions regarding the place of death timely and germane.^{7,8} First, ad-

Context The place where children with complex chronic conditions are dying may be shifting toward residential homes due to the evolving epidemiology of life-threatening childhood conditions, advances in home-based medical technology, and changes in attitudes about pediatric palliative care and hospice services.

Objectives To determine whether pediatric deaths attributed to complex chronic conditions are increasingly occurring in the home and to assess race and ethnicity disparities in the location of death.

Design, Setting, and Participants Retrospective national-level case series drawn from the National Center for Health Statistics’ Multiple Cause of Death Files spanning 1989-2003. Participants included all deceased individuals aged 19 years or younger with a complex chronic condition excluding injury and noncomplex chronic conditions (as classified by *International Classification of Diseases, Ninth Revision* or *International Classification of Diseases, Tenth Revision*).

Main Outcome Measure Place where death occurred.

Results Among the 22.1% of deaths (198 160 of 896 509 total deaths) attributed to a complex chronic condition between 1989 and 2003, the percentage of individuals dying at home increased significantly ($P < .001$) over time for infants (aged <1 year) (4.9% in 1989 and 7.3% in 2003); 1- to 9-year-olds (17.9% and 30.7%); and for 10- to 19-year-olds (18.4% and 32.2%). Adjusting for decedent characteristics, the odds of dying at home increased significantly each year (odds ratio, 1.04; 95% confidence interval, 1.03-1.04) and were reduced among both black and Hispanic decedents (odds ratio, 0.50; 95% confidence interval, 0.48-0.52 and odds ratio, 0.52; 95% confidence interval, 0.50-0.54, respectively) compared with white decedents.

Conclusions Children who die with underlying complex chronic conditions increasingly are dying at home. Racial and ethnic disparities regarding place of death may represent important limitations and opportunities for improvement in the current systems of pediatric chronic and palliative care.

JAMA. 2007;297:2725-2732

www.jama.com

vances in hospital-based pediatric medical and surgical care are enabling more children to survive longer with what previously were swiftly lethal conditions, with the likely result that the

prevalence of children living with life-threatening conditions is increasing, but to an unknown degree.⁹⁻¹¹ Second, the broadening use in the home setting of new and often sophisticated medical

Author Affiliations: The Pediatric Advanced Care Team (Drs Feudtner and Kang), the Pediatric Generalist Research Group (Drs Feudtner and Feinstein, Ms Satchell), the Biostatistics and Data Management Core (Mr Zhao), Children’s Hospital of Philadelphia, Philadelphia, Pa; Division of General Pediatrics (Drs Feudtner and Feinstein, Ms Satchell) and Oncology (Dr Kang), Department of Pediatrics, University of Pennsylvania

School of Medicine; The Leonard Davis Institute and the Center for Bioethics, University of Pennsylvania (Dr Feudtner).

Corresponding Author: Chris Feudtner, MD, PhD, MPH, General Pediatrics, 3535 Market St, Room 1523, The Children’s Hospital of Philadelphia, 34th and Civic Center Boulevard, Philadelphia, PA 19104 (feudtner@email.chop.edu).

regimens and technologies, ranging from complex polypharmacy to mechanical ventilators, may be increasing the residential population of medically fragile children who at any given moment are at an increased risk of death.^{12,13} Third, recent efforts to facilitate the delivery of pediatric palliative care or hospice may be enabling a larger percentage of terminally ill children to be cared for at home.¹⁴ In combination, these 3 trends might be contributing to an increase in the number of deaths occurring at home, whether unexpected or anticipated.

Whereas a variety of studies have examined the place of death for adults who died due to medical diseases,¹⁵⁻²⁹ population-level data regarding the place of death for children and young adults are thus far limited to 2 published studies. In Wisconsin between 1992 and 1996, of the 1538 infants whose deaths were attributed to either congenital anomalies or conditions of the perinatal period, 62 (4%) died at home.³⁰ In Washington State between 1980 and 1998, among children who died with an underlying complex chronic condition, the place of death (especially for infants) was predominantly the hospital but an increasing percentage were dying at home, rising to 41% among the children who died after their first birthday.³¹ Additionally, this study found that a decedent's race and ethnicity, the geographic location of their home, and the local area level of income all affected the likelihood of a child dying at home, with poorer, black, and Hispanic children being more likely to die in the hospital than at home.³¹ If confirmed to be a more general phenomenon, a significant shift in the site of death from the hospital to home (resulting from some combination of unexpected and anticipated deaths) would present several challenges to health care practice and policy. In both instances, ensuring that children living with life-threatening diseases are receiving high-quality care—whether this care seeks cure, life extension, or palliation—is imperative.

We conducted a retrospective national-level case series of all deaths

attributed to a complex chronic condition that occurred before the decedents' 20th birthday in the United States between 1989 and 2003. We specifically sought to test the hypothesis that the percentage of complex chronic condition-related deaths occurring at home increased over the 15-year observation period.

METHODS

Data Sources and Variables

The Children's Hospital of Philadelphia Committee for the Protection of Human Subjects reviewed and approved the conduct of this study. We used National Center for Health Statistics Multiple Cause of Death Files compiled from national death certificate data for all deaths between 1989 and 2003, restricted to only those individuals who died between birth and their 20th birthday. The files included data regarding decedents' age (classified as birth to <1 year, 1-9 years, 10-19 years), sex, race (classified as white, black, or other), Hispanic ethnicity, state of residence (classified into the 4 major geographic regions defined by the US Census), underlying cause of death identified with *International Classification of Diseases, Ninth Revision (ICD-9)* (1989-1998) or *ICD-10* (1999-2003) codes, and place of death (reclassified into 3 major categories of home residence; hospital, clinic, or medical center; and all other places). Data regarding place of death were excluded for 2622 decedents who died with underlying complex chronic conditions in either of 2 states during the years 1989-1990 or 1 state during the years 1989-1996 because of concerns regarding coding of the place of death. For the 2.2% of decedents in the sample who were missing data regarding Hispanic ethnicity, we imputed the missing values on the basis of a multivariate technique (implemented using the Stata-based *ice* and *micombine* programs^{32,33}), fitting a sequence of 5 regression models that imputed the missing value and combining the resulting data sets to perform the regression models described in "Statistical Analyses."

Case Selection and Classification

Complex chronic conditions were defined as medical conditions that can be reasonably expected to last at least 12 months (unless death intervenes) and that involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center. To identify whether an individual died from a complex chronic condition, we used our previously published classification scheme based on *ICD-9* codes, which assigns diagnoses to 1 of 9 categories: neuromuscular, cardiovascular, pulmonary, renal, gastrointestinal, hematologic/immunologic, metabolic, malignancy, and genetic/other congenital defect conditions.^{31,34} For those individuals who died during 1999-2003 and had *ICD-10* codes listed for the underlying cause of death, we recoded the *ICD-10* codes as *ICD-9* codes and then classified the cases into complex chronic condition categories.

We were able to make 2 assessments of these classification procedures using the 1996 Multiple Cause of Death File, which was prepared for public use by the National Center for Health Statistics, in order to contain for each decedent both *ICD-9* and *ICD-10* codes for the underlying cause of death and up to 15 additional secondary diagnoses.³⁵ Using this file, we first assessed the adequacy of using only the single *ICD-9* code listed as the underlying cause of death to classify cases. Compared with using all available primary and secondary cause of death codes, the single underlying cause of death detected 96% of the decedents with complex chronic condition-related deaths. Given this high level of detection, we performed all analyses using the underlying cause of death ICD code as the basis of classification of a decedent's complex chronic condition status. Next, we compared for each decedent in the 1996 Multiple Cause of Death File the complex chronic condition assignment based on the *ICD-9* and *ICD-10* underlying cause of death codes, with 99% agreement of the assignment

to 1 of the 9 specific complex chronic condition categories.

Statistical Analyses

All analyses were conducted using Stata/MP 9.2 statistical software (Stata-Corp, College Station, Tex). First, the absolute counts and proportions of deaths that occurred at the sites of interest were examined and tested for trends using univariate logistic regression, regressing the occurrence of home death on the year of death and examining the significance of the coefficient for the year of death, which we modeled as a continuous variable.

Next, a multivariable logistic regression model was constructed with selection of covariates based on the authors' prior research,³¹ specified a priori to include year of death, age at death, sex, race, Hispanic ethnicity, type of complex chronic condition (using malignancy as the referent), and geographic location of the home (using the Northeast as the referent). The final model demonstrated a pseudo- R^2 value of 0.16 and a C statistic of 0.78. To determine the significance of interactions between specific states and race and ethnicity characteristics on the odds of death occurring at home, we used the likelihood ratio test of nested reduced models with and without the interaction terms.

Graphic depictions of data for the 1989-2003 interval represent either annual counts of decedents who died at the specified sites or the proportions of deaths occurring at home, with lines and 95% confidence intervals fitted using fractional polynomials that can model in a nonlinear manner the proportion of deaths at home for each of the specified stratifying variables. $P < .05$ was set a priori as the level of statistical significance.

RESULTS

Of the 896 509 deaths that occurred during infancy, childhood, or adolescence in the United States between 1989 and 2003, 22.1% (N=198 160) were attributed primarily to an underlying complex chronic condition. Of these complex chronic condition-related

deaths, 55% occurred in males, 57% were younger than 1 year of age, and 76% were white. Overall, 82% of children died in the hospital and 15% died in the home setting (TABLE 1). Ninety-two percent of infants aged younger than 1 year died in the hospital, whereas 70% of children and adolescents aged 1 to 19 years died in the hospital. Among infants, the predominant cause of death was cardiovascular conditions (32%), followed by congenital or genetic (26%), respiratory (17%), and

neuromuscular (14%) conditions. In the older age categories, the leading cause of death was malignancy (43%), followed by neuromuscular (23%) and cardiovascular (17%) conditions.

Over the 15-year observation period, while the number of deaths attributed to complex chronic conditions declined (in keeping with an overall decline in the total number and rate of pediatric deaths³⁶), the number of deaths occurring at home remained steady for infants (456 home deaths in 1989 to 469 in 2003;

Table 1. Demographics of Decedents With Deaths Attributable to Complex Chronic Conditions, 1989-2003

	No. (%) of Decedents		
	1989-1993 (n = 74 853)	1994-1998 (n = 64 540)	1999-2003 (n = 58 767)
Sex			
Male	41 731 (55.8)	35 688 (55.3)	32 431 (55.2)
Female	33 122 (44.3)	28 852 (44.7)	26 336 (44.8)
Age, y			
Birth to <1	44 441 (59.4)	36 815 (57.0)	32 148 (54.7)
1-9	16 435 (22.0)	13 911 (21.6)	12 500 (21.3)
10-19	13 977 (18.7)	13 814 (21.4)	14 119 (24.0)
Race			
White	57 133 (76.3)	49 034 (76.0)	44 313 (75.4)
Black	14 958 (20.0)	12 881 (20.0)	11 782 (20.1)
Other	2762 (3.7)	2625 (4.1)	2672 (4.6)
Ethnicity			
Non-Hispanic	61 867 (82.7)	53 438 (82.8)	47 361 (80.6)
Hispanic	9954 (13.3)	10 077 (15.6)	11 068 (18.8)
Missing	3032 (4.1)	1025 (1.6)	338 (0.6)
Type of complex chronic condition			
Cardiovascular	20 719 (27.7)	16 741 (25.9)	13 046 (22.2)
Malignancy	13 574 (18.1)	12 663 (19.6)	12 552 (21.4)
Neuromuscular	13 394 (17.9)	11 818 (18.3)	10 627 (18.1)
Congenital/genetic	11 974 (16.0)	10 737 (16.6)	11 423 (19.4)
Respiratory	9201 (12.3)	7562 (11.7)	5491 (9.3)
Renal	2406 (3.2)	1846 (2.9)	1775 (3.0)
Metabolic	1363 (1.8)	1323 (2.1)	1976 (3.4)
Hematologic/immunologic	1347 (1.8)	1133 (1.8)	1219 (2.1)
Gastrointestinal	875 (1.2)	717 (1.1)	658 (1.1)
Region			
South	26 892 (35.9)	23 974 (37.2)	22 575 (38.4)
Midwest	17 988 (24.0)	15 136 (23.5)	13 639 (23.2)
West	17 065 (22.8)	15 026 (23.3)	13 872 (23.6)
Northeast	12 908 (17.2)	10 404 (16.1)	8681 (14.8)
Location of death*			
Hospital	62 392 (85.7)	52 530 (82.1)	47 077 (80.1)
Home	8981 (12.3)	10 204 (16.0)	10 372 (17.7)
All other sites	765 (1.1)	752 (1.2)	849 (1.4)
Other care institutions	574 (0.8)	477 (0.8)	400 (0.7)
Unknown	65 (0.1)	31 (0.1)	69 (0.1)

*Data are excluded for 2622 decedents from 2 states for 1989-1990 and from 1 state for 1989-1996 due to concerns regarding coding of location of death.

$P = .75$ for temporal trend), and increased significantly for children and adolescents (1132 home deaths in 1989 to 1655 in 2003; $P < .001$) (FIGURE 1). Consequently, the percentage of deaths occurring at home increased significantly for all age groups (overall, from 10.1% in 1989 to 18.2% in 2003), but with larger increases for deaths beyond infancy (FIGURE 2). The percentage of individuals dying at home increased significantly ($P < .001$) over time for infants (4.9% home deaths in 1989 to 7.3% in 2003); 1- to 9-year-olds (17.9% to 30.7%), and 10- to 19-year-olds (18.4% to 32.2%). During this same period, there was a significant decline in the percentage of deaths occurring in the hospital ($P < .001$ for temporal trend) for each of these 3 age categories.

The percentage of deaths that occurred at home and the pattern of change in this percentage over time var-

ied substantially among the types of complex chronic conditions (FIGURE 3). Malignancy-associated deaths among children and adolescents aged 1 to 19 years were the most likely to occur at home, and with much of the observed increase in home death occurring between 1989 (27.6%) and 1995 (40.3%), with subsequently stable percentages peaking in 2003 (41.1%). Infant deaths associated with respiratory complex chronic conditions were the least likely to occur at home (range, 0.5%-1.3%).

Adjusting for various demographic and clinical characteristics of the decedents (TABLE 2), the odds of death occurring at home increased by 3.8% (95% confidence interval [CI], 3.4%-4.0%) annually. The decedents' race, ethnicity, and region of home residence were significantly associated with death occurring at home. The odds of dying at home were reduced among black and His-

panic individuals (odds ratio [OR], 0.50; 95% CI, 0.48-0.52 and OR, 0.52; 95% CI, 0.50-0.54, respectively) when compared with whites, and were greatest in the western region of the United States (OR, 1.43; 95% CI, 1.37-1.50) when compared with the northeastern region of the United States. Across all age categories, individuals with malignancy, neuromuscular, metabolic, or congenital/genetic complex chronic condition types were consistently associated with the greatest likelihood of death having occurred at home.

The racial and ethnic disparities regarding the percentage of deaths among decedents with complex chronic conditions were evident across the entire study interval (FIGURE 4). Overall among infants, children, and adolescents the percentage of white non-Hispanic decedents who died at home increased from 13.0% in 1989 to 22.5%

Figure 1. Number of Complex Chronic Condition–Associated Deaths Occurring in Home Residences, Hospitals, and Other Sites, 1989-2003

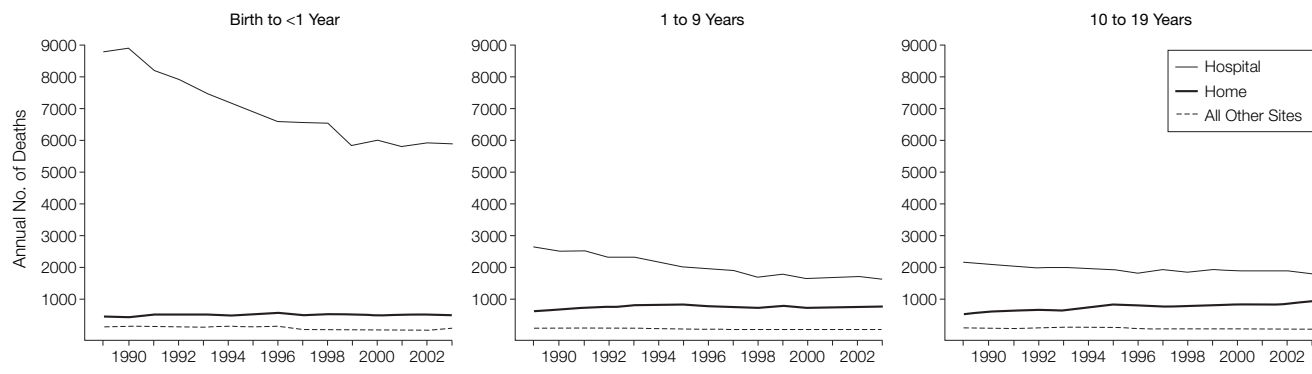
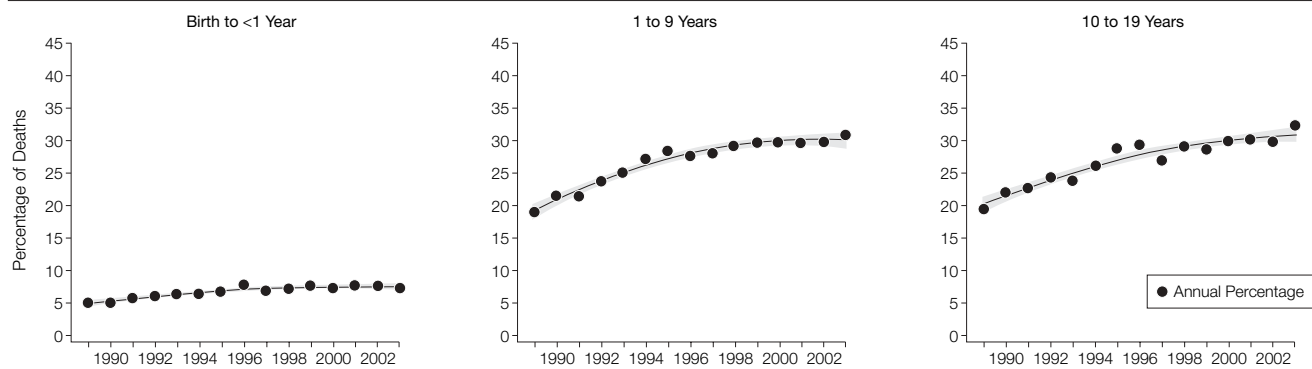


Figure 2. Increasing Percentage of Complex Chronic Condition–Associated Deaths Occurring at Home, 1989-2003



The dots represent the percentage of deaths that occurred at home each year. The curved lines represent the temporal trend in the percentage of deaths that occurred at home as estimated by the best fitting fractional polynomial model, which also estimated the 95% confidence intervals indicated by the shaded areas.

in 2003, whereas the percentage of white Hispanic decedents increased from 6.3% in 1989 to 14.6% in 2003, and the percentage of black non-Hispanic decedents increased from 6.3% in 1989 to 11.2% in 2003.

To illustrate in absolute terms the geographic differences and racial and ethnic disparities previously noted, we examined the percentage of home deaths occurring during the 5-year interval between 1999 and 2003 in the 5 states with the most complex chronic condition-associated deaths, focusing on 3 paradigmatic cases: infants with congenital/genetic conditions; 1- to 9-year-old children with malignancy; and 10- to 19-year-old children and adolescents with neuromuscular conditions (FIGURE 5). Stratifying by the race and ethnicity of the decedents, significant variation in the percentages of home deaths exists both within states and between states ($P < .001$ for tests regarding both state-level differences and

for interactions between specific states and race/ethnicity). For instance, among white non-Hispanic infants dying in Texas with a congenital/genetic condition, 14.1% died at home, while among comparable white Hispanic and black non-Hispanic infants, only 8.9% and 7.4% died at home, respectively. In contrast to the typical pattern of home deaths being less common among black and Hispanic individuals, Florida children and adolescents aged 10 to 19 years who died of neuromuscular conditions did so at home more often if they were black non-Hispanic (45.8%) than if they were white Hispanic (40.0%) or white non-Hispanic (36.8%) children and adolescents ($P = .04$).

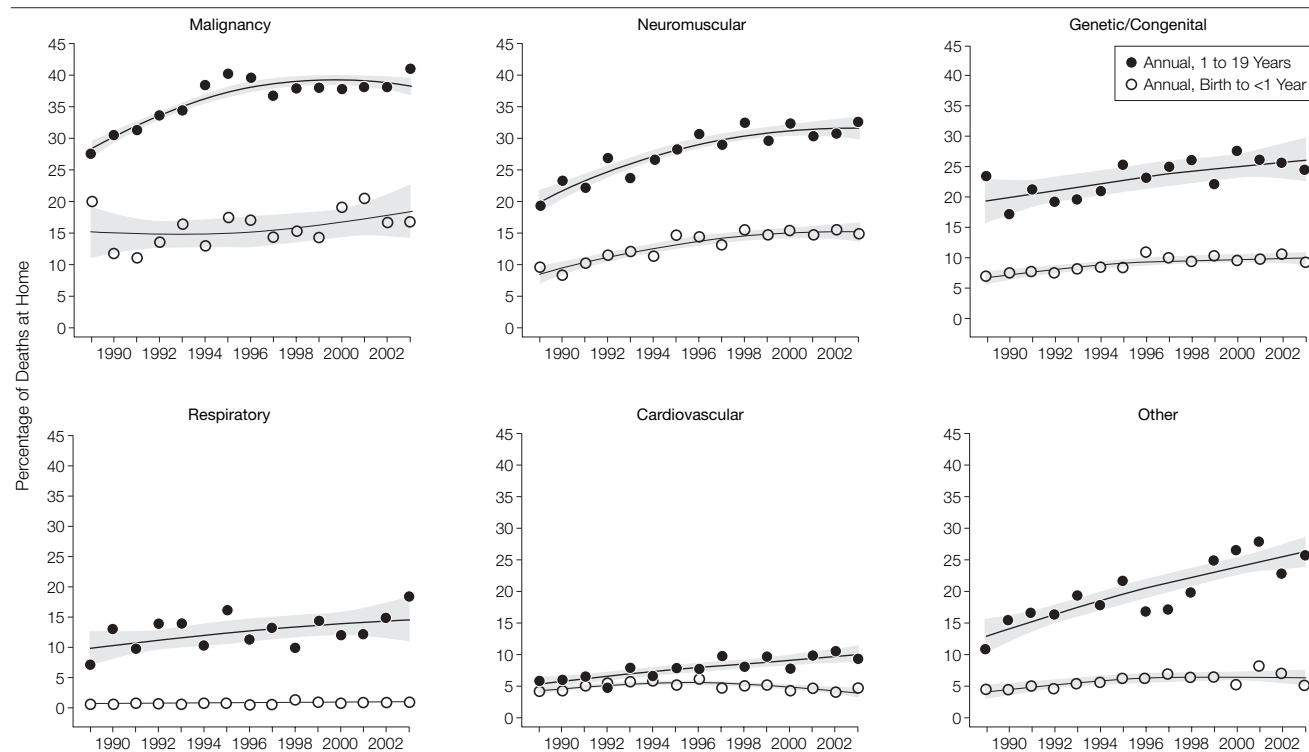
COMMENT

Between 1989 and 2003 across the United States, the place of death shifted from predominantly the hospital increasingly toward the home setting among children whose deaths were at-

tributed to a complex chronic condition. Among this group, which comprised one fifth of all pediatric deaths, significant racial and ethnic disparities were observed in the likelihood of death occurring at home, with these differences persisting even after adjustment for decedents' age, sex, complex chronic condition type, geographic location, and the overall temporal trend.

Before considering the implications of the shift in the place of death toward home, the racial and ethnic disparities, and implications regarding both the structure and equity of pediatric chronic and end-of-life care, the strengths and weaknesses of this study warrant consideration. Three characteristics of the findings support the strength of this study. First, the principal results of this national study accord with a previous study that was limited to only Washington State from 1980 to 1998.³¹ Second, the overall pat-

Figure 3. Percentage of Deaths Occurring at Home by Predominant Types of Complex Chronic Conditions, 1989-2003



The dots represent the percentage of deaths that occurred at home each year. The curved lines represent the temporal trend in the percentage of deaths that occurred at home as estimated by the best fitting fractional polynomial model, which also estimated the 95% confidence intervals indicated by the shaded areas.

tern of the findings, an increasing proportion of deaths due to chronic illness occurring at home with notable differences across racial and ethnic groups, is similar to what has been

noted for adults.^{22,27} Third, the magnitude of the temporal trends and the racial and ethnic disparities regarding where children die are not only statistically significant but substantial and pronounced.

Two limitations may have influenced the detailed precision of the results of this study. First, a small proportion of deaths may have been misclassified as being associated (or not associated) with a specific complex chronic condition category because (1) the data source relies on the original death certificates, some of which may have recorded diagnostic information erroneously (a known problem among adult decedents, especially the elderly^{37,38}); (2) the complex chronic condition classification was based only on the primary underlying cause of death ICD-9 code, which probably resulted in the exclusion of an estimated 4% of deaths associated with complex chronic conditions but which on the death certificate had the complex chronic condition listed only as a secondary cause; and (3) ICD-10 codes were converted into ICD-9 codes (for the years 1999-2003) with an estimated misclassification error of 1%. Second, race or ethnicity may have been misclassified for some decedents due to errors in the original death certificates. A recent community-based study of adults, however, found 97% agreement between race and ethnicity recorded on the death

certificate and the decedents' prior self-reported race and ethnicity.³⁹ Such errors though are unlikely to account for the main finding of the study regarding the increasing percentage over time of complex chronic condition-related deaths occurring at home or to have introduced significant bias into the age-, race-, or ethnicity-specific associations that were observed in this study.

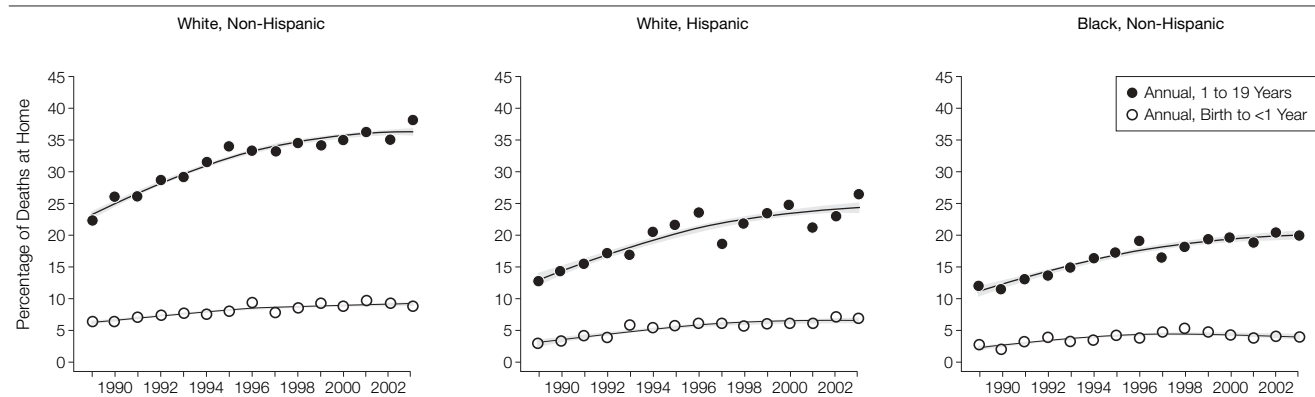
What might explain a greater proportion of children with complex chronic conditions increasingly dying at home and the likelihood of home death being associated with the child's race or ethnicity? Currently, the mechanisms underlying the observed shift in the place of death are unknown and warrant clarification. First, improvements in the medical management of pediatric complex chronic conditions may be prolonging survival, both increasing the prevalence of children living with life-threatening complex chronic conditions and providing more time for advanced decision making. Similarly, advances in medical technology in the home setting, ranging from gastrostomy feeding tubes to home ventilators, may be enabling an increasing percentage of medically fragile or technologically dependent children to spend longer periods of time living at home; hence, the possibility of dying at home (either foreseen or accidental) has risen. Finally, broad shifts in attitudes and decision-making pro-

Table 2. Likelihood of Death Occurring at Home Among Complex Chronic Condition Patients, 1989-2003

	Odds Ratio (95% Confidence Interval)
Year of death*	
Each successive year	1.04 (1.03-1.04)
Sex	
Male	1 [Reference]
Female	1.06 (1.03-1.09)
Age, y	
Birth to <1	1 [Reference]
1-9	2.77 (2.67-2.88)
10-19	2.57 (2.47-2.67)
Race	
White	1 [Reference]
Black	0.50 (0.48-0.52)
Other	0.52 (0.48-0.56)
Ethnicity	
Non-Hispanic	1 [Reference]
Hispanic	0.52 (0.50-0.54)
Region of residence	
Northeast	1 [Reference]
South	1.16 (1.11-1.21)
Midwest	1.27 (1.22-1.33)
West	1.43 (1.37-1.50)
Type of complex chronic condition	
Malignancy	1 [Reference]
Cardiovascular	0.20 (0.19-0.21)
Neuromuscular	0.69 (0.66-0.71)
Congenital/genetic	0.47 (0.44-0.49)
Respiratory	0.09 (0.09-0.10)
Renal	0.10 (0.08-0.12)
Metabolic	0.70 (0.65-0.76)
Hematologic/immunologic	0.26 (0.23-0.29)
Gastrointestinal	0.32 (0.28-0.37)

*Year of death begins at 1989. The model estimates the change in the odds ratio across each successive year (ie, 1989 vs 1990, 1990 vs 1991).

Figure 4. Racial and Ethnic Disparities in the Percentage of Complex Chronic Condition-Associated Deaths Occurring at Home, 1989-2003



The dots represent the percentage of deaths that occurred at home each year. The curved lines represent the temporal trend in the percentage of deaths that occurred at home as estimated by the best fitting fractional polynomial model, which also estimated the 95% confidence intervals indicated by the shaded areas.

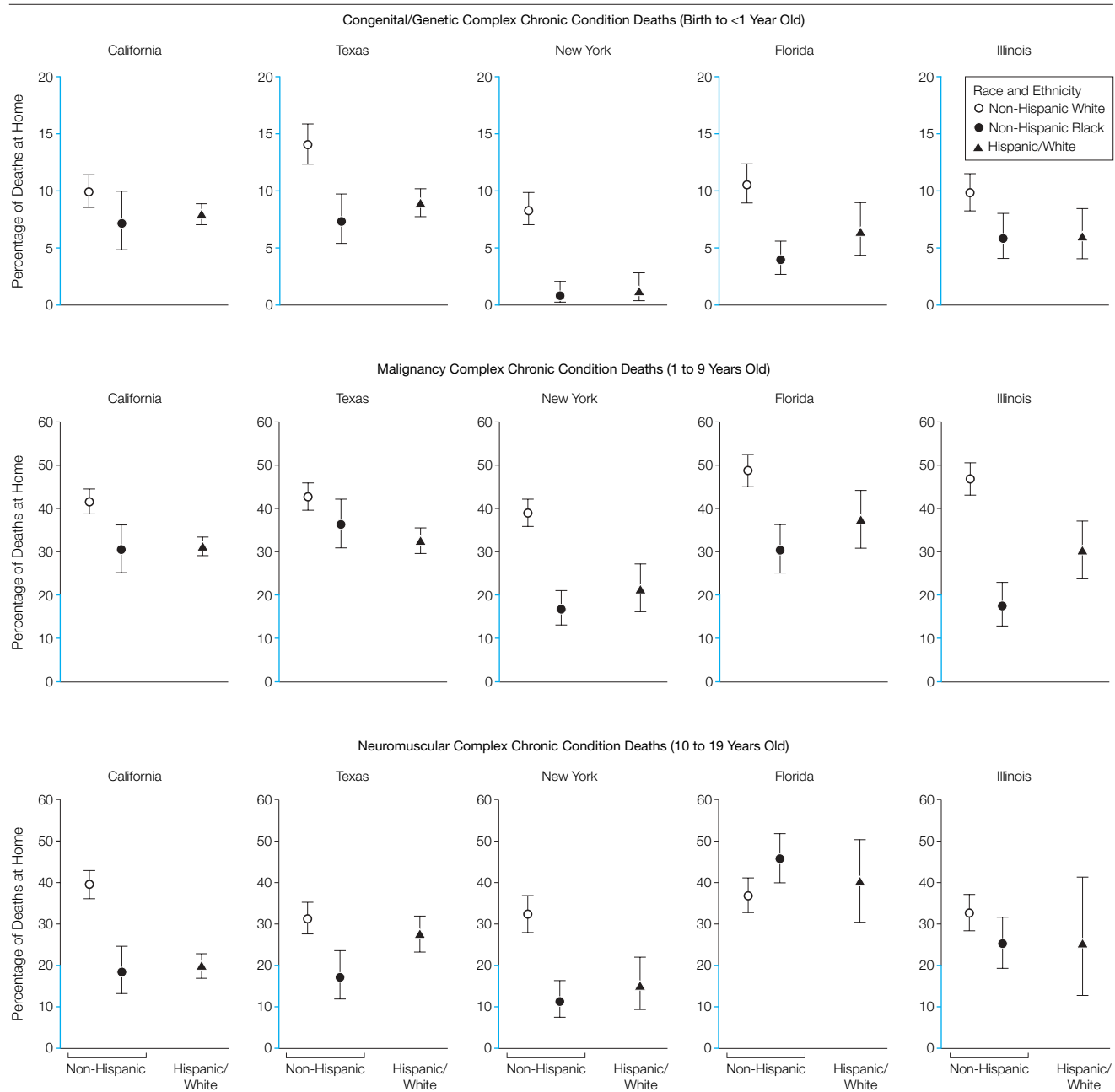
cesses regarding palliative and end-of-life care in US culture and increasing capacity of the health care system to provide home-based services at the end of life may be affecting treatment for children living with life-threatening conditions. Changes in any of these

3 possible underlying mechanisms may also explain the observed racial and ethnic differences, whereby differential access to health care services or medical technology, divergent cultural attitudes or approaches to palliative and end-of-life care decision making, or dif-

fering levels of financial or other support within the patient's or family's social network may make dying at home more or less likely.^{27,40}

Considering the findings of this study, several issues require attention. First, methods to monitor the quality and safety

Figure 5. Percentage of Deaths Occurring at Home for 3 Prototypical Cases by Race and Ethnicity in the 5 Largest States of Residence, 1999-2003



The y-axes differ between the top and lower panels. The blue portion of the y-axes indicate 0% to 20% deaths at home. The confidence intervals (shown as error bars) of percentages are the exact binomial 95% confidence intervals.

of care provided to children with an underlying complex chronic condition who die at home need to be developed, validated, and implemented. Ideally, these methods should be prospective, capable of improving the care of individual children, as well as being tied to quality improvement efforts of all health care organizations that care for children with complex chronic conditions who are residing in their homes. For comparison and improvement in the quality of care across diverse health care systems located in a wide variety of settings, retrospective methods, such as a national mortality follow-back survey with the inclusion of pediatric decedents, are necessary. Second, the capacity of home-based hospice and home nursing agencies to provide care to meet the needs of these pediatric patients for palliative care needs to be assessed and expanded. Finally, as efforts to improve understanding of the sources and remedies of racial and ethnic disparities in pediatric end-of-life care are completed, medical and other concerned professionals need to ensure that all patients have access to necessary care and that all dialogue and interactions regarding decisions about care—whether curative, life-extending, or palliative—are built on mutual understanding, trust, and respect.

Author Contributions: Dr Feudtner had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Feudtner, Kang.

Acquisition of data: Feudtner, Satchell.

Analysis and interpretation of data: Feudtner, Feinstein, Satchell, Zhao.

Drafting of the manuscript: Feudtner, Feinstein.

Critical revision of the manuscript for important intellectual content: Feudtner, Satchell, Zhao, Kang.

Statistical analysis: Feudtner, Feinstein, Zhao.

Obtained funding: Feudtner.

Administrative, technical, or material support: Kang. **Study supervision:** Feudtner, Kang.

Financial Disclosures: None reported.

Funding/Support: The conduct of this study was supported in part by grant K08 HS00002 from the Agency for Healthcare Research and Quality and grant R21-NR008614 from the National Institute of Nursing Research of the National Institutes of Health.

Role of the Sponsor: Neither the Agency for Healthcare Research and Quality nor the National Institute of Nursing Research participated in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or in the preparation, review, or approval of the manuscript.

REFERENCES

- Goldman A, Beardsmore S, Hunt J. Palliative care for children with cancer—home, hospital, or hospice? *Arch Dis Child*. 1990;65:641-643.
- Kreicbergs U, Valdimarsdottir U, Onelov E, Bjork O, Steineck G, Henter JI. Care-related distress: a nationwide study of parents who lost their child to cancer. *J Clin Oncol*. 2005;23:9162-9171.
- Mulhern RK, Lauer ME, Hoffmann RG. Death of a child at home or in the hospital: subsequent psychological adjustment of the family. *Pediatrics*. 1983;71:743-747.
- Lauer ME, Mulhern RK, Schell MJ, Camitta BM. Long-term follow-up of parental adjustment following a child's death at home or hospital. *Cancer*. 1989;63:988-994.
- Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA*. 2000;284:2469-2475.
- Surkan PJ, Dickman PW, Steineck G, Onelov E, Kreicbergs U. Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliat Med*. 2006;20:161-169.
- Committee on Palliative and End-of-Life Care for Children and Their Families; Board of Health Sciences Policy; Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Field MJ, Behrman RE, eds. Washington, DC: National Academies Press; 2003.
- Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med*. 2004;350:1752-1762.
- British Cardiac Society Working Party. Growth-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart*. 2002;88(suppl 1):i1-i14.
- Vincer MJ, Allen AC, Joseph KS, Stinson DA, Scott H, Wood E. Increasing prevalence of cerebral palsy among very preterm infants: a population-based study [published online]. *Pediatrics*. 2006;118:e1621-e1626.
- Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355:1572-1582.
- Palfrey JS, Haynie M, Porter S, et al. Prevalence of medical technology assistance among children in Massachusetts in 1987 and 1990. *Public Health Rep*. 1994; 109:226-233.
- Feudtner C, Villareale NL, Morray B, Sharp V, Hays RM, Neff JM. Technology-dependency among patients discharged from a children's hospital: a retrospective cohort study. *BMC Pediatr*. 2005;5:8.
- Meier DE, Beresford L. Pediatric Palliative Care Offers Opportunities for Collaboration. *J Palliat Med*. 2007; 10:284-289.
- Katz BP, Zdeb MS, Theriault GD. Where people die. *Public Health Rep*. 1979;94:522-527.
- McCusker J. Where cancer patients die: an epidemiologic study. *Public Health Rep*. 1983;98: 170-176.
- Mor V, Hiris J. Determinants of site of death among hospice cancer patients. *J Health Soc Behav*. 1983;24: 375-385.
- Polissar L, Severson RK, Brown NK. Factors affecting place of death in Washington State, 1968-1981. *J Community Health*. 1987;12:40-55.
- Moinpour CM, Polissar L. Factors affecting place of death of hospice and non-hospice cancer patients. *Am J Public Health*. 1989;79:1549-1551.
- Iwashyna TJ, Chang VW. Racial and ethnic differences in place of death: United States, 1993. *J Am Geriatr Soc*. 2002;50:1113-1117.
- Weitzen S, Teno JM, Fennell M, Mor V. Factors associated with site of death: a national study of where people die. *Med Care*. 2003;41:323-335.
- Flory J, Yinong YX, Guroi I, Levinsky N, Ash A, Emanuel E. Place of death: US trends since 1980. *Health Aff (Millwood)*. 2004;23:194-200.
- Mor V, Papandonatos G, Miller SC. End-of-life hospitalization for African American and non-Latino white nursing home residents: variation by race and a facility's racial composition. *J Palliat Med*. 2005;8:58-68.
- Johnson KS, Kuchibhatala M, Sloane RJ, Tanis D, Galanos AN, Tulsky JA. Ethnic differences in the place of death of elderly hospice enrollees. *J Am Geriatr Soc*. 2005;53:2209-2215.
- Enguidanos S, Yip J, Wilber K. Ethnic variation in site of death of older adults dually eligible for Medicaid and Medicare. *J Am Geriatr Soc*. 2005;53:1411-1416.
- Burge F, Lawson B, Johnston G. Where a cancer patient dies: the effect of rural residency. *J Rural Health*. 2005;21:233-238.
- Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*. 2006;332:515-521.
- Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. *CMAJ*. 2003; 168:265-270.
- Davies E, Linklater KM, Jack RH, Clark L, Moller H. How is place of death from cancer changing and what affects it? analysis of cancer registration and service data. *Br J Cancer*. 2006;95:593-600.
- Leuthner SR, Boldt AM, Kirby RS. Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin. *J Palliat Med*. 2004;7:269-277.
- Feudtner C, Silveira MJ, Christakis DA. Where do children with complex chronic conditions die? patterns in Washington State, 1980-1998. *Pediatrics*. 2002;109: 656-660.
- Royston P. Multiple imputation of missing values. *Stata J*. 2004;4:227-241.
- Royston P. Multiple imputation of missing values: update of ice. *Stata J*. 2005;5:188-201.
- Feudtner C, Christakis DA, Connell FA. Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980-1997. *Pediatrics*. 2000;106:205-209.
- Centers for Disease Control and Prevention National Center for Health Statistics. Documentation for the public use multiple cause of death file on comparability between ICD-9 and ICD-10: a double-coded file based on the 1996 data year multiple cause of death file. ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Datasets/Comparability/icd9_icd10/ICD9_ICD10_comparability_file_documentation.pdf. Accessed February 24, 2007.
- Guyser B, Freedman MA, Strobino DM, Sondik EJ. Annual summary of vital statistics: trends in the health of Americans during the 20th century. *Pediatrics*. 2000; 106:1307-1317.
- Lloyd-Jones DM, Martin DO, Larson MG, Levy D. Accuracy of death certificates for coding coronary heart disease as the cause of death. *Ann Intern Med*. 1998;129: 1020-1026.
- Fox CS, Evans JC, Larson MG, et al. A comparison of death certificate out-of-hospital coronary heart disease death with physician-adjudicated sudden cardiac death. *Am J Cardiol*. 2005;95:856-859.
- Caveney AF, Smith MA, Morgenstern LB, Lisa-beth LD. Use of death certificates to study ethnic-specific mortality. *Public Health Rep*. 2006;121:275-281.
- Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care; Board on Health Sciences Policy; Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BD, Stith AY, Nelson AR, eds. Washington, DC: National Academies Press; 2003.