



The Permanente Journal

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*a peer-reviewed journal of medical science,
social science in medicine, and medical humanities*

Original Articles

- 4 The Dartmouth Atlas Applied to Kaiser Permanente: Analysis of Variation in Care at the End of Life
- 10 Puentes Clinic: An Integrated Model for the Primary Care of Vulnerable Populations
- 16 Myocardial Infarction and Its Association with the Use of Nonselective NSAIDs: A Nested Case-Control and Time-to-Event Analysis
- 23 Home Hospice Acupuncture: A Preliminary Report of Treatment Delivery and Outcomes

Case Study

- 39 "The Other Side of the Fence": A Geriatric Surgical Case Study of Error Disclosure

Health Disparities and Care of Vulnerable Populations

- 56 The "Party Drug" Crystal Methamphetamine: Risk Factor for the Acquisition of HIV
- 63 Culture and Medicine: Reflections on Identity and Community in an Age of Pluralism
- 68 Innovation in Our Nation's Public Hospitals: Interview with Five CEOs and Medical Directors
- 75 Beyond Equal Care: How Health Systems Can Impact Racial and Ethnic Health Disparities
- 81 Confronting the Uncomfortable: Health Plans and Health Disparities: A Moral Dilemma in a Morally Driven Industry
- 87 HIV Today: What's Encouraging; What's Discouraging



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On the cover: "Solitude" by James McCormick, MD, is a photograph of California scrub oaks in the morning fog taken in Calabasas, CA.

Dr McCormick is an emergency physician

at the Panorama City Medical Center. His interest in photography was reawakened with the advent of digital imagery, which allows a photographer to move both the color and black and white labs into the house with ease. Dr McCormick says that few things make one feel as self contented as watching someone view and enjoy your work. He also states that it affords him a very relaxing diversion from the tension and pressures of the Emergency Department.

More of Dr McCormick's work can be viewed at the Web site: www.zen-photo.net.

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ORIGINAL ARTICLES

4 The Dartmouth Atlas Applied to Kaiser Permanente: Analysis of Variation in Care at the End of Life.

Matt Stiefel, MPA; Paul Feigenbaum, MD; Elliott S Fisher, MD, MPH

The *Dartmouth Atlas* method for examination of variation in care at the end of life was replicated by Kaiser Permanente (KP). Although KP inpatient care use rates were 25% to 30% lower and hospice use rates were higher than in the surrounding communities, there was still two- to four-fold variation in inpatient care use across KP geographic areas. Results reinforced emphasis on palliative care for patients with chronic conditions and earlier transitions to hospice.

10 Puentes Clinic: An Integrated Model for the Primary Care of Vulnerable Populations.

Lawrence Kwan, MD; Cheryl J Ho, MD; Charles Preston, PhD; Viet Le, MD, PhD

This integrated model to address the needs of a medically vulnerable population of homeless and injection-drug users emphasizes open access, outreach, groups, and a team approach to care. Emergency Department and urgent care visit rates decreased, simultaneous with increased primary care visits.

16 Myocardial Infarction and Its Association with the Use of Nonselective NSAIDs: A Nested Case-Control and Time-to-Event Analysis.

T Craig Cheetham, PharmD, MS; David J Graham, MD, MPH; David Campen, MD; Rita Hui, PharmD, MS; Michele Spence, PhD; Gerald Levy, MD; Stanford Shoor, MD

In a study of 8143 cases and 31,496 matched study control subjects, indomethacin and naproxen were associated with increased odds of adverse cardiovascular outcomes—myocardial infarctions and sudden cardiac death. These events occurred early in therapy.

23 Home Hospice Acupuncture: A Preliminary Report of Treatment Delivery and Outcomes.

Karen Kaufman, PhD, LAC; Ellen J Salkeld, PhD

The increasing incorporation of complementary and alternative medicine modalities into hospice care prompted a preliminary exploration of the process of offering acupuncture to ameliorate undesirable side effects from needed analgesic and sedative medications. Excellent or good results were noted in the charts of 34% of patients whose chief complaint was pain and in 31% of patients with anxiety.

REVIEW ARTICLES

27 Laparoscopic Colorectal Surgery.

CME James Yoo, MD

The use of minimally invasive techniques in colorectal surgery has lagged behind its application in other surgical fields, even though important new studies have demonstrated the benefits and safety of laparoscopic colorectal surgery, making it now the preferred approach.

32 Current Status and Treatment of Primary Hyperparathyroidism.

Dina M Elaraj, MD; Orlo H Clark, MD

Sporadic rather than familial, 80% to 85% of cases of primary hyperparathyroidism are caused by a solitary parathyroid adenoma. Diagnosis is made by hypercalcemia, elevated parathyroid hormone level, and a normal or high 24-hour urine calcium excretion. Multiple studies have demonstrated symptomatic and metabolic benefits of parathyroidectomy in "asymptomatic" patients.

SOUL OF THE HEALER

Original Visual Art

38 "Haleakala—The House of the Sun"
Charlene Hughes, RN

46 "Out of Order"
Denise Fuson, MD

55 "Twenty-five years and two days"
Marilyn Mitchell, RN

62 Nurse Lacasad Paints for Patients: A Service Credo Story to Improve Health Care.
Mia Medcalf

CASE STUDIES

39 "The Other Side of the Fence": A Geriatric Surgical Case Study of Error Disclosure.

Robert Formanek, Jr, MD; Doug Bonacum, MBA, CSA

An unanticipated adverse event after the surgical repair of a hip fracture lead to an exploration of a patient's care experience, through panel discussion, commentary, and excerpts from a letter entitled *The Other Side of the Fence*, written by the daughter of the 90-year-old patient.

47 Giant Colonic Diverticulum: Endoscopic, Imaging, and Histopathologic Findings.

Pejvak Sassani, MD; Hardeep M Singh, MD; Donald Gerety, MD; Maher A Abbas, MD

Two cases of a rare manifestation of diverticulosis illustrate the clinical presentation and surgical management, which is curative and in select cases can be carried out laparoscopically.

CLINICAL MEDICINE

50 Improving Chronic Care: The "Guided Care" Model.

Chad Boulton, MD, MPH, MBA; Lya Karm, MD; Carol Groves, RN, MPA

In a new model now being tested by Kaiser Permanente in the Baltimore-Washington, DC area, a registered nurse works in a practice with several primary care physicians conducting eight clinical processes for 50-60 multimorbid patients.

56 The "Party Drug" Crystal Methamphetamine: Risk Factor for the Acquisition of HIV.

Michael Allerton, MS; William Blake, MD

The use of methamphetamine is highly prevalent among populations at risk for acquiring HIV infection, especially men who have sex with men. A novel intervention tool—the "video doctor"—significantly reduced high-risk behaviors.

Corridor Consult

59 When Is a Computed Tomography Angiogram Necessary to Rule Out Pulmonary Embolus in the Emergency Department?

Joel Handler, MD

In two case examples, use of an evidenced-based diagnostic algorithm to rule out pulmonary embolus seeks to reduce the significant radiation exposure to a patient. A single CTA is equivalent to 400 chest x-rays.

COMMENTARIES

63 Culture and Medicine: Reflections on Identity and Community in an Age of Pluralism.

Sylvestre Quevedo, MD, MPH

This narrative account of a physician-patient relationship explores the meanings and relevance of race, ethnicity, and cultural diversity in the practice of medicine and in our general society.

68 Innovation in Our Nation's Public Hospitals: Interview with Five CEOs and Medical Directors.

Tom Janisse, MD; Winston F Wong, MD

Prominent leaders talk about: developing an integrated system with community clinics and neighborhoods; and, for an ever larger, diverse, and immigrant population, a new simultaneous translation system; and training future doctors by involving them in the hospital's quality improvement committees and clinical projects.

75 Beyond Equal Care: How Health Systems Can Impact Racial and Ethnic Health Disparities.

Kate Meyers, MPP

Factors outside traditional health care delivery—community-based social determinants of health such as environment, pollution, job opportunities, education, income, and support for healthy lifestyles—play equally important roles in disparities improvement by health systems.

EDITORIALS

81 Confronting the Uncomfortable: Health Plans and Health Disparities: A Moral Dilemma in a Morally Driven Industry.

Winston F Wong, MD

Health plans, in fulfilling their obligation to provide a reliable, safe, and secure system of care to millions of users, must also assume a leading role in demonstrating a commitment to abrogate the destructive role of racism and social injustice upon the health care of all Americans.

87 HIV Today: What's Encouraging; What's Discouraging.

Lee Jacobs, MD

There has been real progress in controlling this infection—in the US and in the developing world—however, men having sex with men continues to represent the majority of new infections. Despite tremendously effective medication, poor adherence by patients is all too common.

NARRATIVE MEDICINE

88 Narrative Medicines: Challenge and Resistance.

David B Morris, PhD

All narrative shares the common function of *someone telling something to someone about something*. For decades American medical students have memorized the familiar acronym—S.O.A.P—which identifies patient as subjective and physician as agent of objective fact. Narrative medicine challenges this slippery assumption about a clean division between subject and object. Physicians and patients are immersed in the act of storytelling.

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ERRATUM

Perm J 2007 Fall;11(4):30-40.

In the Original Article, "A Decade of Experience with a Multiday Residential Communication Skills Intensive: Has the Outcome Been Worth the Investment?," an error occurred in the second column of the 26th row of Table 2 on page 35. The percentage should be 3%; the row should read: Psychiatry 17 (3%).

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Article 1.
Myocardial Infarction and Its Association with the Use of Nonselective NSAIDs: A Nested Case-Control and Time-to-Event Analysis
(page 16)

Article 2.
Laparoscopic Colorectal Surgery (page 27)

Article 3.
The "Party Drug" Crystal Methamphetamine: Risk Factor for the Acquisition of HIV (page 56)

Article 4.
When Is a Computed Tomography Angiogram Necessary to Rule Out Pulmonary Embolus in the Emergency Department? (page 59)

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Individuals who read and critique journal manuscripts perform a critically important role ensuring the quality of articles for those who research the literature and for readers who use the content to improve health care for patients. We list here, with gratitude, reviewers for 2007—many of whom reviewed two or more manuscripts—to recognize their work and acknowledge their value.

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The *Dartmouth Atlas* Applied to Kaiser Permanente: Analysis of Variation in Care at the End of Life

By Matt Stiefel, MPA
Paul Feigenbaum, MD
Elliott S Fisher, MD, MPH

Abstract

The *Dartmouth Atlas* method for examination of variation in care at the end of life was replicated by Kaiser Permanente (KP). Variation within KP was analyzed and compared with corresponding *Dartmouth Atlas* Hospital Referral Regions. Although KP inpatient care use rates were 25% to 30% lower and hospice use rates were higher than in the surrounding communities, there was still two- to four-fold variation in inpatient care use across KP geographic areas. Evidence suggests that more, or more intensive, care for this population is neither necessarily better nor desired by patients. If all California (CA) KP residence areas had the hospital day rate of the average of the lowest three, 2005 decedents would have had more than 50,000 fewer hospital days in their last six months of life. High-intensity care accounts for a large proportion of the overall variation in total costs for this population. This strongly reinforces the focus on appropriate intensive care unit (ICU) use in end-of-life care. Greater emphasis on palliative care approaches for patients with chronic conditions and earlier transition to the use of hospice would create a better match between the expressed desires of patients and the care they receive, thus improving member and family satisfaction as well as quality of care. In addition, earlier transition to hospice in KP could be one important tool for avoiding undesired and nonbeneficial ICU use, given the negative correlation between hospice and ICU use identified in this analysis.

Geographic variation in hospital use within KP appears to be correlated with variation in the surrounding communities, even though it is lower on average within KP than outside it. This suggests that KP resource use may be influenced at least in part by broader community practices.

Background: *The Dartmouth Atlas of Health Care*

Wennberg and Gittelsohn published their first study of small area variation in 1973.¹ Since then, they and their colleagues at the Dartmouth Center for the Evaluative Clinical Sciences have consistently

and conclusively demonstrated in the *Dartmouth Atlas of Health Care*² striking unwarranted variation in health care resource use in the US, using innovative methods of measuring population-based use rates. Medicare spending in 2003, for example, after adjustment for age, sex, and race, was twice as

high in Miami as in Minneapolis and 50% higher in Los Angeles as in San Francisco. Recently, Wennberg et al have developed another innovative methodology for cross-sectional comparisons, focusing on end-of-life care of Medicare patients with serious chronic illnesses to address issues of population risk comparability across different geographic regions and institutions. In evaluating variation in hospital days per decedent among the *US News & World Report* "best" academic medical centers,³ for example, they found variation of two- to three-fold (Figure 1). This prompted noted health economist Uwe Reinhardt to comment, "How can the best medical care in the world cost twice as much as the best medical care in the world?"⁴ They have also found dramatic variation within health care systems, as shown in Figure 2, also with two- to three-fold variation in hospital days per decedent among major California (CA) health care systems.⁵ This work provoked the current investigation within Kaiser Permanente (KP), using the *Dartmouth Atlas* methodology to examine internal variation and compare performance with *Dartmouth Atlas* benchmarks.

Focusing on end-of-life care has a number of important advantages. First, it provides insight into important

This prompted noted health economist Uwe Reinhardt to comment, "How can the best medical care in the world cost twice as much as the best medical care in the world?"⁴



Matt Stiefel, MPA, (top) is the Senior Director of the Department of Care and Service Quality for Kaiser Permanente in Oakland, CA. E-mail: matt.stiefel@kp.org.

Paul Feigenbaum, MD, (left) is the Regional Medical Director for Hospital and Continuing Care Operations for The Permanente Medical Group in Oakland, CA. E-mail: paul.feigenbaum@kp.org.

Elliott S Fisher, MD, MPH, (right) is a Professor of Medicine and of Community and Family Medicine at Dartmouth Medical School in Hanover, NH, and Director of the Center for Health Care Research and Reform at the Dartmouth Institute for Health Policy and Clinical Practice. E-mail: elliot.s.fisher@dartmouth.edu.

drivers of total costs. End-of-life care represents a substantial fraction of all health care costs. As noted above, it ensures comparability, because these patients all have the same outcome.

Also, as it turns out, the Dartmouth researchers have found that overall Medicare spending is highly correlated with spending for those at end of life.⁶ Second, differences across regions and providers are largely due to supply-sensitive services, where variation is driven in large part by differences in supply or availability of resources, such as hospital beds and specialists per capita.⁷ Such services include use of a hospital/intensive care unit (ICU) as the site of care, frequency of visits, and frequency of specialist consultations. Third, normative interpretation is possible. What do higher-spending regions (and systems) get? There is no evidence that greater use is associated with health benefits, and preferences are unlikely to explain greater use. There is evidence that the technical quality of care is worse; there is no more elective surgery; and there are more hospital stays, visits, specialist consultations, and tests than in lower-spending regions. Mortality rates are slightly higher, and functional outcomes are no better.^{7,8} There is worse communication among physicians, greater difficulty ensuring continuity of care, greater difficulty providing high-quality care, and an even greater perception of scarcity in higher-spending regions.⁹ Patients are less satisfied with their hospital care, and their access to primary care is worse.^{5,7} Clearly, more is not always better.

Study Design and Methods

The objectives of the KP study were to identify opportunities to improve the quality and cost of care in the last six months of life for KP members through analysis of internal variation and identification of internal and

external performance benchmarks and to provide this information for ongoing efforts to identify and spread successful practices for the care of this population. Study questions included the following:

- How does inpatient and hospice utilization in the last six months of life vary across KP residence areas and Regions?
- What are the patterns of variation?
- How does KP performance compare with *Dartmouth Atlas* benchmarks?
- What are the opportunities associated with reduction of variation?
- What are the implications for identification and spread of successful practices?

The study population consisted of Medicare members age 65.5 years and older, continuously enrolled for the six months prior to death, and who died during calendar year 2005. The analysis period was therefore July 2004 through December 2005.

The minimum age of 65.5 years was selected to accommodate the six-month look-back as a Medicare member. Decedents were identified by linking KP data with data from the Social Security Administration. The

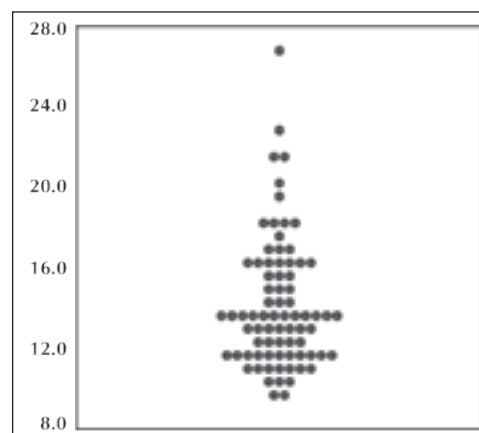


Figure 1. Days in hospital per decedent during last six months of life among patients assigned to the 77 "best" US hospitals (1999-2003). Adapted and reprinted with permission from the author and the British Medical Journal from: Wennberg JE, Fisher ES, Stukel TA, Skinner JS, Sharp SM, Bronner KK. Use of hospitals, physician visits, and hospice care during the last six months of life among cohorts loyal to highly respected hospitals in the United States. *BMJ* 2004 Mar 13;328(7440):607.

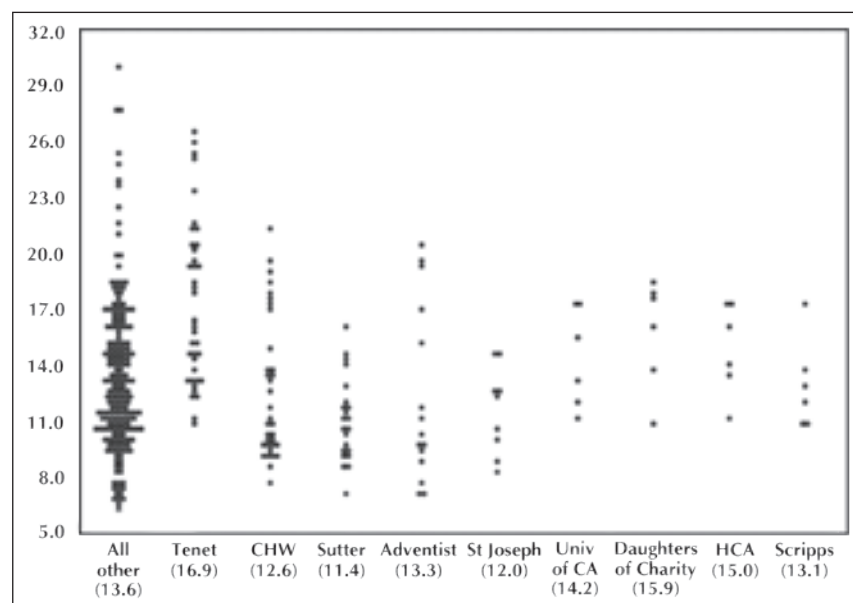


Figure 2. Hospital days per decedent during last six months of life among California hospitals belonging to selected systems (weighted average in parentheses) (1999-2003). Adapted and reprinted with permission from the author: Wennberg JE. Understanding Practice Patterns: A Focus on What the Quality Movement Can Do to Reduce Unwarranted Variations from his PowerPoint presentation at the Institute for Healthcare Improvement 2005 17th Annual National Forum on Quality Improvement in Health Care and available from: www.dartmouthatlas.org/.²

geographic units were KP residence areas in CA and Regions outside of CA. In CA, the substantial majority, but not all, of member use occurs in their residence area. Measures of care in the last six months of life included total hospital days, ICU days, and hospice utilization. For selected measures, Medicare Hierarchical Condition Category (HCC) risk scores, as used for Medicare reimbursement, were used to calculate actual to expected ratios in CA.

Because of data limitations, there were some differences from the *Dartmouth Atlas* in the population identification and measurement specifications. The *Dartmouth Atlas* includes traditional Medicare fee-

for-service patients only, whereas KP members primarily participate in capitated Medicare Advantage. We included all Medicare members regardless of payment mechanism. The *Dartmouth Atlas* includes only those decedents with one or more of 12 major chronic conditions defined by Iezzoni et al,¹⁰ whereas the KP study included all decedents. However, those 12 major chronic conditions account for the vast majority of Medicare deaths.¹¹ In CA, ICU days in non-KP facilities were not separately identified, and therefore outlying areas with high percentages of non-KP hospital use had to be excluded. In addition to chronic condition status, the

Dartmouth Atlas data were further risk-adjusted for age, sex, and race. The KP data were not risk-adjusted beyond decedent status. However, as noted above, Medicare HCC scores were used to calculate actual-to-expected ratios for certain measures. Finally, the *Dartmouth Atlas* study period was 2000–2003, compared with 2005 for KP.

Results

Variation within Kaiser Permanente

Medicare decedents were slightly younger in Southern CA than in Northern CA and regions outside CA. In Southern CA, 31% were age 85 years and older compared

Table 1. Hospital and ICU days per decedent, and hospice enrollment in KP CA residence areas and regions outside CA, and corresponding *Dartmouth Atlas* Hospital Referral Regions

	Northern California		Southern California		Regions outside California	
	KP res. areas	DA HRR's ^a	KP res. areas	DA HRR's	KP Regions	DA HRR's
Number of residence areas/regions	20	10	12	5	6	6
Number of Medicare decedents, 2005	13,365		10,585		4563	
Death rate per total Medicare membership	3.8%		3.4%		2.3%	
Percentage age 85+	35.1%		30.7%		36.6%	
Hospital days per decedent						
Number of residence areas/regions	20		12		6	
Mean (weighted)	8.9		8.7		6.8	
Mean (unweighted)	8.9	10.6	8.8	12.0	7.7	11.5
Minimum	6.8	8.7	6.5	10.8	5.2	8.0
Maximum	12.1	11.9	10.4	14.5	10.3	16.4
Extremal ratio	1.8	1.4	1.6	1.3	2.0	2.0
Mean ratio of KP to corresponding DA HRR	0.8		0.7		0.7	
ICU days per decedent						
Number of residence areas/regions	17	10	10	5	6	6
Mean (weighted)	2.4		3.7		2.2	
Mean (unweighted)	2.4	3.4	3.8	5.1	2.4	2.8
Minimum	0.8	2.1	2.6	3.8	1.1	1.8
Maximum	4.4	4.0	4.9	6.4	3.9	3.4
Extremal ratio	5.6	1.9	1.9	1.7	3.5	2.0
Mean ratio of KP to corresponding DA HRR	0.7		0.7		0.9	
Percentage of decedents enrolled in hospice					na	
Number of residence areas/regions	17	10	10	5		
Mean (weighted)	41%		33%			
Mean (unweighted)	41%	23%	33%	29%		
Minimum	31%	18%	25%	19%		
Maximum	51%	34%	37%	40%		
Extremal ratio	1.6	1.9	1.5	2.1		
Mean ratio of KP to corresponding DA HRR	1.8		1.5			

^a DA HRR = *Dartmouth Atlas* Hospital Referral Regions

with 35% in Northern CA and 37% in Regions outside CA (Table 1). Death rates were calculated as a percentage of deaths among the total Medicare membership. The rates were similar in Northern CA (3.8%) and Southern CA (3.4%) but lower in regions outside CA (2.3%). This is most likely because of the more inclusive algorithm used in CA to link KP and Social Security data sets that include deaths.

There was over two-fold variation in hospital day rates across KP (Figure 3). The Northern CA average was 8.9 days in the last 6 months of life, ranging from 6.8 to 12.1 days across 20 residence areas. The Southern CA average was 8.7 days, ranging from 6.5 to 10.4 days across 12 residence areas. The average for the regions outside of CA was 6.8 days, ranging from 5.2 to 10.3 days across 6 regions. To test the impact of relative population risk on the variation in hospital day rates, actual-to-expected ratios were calculated for the CA residence areas, using average Medicare HCC scores in a residence area to calculate expected rates (actual rate divided by HCC score). The HCC scores are risk-adjustment factors used to adjust Medicare reimbursement, adjusting for demographic and diagnostic differences across populations.¹² This risk adjustment did not have a significant impact on the rank order of observed results across residence areas. The rank-order correlation with raw hospital day rates was .82, suggesting that differences in relative risk across residence areas was not a major factor in explaining the variation.

There was four-fold variation in ICU day rates across KP. The Northern CA average was 2.4 days in the last 6 months of life, ranging from 0.8 to 4.4 days across 17 residence areas. The Southern CA average

was 3.7 days, ranging from 2.6 to 4.9 days across 10 residence areas. The average for regions outside CA was 2.2 days, ranging from 1.1 to 3.9 days across 6 regions.

There was twofold variation across CA residence areas in the percentage enrolled in hospice. The Northern CA average was 41%, ranging from 31% to 51% across 17 residence areas. The Southern CA average was 33%, ranging from 25% to 37% across 10 residence areas.

A correlation analysis among the KP measures was performed. Of note, the percentage enrolled in hospice was negatively correlated with ICU days ($r = -.40$).

Comparison to *Dartmouth Atlas* Benchmarks

The *Dartmouth Atlas* includes 306 Hospital Referral Regions (HRRs) in the US. They are defined by hospital referral patterns, and represent regional health care markets for tertiary medical care.² KP residence areas and Regions were mapped to these HRRs. The 20 residence areas in KP's Northern CA Region were mapped to 10 *Dartmouth Atlas* HRRs; the 12 residence areas in KP's Southern CA Region were mapped to 5 *Dartmouth Atlas* HRRs; and the 6 Regions outside of CA were each mapped to a single *Dartmouth Atlas* HRR.

KP's inpatient use rates during the last six months of life were lower than in their surrounding communities. On average, KP's hospital day rate was 25% lower and the ICU day rate was 30% lower than in the corresponding *Dartmouth Atlas* HRRs. However, KP's hospice percentages were higher than in their surrounding communities, on average 73% higher than in the corresponding *Dartmouth Atlas* HRRs. Although there were differences in the abso-

lute level of use between KP and the surrounding communities, KP's hospital day rate ($r = .39$) and ICU day rate ($r = .63$) were positively correlated with the rates in the corresponding *Dartmouth Atlas* HRRs (correlations significant at .05 level). After combining those KP residence

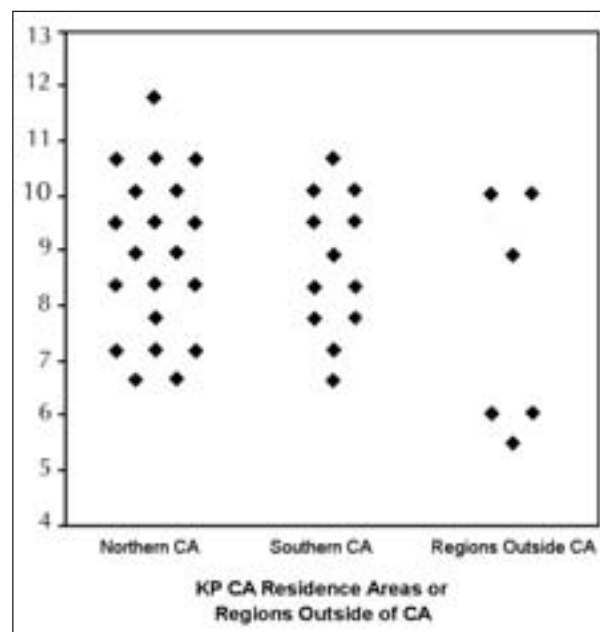


Figure 3. Variation in hospital days per decedent in last six months of life, KP CA Residence areas and regions outside of CA, 2005

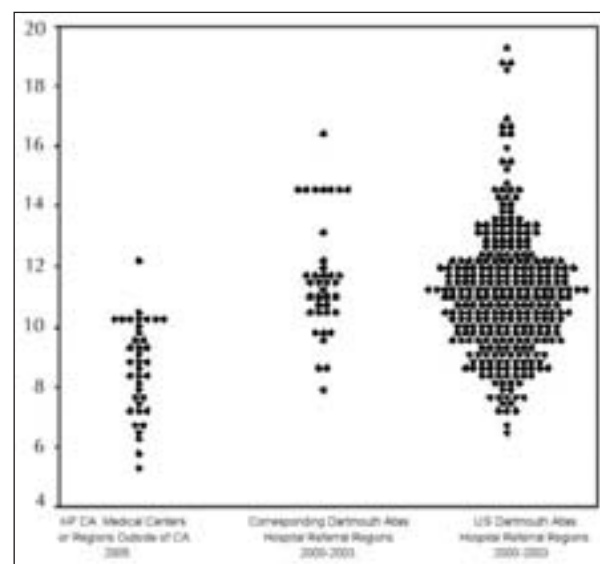


Figure 4. Variation in hospital days per decedent in last six months of life KP vs *Dartmouth Atlas* Hospital Referral Regions.

This strongly reinforces the focus on appropriate ICU use in end-of-life care, especially given evidence suggesting that people prefer not to die in an ICU.¹³

areas where there were multiple residence areas in a single *Dartmouth Atlas* HRR, we found that the correlation in hospital day rates was even higher ($r = .61$, $r^2 = .37$; Figure 5). However, there was no correlation in hospice percentage between KP and the corresponding *Dartmouth Atlas* HRRs.

Discussion

There is substantial variation in inpatient use in the last six months of life across KP, and corresponding opportunity for improvement. For example, if all CA residence areas had the hospital day rate of the average of the lowest three, 2005 decedents would have had more than 50,000 fewer hospital days in their last six months of life. In addition, high-intensity care in the ICU accounts for a large proportion of the overall variation in total costs for this population across KP geographic areas, consistent with general findings in the *Dartmouth Atlas*.⁶ This strongly reinforces the focus on appropriate ICU use in end-of-life care, especially given evidence suggesting that people prefer not to die in an ICU.¹³ The finding

of greater use of hospice in KP than in the surrounding communities is consistent with previously published findings of higher hospice use in managed care compared to fee-for-service patients dying with cancer.¹⁴ Even greater use of hospice in KP, even though it appears to be higher than in the broader community, could be one important option that avoids unwanted and nonbeneficial ICU use, given the negative correlation identified in this analysis.

Geographic variation in hospital use within KP appears to be correlated with variation in the surrounding communities, even though it is lower on average. This suggests that KP resource use may be influenced at least in part by broader community practices. Further investigation is warranted.

Some important limitations and caveats that could influence these findings must be noted:

- The *Dartmouth Atlas* includes only those with major chronic conditions and excludes people with no health care use in last two years of life. This could cause the *Dartmouth Atlas* resource use to look higher.
 - The *Dartmouth Atlas* data are also risk-adjusted for age, sex, race, and chronic conditions.
 - The KP data did not include ICU use in non-KP hospitals in CA. This could have a significant effect even in residence areas with KP facilities, by not including direct emergency admissions and transfers to outside facilities. Information on non-KP hospital use will be included in subsequent analyses.
 - Fewer deaths are identified in the Regions outside of CA compared with CA. Work is underway to improve the algorithm for matching KP and Social Security records.
 - In both KP and the *Dartmouth Atlas*, residence area use does not correspond directly to use of facilities within that residence area, because some patients use facilities outside their residence area and some who reside outside the residence area use facilities in the area. Therefore, comparisons across facilities are not directly supported with this information. It is possible to replicate the study with medical centers as the unit of analysis, but the need for appropriate risk adjustment is greater.
- A national palliative care dashboard, including selected *Dartmouth Atlas* measures, is under development in KP, which will enable ongoing benchmarking and analysis of variation in these measures. In addition, this analysis suggests some potentially valuable areas for further analysis, including investigation of
- The influence of community practice on KP geographic variation and the factors that account for that influence
 - The relationship between measures of resource intensity and quality of care
 - The differences in costs across KP Regions and medical centers
 - The relationship between bed and provider supply in a geographic area within KP and resource use
 - The relationship between structural and process attributes and efficiency of resource use
 - The relationship between end-of-life care and overall care by medical center and Region. ❖

Acknowledgments

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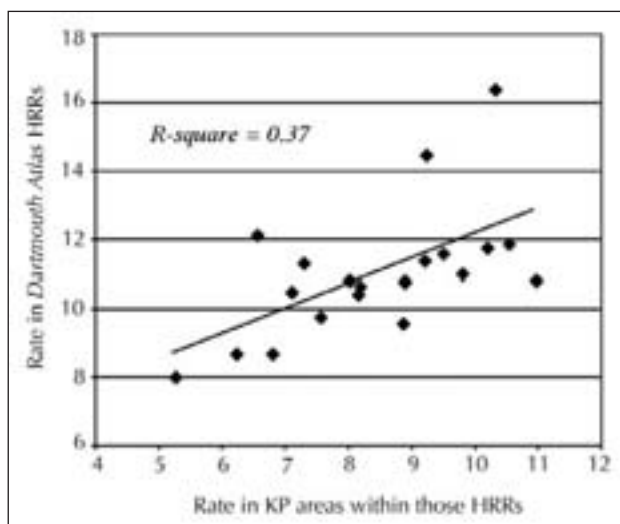


Figure 5. Correlation between KP and fee-for-service practice patterns: hospital days during last six months of life—*Dartmouth Atlas* vs KP.

Jeffrey Bennett of Management Information and Analysis for CA, and their colleagues, for their contributions to this study.

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Phenomenon

Death has ceased to be accepted as a natural, necessary phenomenon.

Death is a failure, a “business lost.”

— *The Hour of Our Death* (1981), Philippe Ariès, 1914-1984,
French medievalist and historian of family and childhood

Puentes Clinic: An Integrated Model for the Primary Care of Vulnerable Populations

By Lawrence Kwan, MD
Cheryl J Ho, MD
Charles Preston, PhD
Viet Le, MD, PhD

Abstract

Traditional primary care models for medically vulnerable populations such as the homeless and injection-drug users do not deliver optimal and efficient medical care. We propose an integrated model for the delivery of primary care to a vulnerable population emphasizing open access, outreach, groups, and a team approach to care.

Methods: We monitored the health care use patterns of a group of 408 injection-drug users during a five-year period at Puentes Clinic, an integrated primary care site within a larger county health care system, Santa Clara Valley Health and Hospital System of California. We specifically compared use patterns before and after the inception of this new primary care site.

Results: Emergency Department and urgent care visit rates decreased from 3.8 visits in the 18 months prior to the clinic's opening to 0.8 visits in the first 18 months of the clinic's operation. Simultaneously, primary care visits increased from 2.8 visits per 18 months prior to the clinic's operation to a current use rate of 5.9 visits per 18 months.

Conclusion: This changing health care use pattern after the implementation of an integrated primary care model suggests that a "medical home" for a vulnerable population can influence the way that populations interact with a larger health care system.

Clinical Vignette

Mr S is a monolingual Hispanic man aged 50 years with a history of injection-drug use and alcoholism who is now sober after recent discharge from prison. Other than addiction, his primary medical condition is hepatitis C. Liver-function tests revealed transaminitis, reflecting a process of inflammation occurring in his liver. Mr S expresses motivation to begin treatment for his liver condition. He works multiple day-labor jobs in the rural part of our county's catchment area and is homeless. Mr S takes his meals at a community soup kitchen, sleeps outside, and struggles with the daily issues of finding shelter and food.

Introduction

Individuals with a history of homelessness and/or injection-drug use are examples of medically vulnerable populations with increased burdens of illness and poor access to care. Traditional primary care settings have had difficulty accommodating the competing priorities and psychosocial needs of these underserved populations. The medical needs of injection-drug users are well documented and include high rates of hepatitis C, hepatitis B, HIV, and soft-tissue infections.¹ Injection-drug users and the homeless also have higher rates of chronic medical conditions when compared with other people living in poverty.¹⁻⁵ Studies have also documented that homeless patients and injection-drug users delay treatment for their conditions, resulting in higher rates of Emergency Department (ED) use and low rates of primary care and preventive services.⁶⁻¹⁰ It is no wonder that the five-year mortality rate among the chronically homeless in one study in Boston was as high as 28%¹¹ and that the average age of death for a homeless individual in a survey of three major cities across the US was age 45 years.¹²⁻¹⁴

The Santa Clara Valley Health and Hospital System (SCVHHS) in California opened Puentes Clinic, a primary care clinic for patients with a history of injection-drug use, in mid-2002 with a pilot grant



Lawrence Kwan, MD, (top, left) is the Medical Director of the Valley Homeless Healthcare Program at Santa Clara Valley Health and Hospital System in San Jose, CA. He is an Affiliated Clinical Instructor in the Department of Internal Medicine at the Stanford University School of Medicine in Stanford, CA. E-mail: lawrence.kwan@hhs.sccgov.org.

Cheryl J Ho, MD, (top, right) is the Associate Medical Director of the Valley Homeless Healthcare Program at Santa Clara Valley Health and Hospital System in San Jose, CA. She is an Affiliated Clinical Instructor in the Department of Internal Medicine at the Stanford University School of Medicine in Stanford, CA. E-mail: cheryl.ho@hhs.sccgov.org.

Charles Preston, PhD, (bottom, left) is the Director of Training for Santa Clara Valley Health and Hospital System in the Department of Psychiatry in San Jose, CA. E-mail: charles.preston@hhs.sccgov.org.

Viet Le, MD, PhD, (bottom, right) is a Psychiatrist for the Valley Homeless Healthcare Program at Santa Clara Valley Health and Hospital System in San Jose, CA. E-mail: viet.le@hhs.sccgov.org.

from the Health Trust, a nonprofit organization in Silicon Valley. Colocated with an outpatient methadone clinic, Puentes Clinic's goal was to provide comprehensive, high-quality primary care access to active and recovering injection-drug users in Santa Clara County. The desired outcome of the clinic's creation was to reduce potential harm to these patients and the community. In 2005, the clinic was incorporated under a federal Public Health Services Act¹⁵ (formerly Health Care for the Homeless Section 330(h)) grant supported by the Health Resources and Services Administration's Bureau of Primary Health Care. This grant broadened the scope of Puentes Clinic to include the primary care of homeless patients. As part of the Valley Homeless Healthcare Program (VHHP), Puentes Clinic's mission evolved to become a "safety net for the safety net," providing primary care to vulnerable populations by integrating addiction, mental health, and medical services.

This article represents five-year quantitative outcome data for our integrated model of primary care and qualitatively describes the operating principles and interventions practiced in our clinic.

Table 1. The members of the Puentes Clinic direct care team

Niniska Casillas	Health service representative
Mercy Egbujor, RNP	Nurse practitioner
Christine Finn, RN	Nurse manager
Kim Fredericks, RN	Charge nurse
Lorna Lindo, MSW	Social worker
Mike Lipman, MBA	Administrator
Terry Osback, MD	Psychiatrist, Architect
Bayardo Parrales, MA	Medical assistant
Amy Pasternack, MSI	Intern
Sergio Salazar	Outreach worker
Maria Serrano, MA	Medical assistant
Psychology Practicum Students	

Methodology

The Model

VHHP is composed of a team of health care professionals, including physicians, nurses, psychologists, social workers, drivers, and administrators, generating more than 5000 visits per year, seeing patients in homeless shelters, mobile medical units, and the Puentes Clinic. Table 1 indicates the members of the Puentes Clinic direct care team. VHHP is embedded in a much larger county outpatient clinic network consisting of seven outpatient clinics generating approximately 700,000 visits per year. VHHP targets care to the most vulnerable patients within the county medical system.

Puentes Clinic is a "medical home" for individuals with a history of injection-drug use or a recent history of homelessness. Along with traditional general medical care, our on-site services include hepatitis C treatment, psychology and psychiatry services, and a pain clinic. Plans for future services include buprenorphine treatment for opiate dependency and functional assessments for helping qualified patients obtain disability benefits. All services at the Puentes Clinic are provided in a nonjudgmental environment.

Measurement: Comparative Use

We monitored the clinical use patterns of 408 patients who accessed services at the Puentes Clinic between August 2002 and February 2004. Use patterns within the entire SCVHHS of these 408 patients were monitored through June 2007. We measured average health care visit rates in our study population sampling 18-month periods starting January 2000 and ending June 2007, with the exception of the period from February 2004 to July 2004, for which there are unfortunately no data available. Our data were obtained from SCVHHS's INVISION databases (Siemens Financials, Munich, Germany). Visit data between February 2004 and July 2004 had been archived and were unavailable for this study. Clinical visits were categorized into three types: primary care (mostly at the Puentes Clinic), urgent care, and ED visits. Use patterns for these patients in the two years prior to the inception of Puentes Clinic were used as historical controls for the data analysis.

Results

Demographic data revealed a higher percentage of men than women in our study population. Fifty-eight percent of the patients were men with an average age of 49 years (range, 26–72 years); 42% were women with an average age of 45 years (range, 22–71 years). All patients in the study group had a history of active or recovering injection-drug use. This finding was consistent with the initial mission of the Puentes Clinic, to provide primary care to patients with an injection-drug use history. The most common diagnoses at the Puentes Clinic were cellulitis and hepatitis C.

Of the 408 patients initially seen in the first two years of the clinic's existence in 2002, 323 patients (79%) were seen in the SCVHHS in the two years prior to the inception of the clinic. The clinical use patterns of these 323 patients served as historical controls. Of the original 408 patients, 230 (56%) continue to be monitored by our county health care system in the most recent 18-month sampling in 2007. Clinical use patterns are detailed both in Table 2 and Figure 1.

We found a marked decrease in ED and urgent care visits that paralleled a concomitant increase in primary care use. Before accessing the Puentes Clinic, patients on average were seen in the ED 2.6 times within an 18-month sampling period and in urgent care 1.2 times within that same period, for a total of 3.8 visits per 18 months for both. After this population was seen at Puentes Clinic, its average ED and urgent care visit rates dropped to 0.5 and 0.3 times, respectively, for a total of 0.8 visits per 18 months, whereas the average primary care visit rate increased to 5.6.

The most noticeable decrease in ED and urgent care visits occurred in the first two years of the Puentes Clinic's inception. Before the opening of the Puentes Clinic in August 2002, the subset of historical control study subjects who visited the ED (237 of the 408) generated 836 ED visits, with an average rate of 3.5 visits to the ED per 18-month period. In the first 18 months of the clinic's existence between August 2002 and January 2004, only 100 of the 408 patients visited the ED, generating 186 visits, with an average visit rate of 1.9. Sixty percent of the sample population stopped using the ED once Puentes

was established. Those patients who continued to use the ED decreased their visit rate by almost half. Subsequent years show the rate of ED and urgent care visits remaining stable and primary care use increasing.

Discussion

Analysis of the Data

This is a use analysis of a clinically challenging population and its response to the introduction of an integrated primary care clinic. In our study, we found that the inception of the Puentes Clinic, a primary care clinic for patients with a history of injection-drug use, dramatically affected health care use patterns. Patients who began to seek primary care at Puentes subsequently decreased visits to both the ED and urgent care. More than half of the patients who began to access primary care at Puentes still regularly use its services five years later, implying that the clinic functions as a "medical home" for this population. In the setting of a busy, urban public hospital's ED, which serves as a major level I trauma center, these data have definite ramifications. Our findings suggest that a primary care clinic like Puentes can change the way a vulnerable population interacts with a larger health care system.

On the other hand, 44% of the original sample population no longer accessed the county health care system in the most recent 18-month sample. The high mortality rate in this population¹¹⁻¹⁴ could account for some of this trend. In addition, patient history and anecdotal data reveal migratory patterns, with patients often moving frequently among various cities. Further study would be required to clarify this.

The Model

We believe that the success of the Puentes Clinic and the VHHP was a result of several key operating principles and concepts in addition to providing quality primary care:

- Outreach: Outreach embodies the concept of meeting patients "where they are." Examples include meeting patients in community settings, such as at a syringe-exchange site, soup kitchens, and shelters.
- Open access and a "chat room": Patients are seen on a first-come, first-served basis during listed clinic hours and are given the option to wait in a "chat room."
- Specialty groups: Patients with specific medical conditions have an opportunity to participate in facilitated group discussions as a therapeutic adjunct to individual sessions in a clinic room.

Table 2. Health care utilization patterns before and after opening of Puentes Clinic

<i>Utilization patterns before opening, January 1, 2000–July 30, 2002 (no. of patients with visits = 323^a)</i>			
Health care delivery site	No. of visits	No. of patients	Average visit rate ^b
Primary care	897	151	2.78
Emergency Department	836	237	2.59
Urgent care	407	177	1.26
<i>Utilization patterns after opening, August 1, 2002–January 31, 2004 (no. of patients with visits = 408^c)</i>			
Health care delivery site	No. of visits	No. of patients	Average visit rate ^b
Primary care	1528	408	3.75
Emergency Department	186	100	0.46
Urgent care	107	64	0.26
<i>Utilization patterns after opening, July 1, 2004–December 31, 2005 (no. of patients with visits = 271)</i>			
Health care delivery site	No. of visits	No. of patients	Average visit rate ^b
Primary care	1374	215	5.07
Emergency Department	154	95	0.57
Urgent care	137	79	0.51
<i>Utilization patterns after opening, January 1, 2006–June 30, 2007 (no. of patients with visits = 230^d)</i>			
Health care delivery site	No. of visits	No. of patients	Average visit rate ^c
Primary care	1350	191	5.90
Emergency Department	137	72	0.60
Urgent care	71	47	0.31

^aOf the 408 patients studied, 323 received services from Santa Clara Valley Health and Hospital System (January 2000–July 2002) before Puentes Clinic opened in August 2002.

^bAverage visit rate = number of site visits divided by number patients surveyed.

^cThe sample population is distinct patients at Puentes Clinic between August 2002 and January 2004.

^dOf the 408 original patients, 178 were no longer receiving care as of January 2006–June 2007.

- Integrated treatment team: VHHP and the Puentes Clinic are composed of a team of health care professionals with distinct areas of expertise who work together to treat the whole patient.

Outreach

Mr S from the clinical vignette was a real patient whom we initially met in our mobile medical unit parked in the rural area of our county. The clinical times of operation of this medical mobile unit coincided with the timing of food service at a local soup kitchen. Mr S had just been released from prison and, at the time of his first encounter, was still abusing methamphetamines. Over the course of a year, he would visit the mobile unit for various urgent issues, all the time expressing a desire to treat his hepatitis C, rehabilitate himself, and reunite with his family in Arizona. Mr S was ultimately able to stop his substance abuse. He and we gained enough trust in one another to begin evaluating him for hepatitis C treatment.

With a history of limited access to and poor experiences with medical care, many of our patients have developed a lack of trust in the health care system. Meeting patients in settings where trust has already been established has been an important way to begin a therapeutic relationship. Our two-room mobile medical unit gives us the flexibility to couple our care with preexisting social services, including a syringe-exchange site in downtown San Jose (urban setting) and a soup kitchen in Gilroy (rural setting). Similarly, our fixed-site primary care clinic at a major shelter in San Jose treats patients who are seeking food and shelter who might not otherwise have had the opportunity to seek care in a physician's office.

Open Access and the Chat Room

Mr S was told to return to the Puentes Clinic in San Jose during our hepatitis C clinic for evaluation. No appointment was given. He was told to show up on any Monday afternoon whenever he had time.

With the many competing priorities of our patients, it was not surprising that our no-show rate at the inception of the Puentes clinic was more than 50%. Many of our patients' complaints required immediate attention, and a follow-up appointment with a specific day and time was often forgotten. As a result, the Puentes Clinic, shelter clinic, and mobile units do not have appointments. Clinic hours are listed and patients are seen on a first-come, first-served basis. Nurses triage patients to assess the severity of their illness and need. Although this open access requires a higher level of nursing skill at the beginning of clinic hours and increases wait times, it keeps our clinic doors open and matches our method

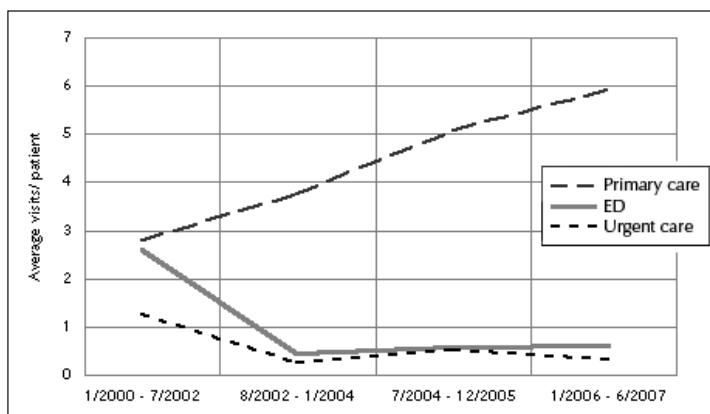


Figure 1. Health care use patterns before and after Puentes Clinic, January 2000 to June 2007. ED = Emergency Department.

of care delivery to our patients' patterns for seeking out care. As in Mr S's case, matching this pattern became an important way for us to establish continuity.

In an attempt to create a welcoming environment for our waiting patients at Puentes Clinic, we opened a separate waiting room with food and coffee, affectionately called the Chat Room. Upon patients' arrival at the clinic, a psychologist or psychology practicum student gives patients the opportunity to wait in a group room. Because this group has different members each time it meets, it does not fit any traditional group-therapy model. Facilitators are participant-observers and discussions are patient-driven. Patients come and go throughout the four hours of Chat Room time.

Given the multiplicity of needs that are often overwhelming to both patients and clinicians, the role of the facilitator is to identify the interplay of the medical, psychiatric, and psychosocial factors for each patient and to provide guidance toward resolution. By initiating conversations among patients, managing patient perceptions of their health care, and providing resources and referrals, the facilitator helps the patients more clearly understand how to address presenting issues. Additionally, the information gained during the group is disseminated to the multidisciplinary treatment team, so they gain a more comprehensive picture of each patient. The Chat Room also offers the opportunity for team members to participate in an experience that is not offered in traditional settings—they interact with patients on a more personal level and can provide information and support in a less directive, more informal atmosphere. Patients and clinicians alike have found the Chat Room beneficial. Patients have reported greater satisfaction with each visit, and clinicians report increased effectiveness in their delivery of treatment services to this complex population.

Meeting patients in settings where trust has already been established has been an important way to begin a therapeutic relationship.

Specialty Groups

Prior to treatment, Mr S was able to see and hear from other patients experiencing the difficult side effects of hepatitis C treatment with pegylated interferon and ribavirin. As a care team, we observed how consistent and committed he was to his treatment. As he started taking the medications, despite having to work through a translator, Mr S was an active part of the hepatitis C group, asking questions about his care and offering advice and support to other patients.

Over time, the clinic has evolved to delivering part of its care in group settings. We have found that facilitated group discussions with patients provide an important adjunct to clinic visits. We have groups within our hepatitis C clinic and pain clinic. We are considering a group for our future buprenorphine clinic.

Each of our specialty groups has been designed primarily from a cognitive behavioral perspective. For these groups the facilitator provides psycho-education about symptoms and treatment, along with encouragement for treatment compliance. Group members are also encouraged to discuss their personal successes and failures with their regimen, which helps other group members have more realistic expectations for their own treatment.

The development and structure of our groups continually evolves on the basis of our patients' needs and direct feedback. For example, in our hepatitis C group, we used the Brief Symptom Inventory as a weekly evaluation tool for depression. Over time, we discovered that patients would consistently underreport symptoms, even when in obvious distress. So that we could develop a more accurate evaluation, we modified the Brief Symptom Inventory questions. Group members acknowledged a belief that if they reported severe symptoms, treatment would be discontinued. The questionnaire was changed to elicit yes or no responses rather than severity ratings, and group members were then questioned during group about positively endorsed items. This change led to greater interactions between group members and more accurate information about changes in group members' mental health.

Despite this evolving group structure and nontraditional approach to group therapy, we have found therapeutic outcomes and factors similar to those reported in more traditional, structured group settings, including the engendering of hope, the impartation of information, imitative behavior, the development of socializing techniques, and catharsis.¹⁶

Integrated Treatment Team

"I esleeping en el parque, is okay?" Mr S would say in his trademark Spanglish. With no place to store his medi-

cations and no walls to separate him from the drug and alcohol abuse he had so recently left behind, he would have been a challenging patient for a lone physician to treat for hepatitis C. Mr S demonstrated a remarkable commitment to treatment, regularly commuting two hours each way on a bus to the clinic. The integrated team at Puentes was able to match Mr S's enthusiasm and brainstorm effective solutions to the logistical challenges in his care. Our nurse agreed to help him with his weekly injections of pegylated interferon, our social worker helped find him housing, and the physicians believed that they could monitor and treat his adverse side effects with weekly primary care and attendance at the hepatitis C group.

The Puentes Clinic uses an integrated treatment team approach, which can be defined as a team of clinicians and staff with distinct areas of expertise together treating all aspects of a person. In contrast, traditional health care is often structured as a set of clinicians and staff with distinct areas of expertise separately treating a patient's symptoms. Jim O'Connell, MD, the president of Boston Health Care for the Homeless Program and one of our heroes, writes: "The care of homeless people is so complex that to put that burden on one person would be impossible. What is impossible in a traditional system is a joy in a system where the care is shared by the team."¹⁷

Patients at the Puentes Clinic interact with a wide range of staff members, one or more at a time, during their clinic visits. It is not uncommon for the psychiatrist, primary care physician, and/or psychologist to see the patient in the examination room at the same time. We have found that all clinicians gain useful and important information that is often not shared in traditional settings where specialties are separate. Because each specialist views a given illness from a different perspective, an integrated evaluation allows for a more thorough assessment. In seeing patients simultaneously, we have found that we have a greater understanding of the whole patient and thereby deliver better care.

A shared office space, nicknamed The Bullpen, has also been critical in fostering this team approach to care. In a traditional practice model, a physician has his or her own office space, which is physically separate from nursing and ancillary staff space. In the Puentes team model, clinical staff are housed in the same physical room, with the primary work area for the medical assistant, nurse, primary care physician, psychologist, and psychiatrist located together. Although this creates problems with noise and highlights our need for larger rooms, it also nurtures an ongoing discussion about more difficult cases and a constant and informal sharing

of perspectives on patients' treatment plans.

More formally, the Puentes integrated approach includes case conferences after every team primary care clinic, before every specialty clinic, and as part of a resident teaching rotation. Nursing, psychology, psychiatry, and primary care specialties meet together after the clinic has closed to discuss the patients seen that day. We have found that each member of the clinical team obtains diverse and relevant information about our patients, including medical conditions, behavior, and life stressors. These conferences provide a forum for discussing difficult cases, as well as an opportunity to teach residents and psychology students our respective professional viewpoints of how to best care for the patient.

Conclusion

Mr S showed up to most weekly group appointments and successfully completed his treatment. Over the course of the year, our social worker found him temporary housing, our psychiatrist and psychologist helped treat his depression, and our nurse provided weekly injections of pegylated interferon. He periodically visits the hepatitis C group to report his status and provide testimony and support to other hepatitis C patients.

The medical care of the medically vulnerable patient requires creative approaches that accommodate the burdens of mental health and substance abuse as well as the competing priorities of shelter and a warm meal. If we do not address the competing priorities of food, housing, substance abuse, and mental illness, health care becomes a distant priority for our patients. For us, an integrated team approach is the critical component in our ability to develop effective treatment for our patients. At the Puentes Clinic, we are fortunate to work as part of a dedicated team of nursing, primary care, psychiatry, psychology, social work, and support staff. Because we work so closely, we recognize the unique contributions of each discipline. As a team, we share the demands of treating the whole patient, allowing each of us to focus on our specialty and simultaneously collaborate with others to treat problems outside our individual domains. The patient-team relationship has been the cornerstone for our trusting and ultimately therapeutic primary care interventions.

We believe that this team approach, along with open access and aggressive outreach, could be applied to the care of any medically vulnerable population and is, in fact, the foundation of good general primary care. ♦

Acknowledgment

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ORIGINAL ARTICLE

Myocardial Infarction and Its Association with the Use of Nonselective NSAIDs: A Nested Case-Control and Time-to-Event Analysis

By T Craig Cheetham, PharmD, MS
David J Graham, MD, MPH
David Campen, MD
Rita Hui, PharmD, MS
Michele Spence, PhD
Gerald Levy, MD
Stanford Shoor, MD

Abstract

Objective: In April 2005, the US Food and Drug Administration issued a public health advisory warning to health care clinicians about the cardiovascular (CV) safety of nonsteroidal anti-inflammatory drugs (NSAIDs). Although the warning about cyclooxygenase-2 selective NSAIDs was anticipated, little data exists about the CV safety of nonselective NSAIDs. We analyzed data from a group of NSAID users to determine if specific nonselective agents were associated with an increased risk of myocardial infarctions (MIs) and sudden cardiac death (SCD).

Design: A nested case-control design was used to study NSAID users ages 18 to 84 years. Cases were defined by a hospital admission for MI or an out-of-hospital SCD. Study control subjects were matched for age, sex, current Kaiser Permanente membership, and geographic location (Northern or Southern California). Odds ratios (OR) were estimated using conditional logistic regression.

Results: Our base population included 1,394,764 NSAID users. From this population we identified 8143 cases and 31,496 matched study control subjects. The median time to event was <100 days for all NSAIDs. Two nonselective NSAIDs were associated with increased odds of adverse CV outcomes: indomethacin (OR, 1.27; 95% confidence interval, 1.04–1.56) and naproxen (OR, 1.14; 95% confidence interval, 1.00–1.30).

Conclusion: Our results suggest that some nonselective NSAIDs are associated with an increased risk of MI and SCD. We found the increased risk to be small compared with the risk associated with rofecoxib. Cardiovascular events occurred early in therapy. Caution is warranted with some nonselective NSAIDs, especially those for which other studies have found evidence of risk.

Introduction

Evidence from both epidemiologic and clinical trials confirm that the selective cyclooxygenase-2 (COX-2) inhibitors are associated with an increased risk of adverse cardiovascular (CV) events.^{1–9} However, little is known about the CV risk associated with nonselective nonsteroidal anti-inflammatory drugs (NSAIDs). Despite a lack of evidence, the US Food and Drug Administration (FDA) issued a warning in 2005 that the nonselective NSAIDs may be associated with an increased risk of serious CV events.¹⁰

Interference with the cyclooxygenase enzyme is thought to be the primary mechanism by which NSAIDs exert their pharmacologic action. NSAIDs, as a class, have a broad range of CV effects that may play a role in causing myocardial infarction (MI) and sudden cardiac death (SCD).^{11,12} Fluid retention, elevations in blood pressure, and interference with antihypertensive medications are well-described adverse effects of these drugs.¹³ NSAID effects on the coronary vasculature are mediated by their relative inhibition of the cyclooxygenase enzymes (COX-1 and COX-2). These two enzymes have opposing effects in the coronary vasculature.^{14–18} COX-1 exists within the platelets and is responsible for

T Craig Cheetham, PharmD, MS, is a Researcher in the Pharmacy Analytical Services Department for Kaiser Permanente Southern California in Downey. E-mail: craig.t.cheetham@kp.org.

David J Graham, MD, MPH, is a Medical Officer in the Office of Drug Safety, Center for Drug Evaluation and Research, Food and Drug Administration in Silver Spring, MD. E-mail: david.graham1@fda.hss.gov.

David Campen, MD, is the Medical Director for Drug Information Service for The Permanente Federation, Pharmacy Operations. E-mail: david.campen@kp.org.

Rita Hui, PharmD, MS, is a Pharmacoeconomic and Outcomes Research Pharmacist in the Pharmacy Outcomes Research Group for Kaiser Permanente Northern California, in Oakland. E-mail: rita.l.hui@kp.org.

Michele Spence, PhD, is a Pharmacy Project Manager in the Pharmacy Outcomes Research Group, Kaiser Permanente Southern California, in Downey. E-mail: michele.m.spence@kp.org.

Gerald Levy, MD, is a Rheumatologist in the Department of Medicine, The Southern California Permanente Medical Group, Kaiser Permanente Southern California, Bellflower. E-mail: gerald.d.levy@kp.org.

Stanford Shoor, MD, is a Rheumatologist in the Department of Medicine, The Permanente Medical Group, Kaiser Permanente Northern California, Santa Clara. E-mail: stanford.shoor@kp.org.

production of thromboxane A_2 , which induces vasoconstriction and platelet aggregation. The COX-2 enzyme predominates in the endothelial cell of the arterial walls and is responsible for generation of prostacyclin, which inhibits platelet aggregation and causes vasodilation.

There is wide variation within the NSAIDs class of drugs with respect to selectivity for COX-1 and COX-2 isoenzymes.^{19–21} Rofecoxib and celecoxib have a high selectivity for the COX-2 isoenzyme, whereas drugs such as flurbiprofen and ketorolac have a high affinity for the COX-1 isoenzyme. Because selective COX-2 inhibitors do not interfere with the COX-1 enzyme at therapeutic doses, it is postulated that the imbalance resulting from the preferential blockade results in vasoconstriction and platelet aggregation, leading to stroke and MI. Nonselective NSAIDs, with balanced effects on COX-1 and COX-2, would not be expected to carry an excess risk for MI.

We studied a group of NSAID users to investigate whether there is an association between current usage and CV events. We wanted to answer two specific questions: First, are any nonselective NSAIDs associated with a higher rate of CV events? Second, how long are patients exposed to NSAID treatment before CV events occur? Data on selective COX-2 inhibitors have been previously published.³

Methods

Kaiser Permanente (KP) is a nonprofit group-model health care organization offering health maintenance plans and providing integrated health care services to more than six million members in California. The KP membership is racially diverse and similar to the US population with respect to age, education, and household income. Electronic files are maintained on member eligibility, physician office visits, hospitalizations, Emergency Department visits, laboratory results, and outpatient drug dispensing. Mortality data are captured either through hospitalization records or by linking membership information with death certificate data supplied by the California Department of Health, Center for Health Statistics.

For this study, we identified a cohort of KP patients, ages 18 to 84 years, who filled at least one prescription for an NSAID (selective COX-2 inhibitor or nonselective NSAID) between January 1, 1999, and December 31, 2001. We used this cohort of patients to conduct a nested case-control study (cases and study control subjects identified within a cohort of NSAID users).²² Twelve months of KP membership prior to a patients' first NSAID prescription was required for study eligibility. To minimize bias, patients with severe and life-threatening diseases were excluded from the cohort, including those in whom

cancer, renal failure, liver failure, severe respiratory disease, or HIV/AIDS had been diagnosed and those who had undergone organ transplantation. Cohort members were monitored from their date of entry until the end of the study period, disenrollment, or the occurrence of a study endpoint, whichever came first.

Cases were defined as having an admission to the hospital for an MI or the occurrence of SCD outside the hospital setting. An MI endpoint (case event) required that the patient be admitted to the hospital with an ICD-9 (International Statistical Classification of Diseases and Related Health Problems, 9th edition) code 410 (acute MI) or an ICD-9 code 411.1 (intermediate coronary syndrome) as long as there was laboratory documentation of myocardial damage (elevated creatine kinase-MB fraction >7 ng/mL and creatine kinase-MB fraction >3% or elevated troponin I ≥ 4 ng/mL). Deaths occurring outside the hospital setting were classified as SCD if the underlying cause of death was listed on the death certificate as hypertensive heart disease, ischemic heart disease, conduction disorders, arrhythmias, heart failure, atherosclerotic heart disease, sudden death, or death from an unknown cause.^{2,23}

Cases were matched to a maximum of four study control subjects, randomly selected from the NSAID user cohort, who were active members on the date of the case event

Table 1. Age and sex distribution

Exposure	n	Percentage women	Age (years) ^a
Cases			
Current	1773	42	67.5
Celecoxib	127	54	70.2
Diclofenac	21	33	65.4
Etorolac	40	45	68.8
Ibuprofen	674	39	66.3
Indomethacin	167	31	67.2
Nabumetone	73	45	68.9
Naproxen	367	43	66.9
Piroxicam	69	49	67.9
Rofecoxib	68	57	71.0
Sulindac	143	44	71.1
Nonsteroidal anti-inflammatory drugs	24	29	64.9
Recent	1712	38	66.7
Remote	4658	37	66.6
Total	8143	38	66.8
Study control subjects			
Current	6557	42	68.6
Recent	6219	39	66.9
Remote	18,720	37	66.4
Total	31,496	38	67.0

^aMean age on the date of the index event.

(index date). Study control subjects were selected on the basis of age, sex, and KP region (Northern or Southern California). The nested case-control design allowed for individuals selected as a control subject for one case to become a case or a control subject for another case at a later date, provided that they remained in the study cohort.²²

NSAID exposure status for cases and control subjects was based on the index date. Exposure classification was determined by the days of medication supply captured from the pharmacy dispensing record. Patients were classified as current users if the duration of their most recent NSAID prescription overlapped the index date. Remote users were those whose medication supply ended more than 60 days before the index date. These patients were used as the reference exposure group because it was unlikely that they were continuing to take the prescription NSAID at the time of the index date. Recent users were those individuals whose NSAID prescriptions ended between 1 and 60 days before the index date.

Beginning 365 days before the index date, we collected CV risk factors for cases and control subjects. Prior hospitalizations were grouped into the following

categories on the basis of diagnosis-related group coding: major CV events (MI, cardiac arrest, and revascularization procedures), angina, congestive heart failure (CHF), other ischemic heart disease (atherosclerosis and ischemia), cardiac arrhythmias, other CV hospitalizations (major CV procedures, peripheral vascular disease, valve disease, cerebrovascular disease, and peripheral vascular procedures), and non-CV hospitalizations. We captured Emergency Department visits for CV and non-CV reasons, same-day hospitalizations for medical procedures, and outpatient diagnoses for tobacco use. Prescription use was recorded for thiazide diuretics, loop diuretics, angiotensin-converting enzyme inhibitors or angiotensin-receptor blockers, calcium channel blockers, beta-blockers, digoxin, nitrates, antiarrhythmics, 3-hydroxy-3-methyl-glutaryl coenzyme A reductase inhibitors (statins), fibrates, niacin, antiplatelet agents (ticlopidine, clopidogrel), anticoagulants (warfarin, low-molecular-weight heparin), insulin, and oral hypoglycemics.

Conditional logistic regression was used to estimate the odds ratios and 95% confidence intervals. Non-selective NSAIDs with 20 or more currently exposed

Table 2. Percentage prior hospitalizations: cases and study control subjects in the year prior to the index date

Exposure	n	Major cardiovascular event ^a	Angina	Congestive heart failure	Other ischemic heart disease ^b	Arrhythmia	Other cardiovascular event ^c	Hospitalization for noncardiovascular event	Emergency Department cardiovascular event	Emergency Department noncardiovascular event
Cases										
Current	1773	3.3	2.3	2.8	4.1	1.8	3.0	15.0	3.0	32.4
Celecoxib	127	3.1	2.4	3.1	3.1	3.1	1.6	15.0	2.4	45.7
Diclofenac	21	—	—	9.5	4.8	—	4.8	19.0	4.8	38.1
Etodolac	40	2.5	—	—	5.0	—	—	15.0	2.5	35.0
Ibuprofen	674	2.7	2.2	2.7	4.5	1.3	3.3	15.7	3.0	30.3
Indomethacin	167	7.8	1.8	4.8	4.2	3.0	6.6	17.4	7.2	32.3
Nabumetone	73	2.7	2.7	2.7	4.1	4.1	4.1	16.4	8.2	39.7
Naproxen	367	3.0	2.7	1.6	3.0	1.6	1.1	12.5	0.8	30.5
Piroxicam	69	7.2	1.4	1.4	2.9	1.4	1.4	14.5	2.9	29.0
Rofecoxib	68	2.9	1.5	5.9	7.4	2.9	5.9	19.1	2.8	42.6
Sulindac	143	1.4	3.5	2.8	4.2	0.7	3.5	11.2	2.1	27.3
Nonsteroidal anti-inflammatory drugs	24	—	—	4.2	4.2	4.2	—	20.8	4.2	33.3
Recent	1712	3.3	3.2	3.4	2.8	2.0	2.8	17.2	4.4	36.7
Remote	4658	1.9	2.9	3.8	5.0	2.6	4.4	17.3	4.5	33.8
Total	8143	2.5	2.8	3.5	4.3	2.3	3.7	16.8	4.1	34.1
Study controls subjects										
Current	6557	0.5	0.8	0.4	0.7	0.5	0.6	8.0	0.7	19.6
Recent	6219	0.5	1.0	0.4	0.4	0.6	1.0	7.5	0.9	23.9
Remote	18720	0.4	0.8	0.3	0.6	0.7	1.1	8.1	0.9	22.2
Total	31496	0.4	0.9	0.3	0.6	0.6	0.9	8.0	0.9	22.0

^aMyocardial infarction, cardiac arrest, and revascularization procedures.

^bAtherosclerosis and ischemia (except myocardial infarction).

^cMajor cardiovascular procedures, peripheral vascular disease, valve disease, and vascular procedures.

case events were analyzed individually. The remaining NSAIDs were placed into a single group.

In analyzing time to event, we selected cases and control subjects classified as currently exposed to NSAIDs. For these patients, we determined continuous NSAID exposure for the preceding 365 days. Exposure was defined as continuous if gaps between prescription refill dates did not exceed 50% of the days' supply. For example, if a patient received an NSAID prescription for a 30-day (one-month) supply, exposure was classified as continuous if the next prescription was filled within 45 days (1.5 months) of the previous dispense date. Median time to event and interquartile ranges are reported using box-plots.

Statistical analyses were performed using SAS version 9.1 (SAS Institute Inc, Cary, NC). The institutional review boards of both the Northern and Southern Divisions of KP California approved this study.

Results

During the study period, 8143 cases were identified and matched to 31,496 control subjects from

our population of 1,394,764 NSAID users. The cases included 6635 patients admitted to the hospital for MI and 1508 with SCD. Eleven percent ($n = 702$) of patients hospitalized for MI died during their hospital stay. Demographic information for cases and control subjects are shown in Table 1. In all groups except for the group taking selective COX-2 inhibitors (celecoxib, 54% women; rofecoxib, 57% women), the case-patients were predominantly men.

The distribution of CV risk factors by specific NSAID are presented in Table 2 (hospitalizations and emergency care) and Table 3 (prescription use). Although percentages varied between the individual NSAIDs, cases had higher overall rates for CV risk factors compared with study control subjects. In most instances, the prevalence of risk factors in cases was several orders of magnitude higher than in control subjects. This was not unexpected, given the study design and the criteria used to define cases.

We identified eight nonselective NSAIDs and two COX-2 inhibitors with sufficient CV events during the three-year study period to include in the multivariate regression

Table 3. Percentage prior medications: cases and study control subjects in the year before the index date

Exposure	n	Anti-platelets ^a	Anti-coagulants ^b	Anti-arrhythmics ^c	Anti-diabetics ^d	Anti-hypertensives ^e	Loop diuretics ^f	Digoxin	Nitrates	Anti-hyperlipidemics ^g
Cases										
Current	1773	4.3	4.7	2.5	30.1	73.0	21.5	9.5	31.4	33.4
Celecoxib	127	5.5	10.2	3.9	25.2	78.0	24.4	15.0	33.9	36.2
Diclofenac	21	-	4.8	4.8	28.6	90.5	19.0	4.8	47.6	47.6
Etodolac	40	5.0	7.5	2.5	17.5	70.0	7.5	5.0	32.5	42.5
Ibuprofen	674	3.9	4.0	2.4	32.8	72.0	20.6	7.7	31.0	31.9
Indomethacin	167	12.0	6.6	1.8	25.7	79.6	32.9	16.2	38.3	38.3
Nabumetone	73	2.7	1.4	1.4	35.6	75.3	28.8	11.0	28.8	38.4
Naproxen	367	3.0	2.7	1.9	29.7	66.8	17.2	8.4	25.3	30.0
Piroxicam	69	1.4	4.3	5.8	24.6	71.0	24.6	7.2	26.1	27.5
Rofecoxib	68	5.9	10.3	5.9	26.5	80.9	25.0	5.9	35.3	45.6
Sulindac	143	1.4	3.5	2.1	32.2	76.9	19.6	9.8	37.1	30.1
Nonsteroidal anti-inflammatory drugs	24	4.2	12.5	—	37.5	70.8	16.7	20.8	33.3	37.5
Recent	1712	4.8	5.6	2.7	25.2	71.0	21.3	9.8	28.4	33.9
Remote	4658	5.9	6.7	2.7	26.4	70.0	20.8	10.2	28.8	34.9
Total	8143	5.3	6.1	2.7	27.0	70.9	21.0	9.9	29.3	34.4
Controls										
Current	6557	1.2	2.8	1.2	12.8	54.7	8.7	3.7	9.8	20.5
Recent	6219	1.3	2.6	0.8	11.3	50.6	6.5	3.3	8.9	19.6
Remote	18,720	1.5	3.6	1.1	11.7	46.5	6.6	3.6	7.8	18.7
Total	31,496	1.4	3.2	1.1	11.9	49.0	7.0	3.6	8.4	19.3

^aTiclopidine and clopidogrel.

^bHeparin, low-molecular-weight heparin, and warfarin.

^cMexiletine, procainamide, propafenone, flecainide, esmolol, ibutilide, dofetilide, quinidine, and adenosine.

^dInsulin, sulfonylureas, metformin, and thiazolidinediones.

^eAngiotensin-converting enzyme inhibitors or angiotensin-receptor blockers, calcium channel blockers, β -blockers.

^fFurosemide, bumetanide, ethacrynic acid.

^g3-hydroxy-3-methyl-glutaryl coenzyme A reductase inhibitors (statins), fibrates, niacin antiplatelets, anticoagulants, antiarrhythmics, antidiabetics, antihypertensives, loop diuretics, and antihyperlipidemics.

analysis. Ten other nonselective NSAIDs have low usage within KP California and were grouped together. This NSAID group had a combined 24 case events and included the following drugs (number of cases): diflunisal (2), fenoprofen (0), flurbiprofen (2), ketoprofen (1), ketorolac (4), meclofenamate (10), mefenamic acid (0), meloxicam (0), oxaprozin (0), and tolmetin (5).

Table 4 lists the adjusted odds ratios (OR) and the 95% confidence intervals (CIs) for the NSAIDs included in the analysis. The point estimates were close to 1.0 for all of the nonselective NSAIDs. Two nonselective NSAIDs (indomethacin: OR, 1.27, and 95% CI, 1.04–1.56; naproxen: OR, 1.14, and 95% CI, 1.00–1.30) were associated with a small but statistically significant increase in adverse CV outcomes.

The median time to event was <100 days for all of the NSAIDs we studied. Figure 1 provides a visual representation of the median time, the interquartile range, and the upper and lower extremes for a few selected drugs. These data suggest that the vast majority of CV events occurred within the first eight months of continuous exposure.

Discussion

We studied a group of NSAID users to determine if specific nonselective NSAIDs were associated with a higher risk of adverse CV outcomes. Our results suggest that indomethacin and naproxen may be associated with

a small but significant increased risk of CV endpoints compared with remote use of NSAIDs. The additional risk seen with indomethacin and naproxen (27% and 14%, respectively) is much lower than the threefold increase seen with high-dose rofecoxib. In this study, celecoxib was not associated with an increased CV risk. This is consistent with results from previous epidemiologic studies^{4,6,24–28} but is not consistent with some clinical trial results.^{7,9} One possible explanation for this difference is the fact that celecoxib users in our population were generally receiving low doses of the drug (68% of the patients were taking ≤ 200 mg/d of celecoxib).

Our results also suggest that MIs and SCDs occur earlier in the course of therapy than has been previously reported.⁵ The median time to event was <100 days for all of the NSAIDs we studied.

In April 2005, the FDA issued a report stating that nonselective NSAIDs may be associated with adverse CV events.¹⁰ The agency developed a patient medication guide, to be provided each time a prescription NSAID is dispensed, informing patients that “NSAID medicines may increase the chance of a heart attack or stroke that can lead to death.”²⁹ The agency also required labeling changes for over-the-counter NSAIDs sold without a prescription.³⁰ These actions were mandated even though the FDA recognized that there were little data and no long-term placebo-controlled clinical trials to adequately assess CV risk. Patients and physicians were left with questions and very little data about nonselective NSAIDs’ CV risk and how best to manage pain and inflammation with these drugs.

Our results provide information on the comparative safety of several nonselective NSAIDs. We elected to test individual drugs, versus grouping all of the nonselective NSAIDs together, because each of these drugs has a different pharmacologic profile with respect to cyclooxygenase inhibition, nitric oxide metabolism, and the risk for inducing hypertension and fluid retention.

Epidemiologic studies published since 2000, looking at MI risk and NSAID exposure,^{2,4,23–28,31–35} have focused on selective COX-2 inhibitors and report results on only one or two nonselective agents. Some of these studies included small numbers of patients,^{26,31} had restricted populations based on age or socioeconomic status,^{2,23,24,27,28,33,35} or used hospital admissions for MI as their only endpoint,^{4,24,27,28,32–35} limiting the ability to generalize the results to other groups.

Our study has several other advantages over previous epidemiologic studies. First, KP membership is relatively diverse with respect to age and ethnicity. Our primary endpoint included SCD as well as hospitaliza-

Table 4. Risk of acute myocardial infarction with the use of various NSAIDs

NSAID exposure group	Cases	Study control subjects	Adjusted odds ratio ^a	95% confidence interval	p
Remote use	4658	18720	1.00	Comparator	
Current use (cases)	1773	6557			
Celecoxib	127	496	0.87	(0.69–1.08)	0.21
Diclofenac	21	54	1.72	(0.98–3.01)	0.06
Etodolac	40	129	1.34	(0.91–1.98)	0.14
Ibuprofen	674	2588	1.08	(0.97–1.20)	0.15
Indomethacin	167	471	1.27	(1.04–1.56)	0.02
Nabumetone	73	248	1.09	(0.81–1.47)	0.56
Naproxen	367	1416	1.14	(1.00–1.30)	0.05
Piroxicam	69	335	0.87	(0.66–1.15)	0.33
Rofecoxib ≤ 25 mg/d	58	188	1.23	(0.89–1.74)	0.21
Rofecoxib > 25 mg/d	10	8	3.01	(1.10–8.31)	0.03
Sulindac	143	531	1.18	(0.95–1.45)	0.13
NSAIDs ^b	24	92	1.11	(0.67–1.81)	0.69
Recent use	1711	6219	1.15	(1.07–1.23)	<0.01

^aAdjusted for age, sex, Health Plan region, major cardiovascular events, angina, heart failure, other ischemic heart disease, cardiac arrhythmias, noncardiac hospitalization, other cardiovascular hospitalizations, antiplatelets, anticoagulants, antiarrhythmics, antidiabetics, antihypertensives, loop diuretics, and antihyperlipidemics.

^bNSAIDs: diflunisal, flurbiprofen, ketoprofen, ketorolac, meloxicam, oxaprozin, and tolmetin.

tions for MI, which is important, considering that SCD accounted for 18.5% of the CV events. Furthermore, we restricted the analysis to only those nonselective NSAIDs with a sufficient number of case events, which helped reduce error around the point estimates.

Several limitations exist with our study. We are not able to capture all of the known CV risk factors from our electronic databases (ie, smoking history, family history of MI, and use of low-dose aspirin). Our systems also do not capture use of over-the-counter NSAIDs. To assess these issues, a telephone survey of study control patients was undertaken for the previous study, which found no difference in aspirin use, over-the-counter NSAID use, smoking history, or a family history of MI in first-degree relatives between different groups of NSAID users.³ These results are similar to data cited by Solomon et al,⁴ who noted that a Medicare Current Beneficiary Survey found no difference in body mass index, tobacco use, aspirin use, annual household income, and educational attainment between users of nonselective NSAIDs and users of selective COX-2 inhibitors. Although these data were not captured electronically, it does not appear to occur preferentially within any one group of NSAID users and therefore is unlikely to bias the results.

A statistical limitation exists with our results in that the excess risk associated with naproxen and indomethacin is small; therefore, unmeasured residual confounding may affect point estimates and the level of significance. If all of the CV events or covariates are not captured, residual confounding can have a significant effect on results.

Our results suggest that the risk of adverse CV events associated with nonselective NSAIDs is small relative to a drug such as rofecoxib. This information is important to patients and physicians. It is unlikely that long-term controlled safety studies will be conducted with nonselective NSAIDs, because they are available as generic products. Therefore, we need to rely on well-conducted epidemiologic studies as a means of identifying risk.

One exception to this is a recently initiated study, the PRECISION trial,³⁶ funded by Pfizer Pharmaceuticals, the manufacturer of Celebrex, which is investigating CV risk and the general safety of celecoxib, ibuprofen, and naproxen. The results from PRECISION will not be available for several years, and the study includes only three drugs from the NSAID class.

More work needs to be done to understand the CV risk associated with the NSAID class in general and nonselective NSAIDs in particular. This should be a priority, given the large number of NSAID prescriptions dispensed annually in the United States, which is estimated to be in excess of 100 million.³⁷ Until

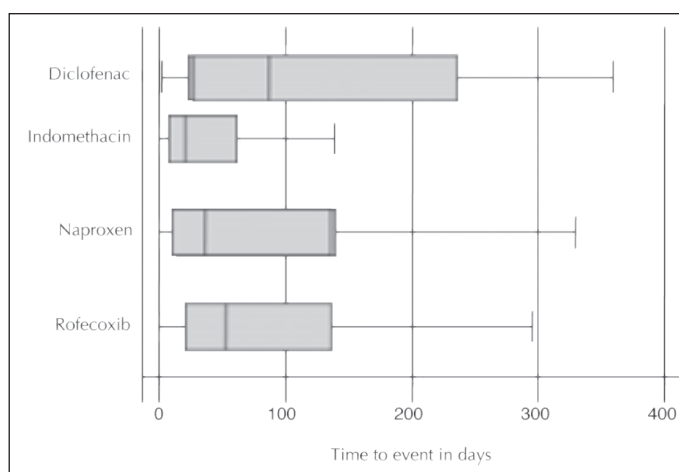


Figure 1. Time to event analysis—box and whisker plot.

more evidence is available, it seems prudent to avoid nonselective NSAIDs found to have an association with adverse CV events. The risk for these adverse effects is likely greatest in patients with a prior history of—or at high risk for—CV disease. ♦

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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Home Hospice Acupuncture: A Preliminary Report of Treatment Delivery and Outcomes

By Karen Kaufman, PhD, LAc
Ellen J Salkeld, PhD

Abstract

In recent years, complementary and alternative medicine modalities, including acupuncture, have been incorporated into hospice care both to address symptom distress and to enhance quality of life. Beginning in 1997, Kaiser Permanente Northwest Hospice began offering limited acupuncture services to hospice patients and, in some cases, their caregivers. Data collection—comprising a chart review ($n = 71$) and in-depth interviews with the two program acupuncturists—was initiated to explore in a preliminary fashion both the processes involved in acupuncture delivery and outcomes associated with this intervention. Information culled from the patient charts (representing the year 2003) revealed a median age of 68.5 years, a cancer diagnosis in 63% of cases, and a median hospice length of stay of 102 days. The most commonly cited chief complaints presented to the acupuncturists included pain (70%), anxiety (45%), shortness of breath (27%), and nausea/vomiting (14%). Patients received a median of three acupuncture treatments; excellent or good results were noted in the charts of 34% of patients whose chief complaint was pain, in 31% of anxiety chief complaints, in 22% of shortness-of-breath chief complaints, and in 29% for nausea/vomiting chief complaints. The program acupuncturists described their practice with this group of patients as a departure from how they treat patients in a typical practice context. They described a greater focus on providing comfort through ameliorating symptoms and a diminished focus on more holistic goals, which often are typical elements in an acupuncture intervention. Nonetheless, acupuncturists also observed instances of outcomes in psychological, social, and spiritual domains, regardless of whether these outcomes were the principal focus of treatment. These data add to the accumulating anecdotal reports suggesting that acupuncture is a promising adjunctive therapy for those nearing the end of life in the home hospice setting. More in-depth and precise assessment is warranted to comprehensively evaluate acupuncture as a viable adjunct to current usual and customary hospice care.

Introduction

Increasingly, complementary and alternative medicine modalities, including acupuncture, massage, Reiki, and music therapy, have been incorporated into hospice care to treat both terminally ill patients and their caregivers to reduce or eliminate symptom distress, decrease medication use, and enhance quality of life.¹⁻⁴ A recent systematic review indicated that acupuncture may constitute a nonpharmacologic means of pain relief for patients nearing the end of life and may also prove beneficial for the relief of dyspnea.⁵

Beginning in 1997, Kaiser Permanente Northwest (KPNW) Hospice began offering acupuncture services on a limited basis to hospice patients and their caregivers to complement current medical treatment by offering a method to ameliorate undesirable side effects from needed analgesic and sedative medications. This program, funded by donations, typically offers a series of five acupuncture treatments to those referred by hospice staff or to those requesting acupuncture treatment. On receipt of a referral, one of two program acupuncturists will visit the patient at home, assess the patient's condition, and deliver a treatment. Both acupuncturists have contracted with KP since the acupuncture project's inception, are licensed with the State of Oregon, and have completed master's-level training in acupuncture and Oriental medicine. We report here on the initial evaluation of this acupuncture program, through an analysis of both qualitative and quantitative data, assessing processes and outcomes associated with acupuncture treatment delivered to patients receiving home hospice services.

Methods

Interviews with Program Acupuncturists

In-person, audiotaped interviews were conducted with the two program acupuncturists to obtain sub-

Editors Note

This preliminary report is being published to complement the article in this issue "The *Dartmouth Atlas Applied to Kaiser Permanente: Analysis of Variation in Care at the End of Life*" in which the authors conclude: "Greater emphasis on palliative care approaches for patients with chronic conditions and earlier transition to the use of hospice would create a better match between the expressed desires of patients and the care they receive, thus improving member and family satisfaction as well as quality of care. In addition, earlier transition to hospice in KP could be one important tool for avoiding undesired and nonbeneficial ICU use, given the negative correlation between hospice and ICU use identified in this analysis."

Karen Kaufman, PhD, LAc, (left) is a T-32 Research Fellow in the Department of Neurology, Oregon Health and Science University, and Helfgott Research Institute, National College of Naturopathic Medicine, Portland, OR. E-mail: kkaufman@ncnm.edu.

Ellen J Salkeld, PhD, (right) is a visiting scholar in the Department of Anthropology, University of Arizona, Tucson, AZ. E-mail: esalkeld@email.arizona.edu.



jective and descriptive information about the acupuncture program. The 90-minute interviews explored how they practiced with hospice patients and what they perceived as successful treatment outcomes, both expected and experienced. The acupuncturists were asked a series of open-ended questions designed to elicit information regarding provision of care to home hospice patients. Overarching questions/topics included the following:

- How do you practice with patients?
- Describe health and disease/illness, healing, or cure
- Describe the outcomes of successful intervention.

The audiotaped interviews were transcribed verbatim, and content analysis⁶ was performed with the interview data to identify and code systematically the treatment-delivery processes and treatment outcomes described by practitioners. To ensure reliability, a second researcher read transcripts, coded interview passages, and discussed preliminary findings.

Retrospective Chart Review of Home Hospice Patients

The first author and one of the study acupuncturists audited electronic chart data representing the hospice patients enrolled in KPNW Hospice in 2003. The chart review focused on patient demographic and health characteristics, chief complaints, treatment modalities used, and treatment success, which were typically available for collection despite often incomplete charting. A relatively crude metric was used to determine degrees of treatment success: Outcomes were deemed fair, good, or excellent on the basis of whether these or similar words were used to describe progress. A judgment was also made regarding categorization on the basis of con-

sistent progress noted versus progress noted only at one point; for example, if a superlative was used to describe progress on more than one occasion, outcomes were deemed excellent. (It should be noted that there was not a category for no outcome or poor outcomes: When a progress note was not made, it was unclear whether the omission was due to no treatment results or to no charting).

Results

Acupuncturist Interviews: Results from Narratives

1. *Delivery of Acupuncture Treatment:* Both practitioners described how the nature and condition of the patients, as well as the practical realities relating to the home setting, influenced their treatment procedure. These issues affected the treatment process, constituting a departure, to varying degrees, from the way they typically delivered therapy. For example, both acupuncturists discussed differences in how they assessed patients:

"I perform tongue [inspection] and pulse and palpation, but mostly as an introduction to the patient. I'm not getting a lot of information from that. I use that as a way of initially touching them. I do get information, but generally I already know that these people are gravely ill."

Both acupuncturists also noted that their goals for healing were different in this patient population:

"Their tongues are black and they take many medications and they can't breathe and they hurt, and I'm not going to give them health—there is nothing I can do for that. I think of healing as ... giving them whatever kind of peace and whatever kind of relief I can bring them."

In terms of treatment delivery, features of the home setting both

influenced how treatments were administered and provided additional assessment information:

"When I go into their home, the only piece of equipment I take, other than my bag full of needles and swabs and such, is a little folding stool that I whip out and sit on, move around if I need to. In some homes I need to use it as a little table because there is literally nowhere else to put things, because their things are piled everywhere—like in my dining room—only in their houses things are everywhere because they are dying and nobody is around who has energy to take care of the day-to-day things."

"It's an amazing experience; so different from working privately, where you see only what the patient chooses to show you. When you go to their home, you see everything; you see how they live. You see the family dynamic."

2. *Intervention Outcomes Observed by Practitioners:*

a. *Symptom Control:* Both practitioners noted that symptom control was a central goal and often a resultant outcome of treatment. For example:

"Anxiety usually responds pretty well, and so do nausea and different kinds of pain. Lung symptoms, like cough and shortness of breath, also respond pretty well."

b. *Psychosocial and Spiritual Outcomes:* Practitioners also observed what they considered additional psychosocial and spiritual outcomes. Often these outcomes arose as a result of ameliorating or attenuating pain symptoms or other chief complaints. In other cases, these outcomes were perceived to arise directly from the treatment. For example:

I think of healing as ... giving them whatever kind of peace and whatever kind of relief I can bring them.

“They get to that place where their spirit is at peace, and it may be only while the needles are in, or for an hour afterwards, but getting there is like meditating—you take that moment and what it gives you, whatever insight, whatever momentary relief.”

“Reduced pain is another part of the picture—the acupuncture treatments in many cases give people that little time when you see their face change and they relax.”

Retrospective Chart Review

The median length of stay in hospice for this sample was 102.5 days. The median time from admission-to-hospice to acupuncture referral was 7 days (range, 0–147 days). Selected hospice patient characteristics are presented in Table 1.

Acupuncture was the most-used treatment modality. Ear seeds, essential oils, and magnets, all within the scope of practice for acupuncturists, were also employed in limited cases. (Note: Ear acupuncture points may be stimulated for a longer period of time by using small seeds from the Vaccaria plant, which are held in place on the ear with a small piece of adhesive tape. To facilitate relaxation, calming essential oils, such as lavender, were occasionally employed as were magnets instead of needles on particular acupuncture points to facilitate energy flow.) Each treatment/acupuncture point prescription was tailored to the individual patient. The median number of treatments was three.

A cancer diagnosis was noted for 63% of the acupuncture program patients in 2003 (Table 2).

Only excellent or good results were noted (fair results not included) in the charts of 24 patients for pain (34%), 14 patients for anxiety (31%), 6 pa-

Table 1. Characteristics of hospice patients (n = 71)			
Demographic	Low	High	Median
Age (years)	26	94	68
Sex	45% (male)	55% (female)	—
Hospice length of stay (days)	15	730	102.5

tients for shortness of breath (22%), and 4 patients for nausea/vomiting (29%). Other health and outcome data regarding acupuncture recipients are summarized in Table 3.

As a routine, at the beginning of each visit, the acupuncturists would ask the patient: “How are you doing? Did the acupuncture seem to help?” In their chart note of the patient’s response, they would report any adverse events—such as significant bleeding, injury from a needle, etc. None was noted for any patient. One spot of rash at the site of a magnet was noted, but after that the practice was discontinued.

Discussion

Acupuncturist Interviews

Two important issues emerged from the acupuncturist interviews. First, the acupuncturists noted that the nature and condition of both the patient and the realities of the home setting influenced their treatment procedure, which constituted a departure from the way they typically delivered therapy. The home setting provided the practitioners with additional information pertaining to patients and their family life that they would not glean from an office visit. The home visit, however, could involve limited space and chaotic conditions, often requiring practitioners to problem-solve regarding setting up their treatment space and positioning patients to treat them. The advanced nature of the disease process in hospice patients required the practitioners to modify healing goals and to deliver treatments focused on symptom control: “giving them whatever kind

of peace and whatever kind of relief I can bring them.”

Second, the acupuncturists noted that symptom control was a central goal and a resultant outcome of treatment. However, they observed that additional psychologic, social, and spiritually oriented outcomes resulted from treatment, regardless of whether these outcomes were the principal goal of treatment. These observations echo those of four other hospice acupuncturists working throughout Oregon who were interviewed as part of an ongoing qualitative study (KK, ES, unpublished data, 2005).

Patient Chart Reviews

Information culled from review of the charts of 71 patients (representing the year 2003) revealed a median age of 68 years, a 55% female sample, and a principal diagnosis of cancer in 63% of cases. The most commonly cited chief complaints were pain (70%), anxiety (45%), shortness of breath (27%), and nausea/vomiting (14%). Positive results from acupuncture intervention were noted in many instances. Results suggest that acupuncture may assist hospice patients in control of symptoms often affecting this population and contributing to a diminished quality of life.

A recent study evaluating the experience of dying patients in both

The home setting provided the practitioners with additional information pertaining to patients and their family life that they would not glean from an office visit.

Table 2. Diagnosis demographics		
Principal diagnosis	Number	Percentage of total sample
Cancer	45	63
Chronic obstructive pulmonary disease	8	11
Congestive heart failure	8	11

Table 3. Chief complaints and symptom relief

Chief complaints ^a	Number	Percentage of total sample	Symptom relief (excellent/good)	
			No. of patients	Percentage ^b
Pain	70	99	24	34
Anxiety	45	63	14	31
Shortness of breath	27	38	6	22
Nausea/vomiting	14	20	4	29

^aChart information typically included more than one chief complaint.

^b Percentage is based on total number of patients reporting that chief complaint (eg, 14 people reported excellent/good relief for anxiety; 45 cited anxiety as a chief complaint: 14/45 = 31%).

home and institutional settings reported that approximately one-quarter of patients did not receive adequate treatment for pain or dyspnea.⁷ Even when medications used in end-of-life care are effective in relieving or attenuating symptoms, they generally are not without side effects. Indeed, the Joint Commission (known until 2007 as the Joint Commission on the Accreditation of Healthcare Organizations) standards emphasize the use of nonpharmacologic means of addressing symptom management for terminally ill patients.

In their interviews with patients after admission to palliative care units, Cohen et al⁸ reported that patients discussed improvements in quality of life beyond those relating to symptom control, including changes in physical, emotional, and interpersonal functioning; spiritual outlook; and preparation for death. The use of acupuncture as an adjunct to standard hospice care may prove beneficial to this group of health care recipients.

Conclusion

The hospice program acupuncturists described their practice with this group of patients as a departure from how they treat patients in a typical practice context, with a greater focus on providing comfort through ameliorating symptoms and a diminished focus on more holistic goals, which are typical elements of an acupuncture intervention. Nonetheless, the acupuncturists observed additional outcomes in psychological, social,

and spiritual domains, regardless of whether these outcomes were the principal focus of treatment.

Results from this preliminary evaluation lend support to the assertion that acupuncture constitutes a promising and effective intervention to be employed in an integrative fashion in the palliative care/end-of-life context. Interview data align with outcomes that reflect the underlying philosophic orientation of hospice, acupuncture, and the models underlying current quality-of-life instruments for end of life.⁹⁻¹¹ For example, the fundamental ideologies of each emphasize patient autonomy, treating the whole person, and healing or making one whole.

Chart data were incomplete, so we are now looking at additional, more comprehensively annotated charts. Taken together, these data comprise a preliminary expansion and clarification of the accumulating anecdotal reports that acupuncture is a promising adjunctive therapy for those nearing the end of life in the home-hospice setting. Likewise, systematic evaluation of programs like this will help to focus the design of future clinical studies in this important domain. For example, what are the best outcome instruments to use and endpoints to gauge in this population? Future preliminary studies will examine the expectations and experiences of both patients and their caregivers regarding the receipt of acupuncture while enrolled in hospice. ♦

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REVIEW ARTICLE

Laparoscopic Colorectal Surgery

By James Yoo, MD

Introduction

Laparoscopic colon resections are being performed with increasing frequency in the United States, though the use of minimally invasive techniques in colorectal surgery has lagged behind its application in other surgical fields. Since the first laparoscopic colectomy was described in 1991, a great deal of controversy has surrounded its use, particularly in the management of colorectal cancer. Several important new studies¹⁻³ have demonstrated the benefits and safety of laparoscopic colorectal surgery, making it now the preferred approach in the surgical management of many colorectal diseases.

History of Laparoscopic Colectomy

In the early 1990s, laparoscopic colectomy was an evolving technique whose oncologic safety had not been proved. Initial case reports describing port-site metastasis as a complication of laparoscopic surgery for cancer caused great alarm, with early reports in small case series noting metastasis rates as high as 21%.⁴ Many surgeons questioned whether there was a novel risk for tumor cell dissemination during laparoscopy compared to open, or conventional, surgery. Proposed mechanisms included cancer cell implantation during the release of pneumoperitoneum, direct tumor implantation from a contaminated instrument or during extraction of the specimen through a small incision, stimulation of tumor growth by the insufflating gas, and the laparoscopic technique itself.

Döbrönte et al first described port-site metastasis in 1978 after an ovarian cancer operation.⁵ Though the underlying etiology is still unclear, the development of recurrent cancer at a previous surgical site is not unique to laparoscopic surgery but occurs after open surgery as well. Two retrospective reviews of open colectomy for colorectal cancer, each with more than 1500 patients, demonstrated an incidence of 0.6% to 0.68% of incisional tumors, with overall abdominal wall tumors having an incidence of 1%.^{6,7} Multiple studies have now demonstrated that the incidence of port-site metastasis

after laparoscopic surgery is low. A prospective evaluation by the Laparoscopic Bowel Surgery Registry, which was initiated in 1992 by the American Society of Colon and Rectal Surgeons, the American College of Surgeons, and the Society of American Gastrointestinal Endoscopic Surgeons, reported the rate of this complication to be at 1.1%,⁸ similar to the results for open surgery. Recent trials evaluating the outcomes of laparoscopic colectomy for cancer have also reported a similarly low incidence of port-site metastasis.^{1,9} Today these operations are performed with almost no thought of this now historical concern. However, it was only after the publication of a report on the Clinical Outcomes of Surgical Therapy (COST) Study Group¹ trial in 2004 that laparoscopic surgery became an accepted practice in the management of colorectal cancer. With the publication of several multi-institutional, prospective randomized trials,^{1,3} it became clear that laparoscopic colectomy is equivalent to open colectomy in terms of oncologic safety for all stages of colon cancer. Margins of resection, number of lymph nodes harvested, cancer-related survival rates, and rates of complications and mortality are the same whether the operation is performed open or laparoscopically.^{1,3,9-13}

Are There Immune Benefits to Laparoscopic Surgery?

A consequence of those early concerns was an increasing interest in understanding the physiologic consequences of surgery, both open and laparoscopic, and its effects on tumor biology and immune function. It is well known that surgery leads to transient immunosuppression, though the underlying etiology remains unclear. A well-known cascade of physiologic and immunologic responses occurs after surgery. Inflammation involves the recruitment of macrophages and neutrophils at sites of tissue injury, release of proinflammatory cytokines and growth factors to promote wound healing (and that may also stimulate tumor growth), and activation of T cell (cellular) and B cell (humoral) immunity. Surgery has been shown

James Yoo, MD, is an Assistant Professor at the University of California, Los Angeles Department of Surgery and the Course Director of UCLA Laparoscopic and Hand-Assisted Colectomy. E-mail: jayoo@mednet.ucla.edu.



Systemic immune function and tumor growth may be differentially regulated by the degree of surgical trauma.

to dampen each of these responses, leading to varying degrees of immunosuppression. Laparoscopic surgery, which is associated with less patient trauma through smaller incisions and less postoperative pain, may be associated with less immunosuppression, compared with open surgery, though the data remain a subject of debate and the clinical significance of this effect remains unclear.¹⁴

Experimental models have demonstrated differences in the function of macrophage, neutrophil, lymphocyte, and T cell populations, differences in the level of secreted pro-inflammatory cytokines (interleukin 6, tumor necrosis factor), and alterations in delayed-type hypersensitivity (an indicator of cell-mediated immunity) comparing laparoscopic and open techniques.

In other models, stimulation of tumor growth or metastases after surgery has been shown to be reduced in laparoscopically treated patients compared with those who underwent open surgery. This could possibly be due to differences in the levels of angiogenic/growth factors secreted at the time of surgery. Vascular endothelial growth factor is a potent angiogenesis factor, and serum levels are elevated in patients with colon cancer. In a study by Belizon et al, patients who underwent surgery for colon cancer had further elevations in serum vascular endothelial growth factor levels during the early postoperative period.¹⁵ The increase occurred earlier, and was more profound, in patients having open surgery compared with laparoscopically treated patients. Levels also increased in proportion to incision length. Insulin and insulin-like growth factor are also associated with tumor growth; elevated levels may place patients at increased risk for the development of colon cancer. Studies have demonstrated lower levels of the tumor inhibitor insulin-like growth factor binding protein 3 in patients having open surgery, whereas no decrease was seen in laparoscopically treated patients.¹⁶

To date, no survival differences have been found comparing cancer patients treated by the open method and those treated laparoscopically; however, some intriguing trends have been seen in smaller studies. Systemic immune function and tumor growth may be differentially regulated by the degree of surgical trauma. Though the clinical impact of these findings is uncertain, the concept certainly warrants further study.

How Is Laparoscopic Colectomy Done?

The technique of laparoscopic colectomy has a long learning curve because of the advanced laparoscopic skills it entails. Unlike other laparoscopic procedures,

such as the Nissen fundoplication or cholecystectomy, colorectal procedures involve dissection and mobilization of intra-abdominal organs in multiple quadrants. Laparoscopic colorectal surgery involves the use of several small incisions through which a specialized camera and several laparoscopic instruments are inserted (Figures 1, 2). An insufflator blows carbon dioxide (CO₂) into the peritoneal cavity, creating a pneumoperitoneum that provides a working space to perform the operation. Tilting of the operating-room table in various positions during an operation uses gravity to allow intra-abdominal organs to fall away from the area of dissection, providing necessary exposure that would normally be achieved through the use of retractors. Intestinal resection requires laparoscopic ligation of large vessels, mobilization and removal of a long floppy segment of colon, and restoration of intestinal continuity. Once the colon segment has been completely mobilized and its blood supply divided, a small skin

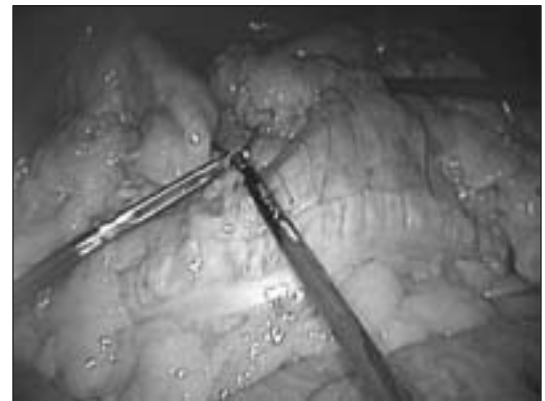


Figure 1. Typical view during a laparoscopic colectomy.



Figure 2. Typical scars after a laparoscopic right colectomy.

incision is made to exteriorize the colon, a resection and anastomosis are performed extracorporeally, and the rejoined colon is placed back into the abdomen.

Indications, Advantages, and Disadvantages of Laparoscopic Colectomy

Most patients are candidates for a laparoscopic approach. When the surgeon is experienced, even patients with a history of abdominal surgery are candidates. Though there are clear benefits, they have not been as compelling when compared to the clear advantages associated with other laparoscopic procedures. The main reason is that a colectomy, whether open or laparoscopic, results in a delayed return of bowel function. Though recovery of bowel function is quicker after laparoscopic surgery, the difference is on the order of one or two days, resulting in a similar reduction in length of hospital stay. Also, the laparoscopic approach is associated with longer operating-room times. Even if long-term benefits are equivalent between open and laparoscopic techniques, the short-term benefits are real advantages for patients. In practical terms, the laparoscopic approach is associated with less pain, a faster recovery, earlier return of bowel function, a shorter hospital stay, possible immune benefits, and smaller scars, making it the preferred method for intestinal resection.

Technical Pearls—Use of Carbon Dioxide Colonoscopy

The lack of tactile feedback during laparoscopic surgery can make tumor localization difficult, especially if the lesion location has not been tattooed on the colon wall before surgery. It is imperative that the exact location of the tumor is known prior to proceeding with colectomy. Even when the lesion location has been tattooed onto the colon, often the mark can be difficult to see, or there may be confusion regarding the location of the tattoo in relation to the tumor (proximal or distal), which can affect surgical margins. Intraoperative colonoscopy is a way of definitively localizing a lesion and should be available during all laparoscopic colectomies. Traditional colonoscopy uses room air as the insufflating gas, which leads to significant bowel distension and requires clamping of the proximal colon to minimize this effect. Clamping the bowel can lead to injury, and even when it is successfully performed, the degree of distension often makes simultaneous laparoscopic visualization difficult. These problems can be circumvented with the use of CO₂, rather than room air, as the insufflating gas (Figure 3). Because



Figure 3. Endoscopic carbon dioxide insufflator and colonoscope.

CO₂ is absorbed much more rapidly than room air, bowel distension is minimized and dissipates quickly, making proximal clamping unnecessary. Use of CO₂ allows for laparoscopic and endoscopic procedures to be performed simultaneously (Figure 4), and this technique has been shown to be safe and clinically useful.¹⁷ Besides tumor localization, CO₂ colonoscopy may have other potential applications.

How Is Laparoscopic Colectomy Evolving?

The laparoscopic approach continues to gain popularity and has evolved to include not just “pure” laparoscopic techniques but also hand-assist devices. Hand-assisted surgery can be used as a bridge for surgeons who are not completely familiar or facile with laparoscopic techniques, and even for the most experienced laparoscopic surgeons, it is often the preferred technique for surgery involving left-sided pathology (descending or sigmoid colon and rectum; Figure 5). Use of a hand-assist device decreases the learning curve associated with laparoscopy, provides tactile feedback for the surgeon, and shortens operating-room time while still preserving many of the advantages of laparoscopic surgery.¹⁸ By combining laparoscopic surgery with the tactile feedback of a hand-assist device, surgeons can reduce operating-room time and have a lower procedure conversion rate. The technique involves making an incision the width of a hand and placing a hand-assist device to facilitate laparoscopic dissection. New hand port devices make this technique possible without loss of pneumoperitoneum, which is essential for performing laparoscopic procedures. Because an incision (4–5 cm) is necessary to remove the colon specimen at the end of a laparoscopic operation, the difference between a pure laparoscopic procedure and a hand-assisted operation is generally a few additional



Figure 4. Combined laparoscopy and CO₂ colonoscopy.



Figure 5. Commonly used hand-port device (GelPort).

centimeters (3–4 cm) of incision length. Several clinical trials have demonstrated that there is no difference in patient recovery or discharge for laparoscopic versus hand-assisted techniques.^{19,20} Because larger incisions are often needed and because of the increased risk of wound infections and pulmonary complications, this technique has particular advantages with overweight or obese patients.

What Is the Future of Laparoscopic Colectomy?

Laparoscopic techniques are currently used in the surgical management of diverticulitis, Crohn's disease and ulcerative colitis, familial polyposis, rectal prolapse, and benign and malignant colorectal neoplasms. As technology moves forward, minimally invasive surgery continues to evolve. Endoluminal approaches are being explored as an alternative or complimentary surgical technique.

Combined laparoscopic and colonoscopic procedures may bridge the gap to future developments in endoluminal surgery. In the past, simultaneous laparoscopy and colonoscopy was technically difficult because colonoscopy used room air as the insufflating gas, leading to significant bowel distension that obscured

the laparoscopic view and prohibited its simultaneous use. With CO₂ colonoscopy, combined laparoscopic and endoscopic procedures can be performed simultaneously and may have many potential applications, including the management of benign colonic polyps that are not removable by traditional endoscopic techniques. These polyps often require a colectomy because of the risk that they harbor cancer within them, as well as the future risk of developing cancer. However, an alternative approach in this setting may be a combined laparoscopic and CO₂ colonoscopic polypectomy. When these procedures are combined, a polyp can be removed without a formal bowel resection. This combined procedure allows for both intra- and extraluminal manipulation of the bowel wall to aid in endoscopic polyp removal (Figure 6). If the frozen section is found to be benign, the procedure is completed. However, if cancer is suspected, a formal laparoscopic colectomy can be performed. Any full-thickness injury to the bowel wall during endoscopic polyp removal is visualized at the time of surgery and can be managed laparoscopically.

Conclusion

The use of minimally invasive approaches in the surgical management of colorectal diseases continues to gain popularity. Laparoscopy has clear advantages and can be performed in a majority of patients at surgical centers with experienced surgeons. Use of hand-assist devices and CO₂ colonoscopy are essential tools in the operating room. As technology marches forward, newer techniques will continue to advance the quality of patient care. ♦

Disclosure Statement

Dr Yoo discloses that he is a consultant with Covidien.

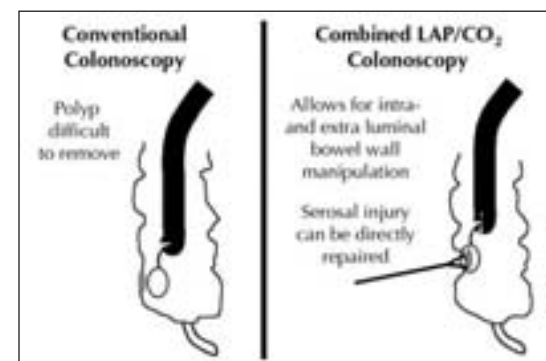


Figure 6. Combined laparoscopic and CO₂ colonoscopic polypectomy.

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Feel Kindly

We do not go to the operating table as we go to the theatre, to the picture gallery, to the concert room, to be entertained and delighted; we go to be tormented and maimed, lest a worse thing should befall us The experts on whose assurance we face this horror and suffer this mutilation should have no interests but our own to think of; should judge our cases scientifically; and should feel about them kindly.

— The Doctor's Dilemma, preface (1913), *George Bernard Shaw, 1856-1950, Irish poet and playwright, 1925 Nobel Laureate in Literature*

Current Status and Treatment of Primary Hyperparathyroidism

By Dina M Elaraj, MD
Orlo H Clark, MD

Abstract

Primary hyperparathyroidism (HPT) is diagnosed in approximately 100,000 patients in the US each year, with a 2–3:1 female-to-male distribution. In most cases, occurrence is sporadic rather than familial, and 80% to 85% of cases of sporadic primary HPT are caused by a solitary parathyroid adenoma. The diagnosis is made by hypercalcemia with an inappropriately elevated parathyroid hormone (PTH) level and a 24-hour urine calcium excretion level that is normal or high. Truly asymptomatic primary HPT is rare, as most patients have symptoms or metabolic complications when carefully evaluated by standardized health questionnaires. The National Institutes of Health (NIH) published guidelines in 2002, recommending parathyroidectomy for all symptomatic patients and for asymptomatic patients less than age 50 years or those who cannot participate in medical surveillance. These criteria have been called into question as being too limited, because multiple studies have demonstrated symptomatic and metabolic benefits of parathyroidectomy in “asymptomatic” patients. Given the studies showing an improvement in quality-of-life measures, future risk for developing renal calculi, bone density, cardiovascular health, and risk of death, we believe that virtually all patients with primary HPT should undergo surgical resection. An improvement in preoperative localization studies as well as the development of a rapid intraoperative PTH assay has changed the approach to parathyroid surgery since the 1980s. Because most sporadic primary HPT is caused by a single gland adenoma, our preferred procedure has now changed from a bilateral neck exploration to a focused or unilateral approach, with similar rates of success in patients with a solitary tumor identified preoperatively.

Background

Primary hyperparathyroidism (HPT), which is characterized by the autonomous overproduction of parathyroid hormone, is diagnosed in approximately 100,000 patients in the US each year.¹ It is two to three times more common in women than in men, affecting 1 in 500 women

and 1 in 1100 men older than age 60 years.² Its incidence increases with age, affecting about 1% of the population overall and 2% of people older than age 55 years.³

Primary HPT may be sporadic or familial. In most cases (80%–85%), sporadic primary HPT is caused by a solitary parathyroid adenoma,

with the remainder of cases due to double adenomas (about 4%), multiple-gland hyperplasia (10%–15%), and parathyroid carcinoma (<1%).^{3–6} Familial syndromes associated with primary HPT include multiple endocrine neoplasia types 1 and 2 (MEN1 and MEN2), non-MEN familial HPT, HPT–jaw tumor syndrome, and familial neonatal HPT. These familial syndromes are associated with (usually asymmetric) multiple-gland hyperplasia. In addition, nonMEN familial HPT and HPT–jaw tumor syndrome are associated with an increased risk of parathyroid cancer.^{7,8}

The exact cause of sporadic primary HPT is unknown and is likely multifactorial, with environmental and genetic causes. It is associated with a history of radiation exposure^{9,10} as well as with prolonged lithium use.^{11,12} Genetic associations in sporadic primary HPT include overexpression of the PRAD1 oncogene (encoding cyclin D1) and an inactivating mutation of the MEN1 tumor-suppressor gene (encoding menin).¹³ The MEN1 gene is also associated with familial HPT, as are RET (associated with MEN2), HRPT2 (encoding parafibromin, associated with HPT–jaw tumor syndrome), and the CASR gene (encoding the calcium-sensing receptor, associated with neonatal primary HPT).



Dina M Elaraj, MD, (left) is an Endocrine Surgeon and Professor of Surgery at Northwestern University Feinberg School of Medicine. E-mail: delaraj@nmh.org.
Orlo H Clark, MD, (right) is an Endocrine Surgeon and a Professor of Surgery at the University of California, San Francisco. E-mail: clarko@surgery.ucsf.edu.

Parathyroid disease is a relatively recent discovery in modern medicine, as the parathyroid glands themselves were the last major organ to be recognized in humans. They were first described by Ivar Sandström, a Swedish medical student, in 1879.¹⁴ The first parathyroidectomy for HPT was performed in a patient with von Recklinghausen disease and crippling bone disease by Felix Mandl in Vienna in 1925. In the US, HPT was first diagnosed in 1926 by Eugene DuBois. The patient, Captain Charles Martell, had severe bone demineralization and fractures and underwent six negative neck explorations before finally having a mediastinal parathyroid adenoma resected via median sternotomy by Edward Churchill and Oliver Cope at the Massachusetts General Hospital in 1932.¹⁵

Prior to 1932, all patients with HPT presented with osteitis fibrosa cystica, a bone disease characterized by increased osteoclastic resorption of bone and replacement by fibrous tissue. It was, in fact, initially thought that this bone disease caused parathyroid enlargement. Since that time, we have gained an understanding of calcium metabolism and parathyroid hormone physiology and know that it is the HPT that is responsible for bone demineralization, which in its most severe form is manifested by osteitis fibrosa cystica.

Diagnosis

Common symptoms of HPT are described by the pentad “painful bones, kidney stones, abdominal groans, psychic moans, and fatigue overtones,” which refers to typical signs and symptoms, including a decrease in bone mineral density with osteopenia, osteoporosis, or osteitis fibrosa cystica; joint or bone aches and pains; gout; nephrolithia-

sis; heartburn; peptic ulcer disease; pancreatitis; constipation; neuropsychiatric changes; and fatigue.¹⁶ A complete list of symptoms and associated conditions of HPT appears in Table 1. Even patients who are thought to be asymptomatic will often have symptoms or metabolic complications when carefully evaluated with standardized health questionnaires.^{17,18} Truly asymptomatic HPT is rare, occurring in only 2% to 5% of patients.^{16,19}

Even so, HPT is most often diagnosed by routine laboratory screening for serum calcium.³ HPT is the most common cause of hypercalcemia in the outpatient setting, and the diagnosis is made on the basis of hypercalcemia, with an inappropriately elevated intact parathyroid hormone (PTH) level, and a normal or increased 24-hour urinary calcium concentration. Occasionally patients with primary HPT can have intermittently elevated or normal serum calcium levels (intermittent or normocalcemic primary HPT); these patients will usually have an elevated ionized calcium level.³ Other causes of an elevated serum calcium with an inappropriately elevated PTH level include thiazide diuretics, lithium, and benign familial hypocalciuric hypercalcemia (BFHH), an autosomal-dominant condition caused by a heterozygous mutation in the CASR gene. To exclude these as causes for hypercalcemia with an elevated PTH level, the physician should have the patient discontinue medications such as thiazides and lithium and should have the patient retested. It is also important to exclude BFHH as a cause for hypercalcemia with an elevated PTH level, as these patients will not benefit from parathyroidectomy. BFHH can be excluded by documenting a previous normal blood calcium level or

Table 1. Symptoms and associated conditions in patients with primary hyperparathyroidism

Symptoms	
Fatigue	Depression
Weakness	Memory loss
Polydipsia	Loss of appetite
Polyuria	Nausea
Nocturia	Heartburn
Joint/bone pain	Pruritus
Constipation	
Associated conditions	
Nephrolithiasis	
Hematuria from passage of stones	
Renal dysfunction	
Osteopenia/osteoporosis/bone fracture	
Hypertension	
Joint swelling	
Gout/pseudogout	
Weight loss	
Gastric/duodenal ulcer	
Pancreatitis	

if the 24-hour urine calcium level is not low (ie, not less than 100 mg per 24 hours), with a ratio of urine calcium to creatinine clearance of >0.02 (this ratio is usually <0.01 in patients with BFHH).²⁰

Other laboratory derangements sometimes seen in patients with primary HPT include a low or low-normal phosphorous level, an increased chloride-to-phosphorous ratio (>33), a high or high-normal 1,25-dihydroxy vitamin D level, and an increased alkaline phosphatase level.^{21,22} The latter signifies high-turnover bone disease, and these patients are at risk for developing hypocalcemia after parathyroidectomy.

Treatment

The treatment of primary HPT is parathyroidectomy. For those patients who are symptomatic (eg, those with nephrolithiasis, fractures, or neuromuscular symptoms), this treatment recommendation is obvious. However, when the patient is “asymptomatic,” the referring physician may be reluctant to rec-

Common symptoms of HPT are described by the pentad “painful bones, kidney stones, abdominal groans, psychic moans, and fatigue overtones ...”

commend surgery and the patient may be reluctant to accept the recommendation, given the lack of symptoms or signs.

The recommendations regarding which patients should undergo surgery have changed since the 1980s.

The effects of HPT on fracture rates and cardiovascular disease have also been demonstrated.

In 1990, the National Institutes of Health (NIH) convened a consensus conference on the management of asymptomatic primary hyperparathyroidism.¹ These guidelines were then revised in 2002, at the Workshop on Asymptomatic Primary Hyperparathyroidism: A Perspective for the 21st Century.²³ Table 2 summarizes the differences in recommendations between these two conferences. The 2002 guidelines currently recommend parathyroidectomy for patients 1) with a serum calcium >1.0 mg/dL (0.25 mM) above the reference range; 2) with 24-hour calcium excretion >400 mg (10 mmol); 3) with creatinine clearance reduced by 30% compared with age-matched control subjects; 4) with forearm, lumbar spine, or hip T score reduced by >2.5SD on bone mineral density scan; 5) who are younger than age 50 years; and 6) for whom medical surveillance is either not desirable or possible.

The current recommendations for patients with primary HPT who do not undergo surgery include biannual serum calcium measurements and annual serum creatinine measurements and bone mineral density scans.

Multiple studies have shown symptomatic and metabolic benefits of parathyroidectomy for patients with “asymptomatic” primary HPT, raising the question of whether the NIH criteria are too limited. One study concerned 178 patients who underwent parathyroidectomy and were divided into two groups on the basis of whether they met the NIH criteria for parathyroidectomy; they were compared with a control group of 63 patients who underwent thyroidectomy.²⁴ Of 14 symptoms queried on a preoperative and postoperative questionnaire, both groups with primary HPT who underwent parathyroidectomy experienced a significant improvement in symptoms at an average follow-up of one month, and there was no difference in the frequency of improvement between the NIH and nonNIH groups. Another study of 100 patients, 82 of whom were followed for more than one year, similarly demonstrated an improvement in general health, muscle strength, mood, level of anxiety, and energy

level after parathyroidectomy.²⁵ An additional study, which randomized 53 patients to parathyroidectomy versus regular follow-up, demonstrated a statistically significant increase in bone density at the femoral neck and total hip, as well as a modest improvement in quality of life and psychologic function as measured by a standardized health survey form.²⁶

In addition to improvement of symptoms after parathyroidectomy, multiple studies have shown an improvement in conditions associated with primary HPT. The effect of parathyroidectomy on the future risk for developing renal calculi was studied in a cohort of 258 patients in Milwaukee, Wisconsin with primary HPT who underwent parathyroidectomy.²⁷ The authors found that of 71 patients with nephrolithiasis documented preoperatively, only four passed stones postoperatively, resulting in a decrease in the rate of stone formation per patient per year from 0.36 to 0.02.

The effects of HPT on fracture rates and cardiovascular disease have also been demonstrated. A retrospective study of 1569 patients (452 underwent parathyroidectomy versus 1117 were observed) found that parathyroidectomy was independently associated with a decreased fracture risk (hazard ratio,

Table 2. Differences between the 1990 and 2002 National Institutes of Health recommendations for parathyroidectomy as the treatment of primary hyperparathyroidism

	1990 recommendations	2002 recommendations
Serum calcium level	>1.0–1.6 mg/dL (0.25–0.4 mM) above reference range	>1.0 mg/dL (0.25 mM) above reference range
24-hour urine calcium excretion	>400 mg (10 mmol)	Unchanged
Creatinine clearance	Reduced by 30% compared with age-matched controls	Unchanged
Bone mineral density	Reduced by >2 SD compared with age-, sex-, and race-matched controls (Z score; forearm)	Reduced by >2.5 SD compared with sex- and race-matched controls (T score; forearm, lumbar spine, or hip)
Patient age	<50 years	Unchanged
Other	Patients for whom medical surveillance is either not desirable or possible	Unchanged

0.68) on multivariate analysis.²⁸ Similarly, a cohort study of 674 patients who underwent parathyroidectomy compared with 2021 age- and sex-matched controls showed that the patients with HPT had an increased relative rate of fracture before surgery (1.8) but that the rate returned to normal (1.0) after surgery.²⁹ Furthermore, the increased risk of fracture was evident for up to ten years before parathyroidectomy and was independent of serum calcium concentration. A separate analysis of this same cohort³⁰ showed an increased risk of acute myocardial infarction for up to ten years prior to surgery (relative risk, 2.5) and within the first year after surgery (relative risk, 3.6) but decreased to a normal level more than one year after surgery. This may be related to a regression of left ventricular hypertrophy, as demonstrated in a study using echocardiography to evaluate left ventricular hypertrophy in 43 patients with HPT compared to 43 age- and sex-matched controls.³¹ This study found that the left ventricular mass index was statistically significantly higher in those with HPT than in the controls and that this correlated with PTH values. Furthermore, there was statistically significant decrease in left ventricular mass index six months after parathyroidectomy.

As a further consequence of the increased risk of cardiovascular events in patients with untreated HPT, there is also an increased risk of death. A study from a national patient registry in Sweden of 4461 patients who underwent parathyroidectomy between 1987 and 1994 demonstrated a significantly increased risk of death compared with the general population.³² This was due to cardiovascular disease, with a risk ratio of 1.71 for men and 1.85 for women.

Given the data demonstrating improvements in quality-of-life measures, future risk for developing renal calculi, bone density, cardiovascular health, and risk of death after parathyroidectomy, we believe that virtually all patients with a diagnosis of primary HPT should undergo surgical resection. The surgical gold standard is a bilateral neck exploration with identification of all four parathyroid glands and resection of the abnormal gland(s). This procedure has a success rate of approximately 97% for curing primary HPT, with complication rates of 1% to 2% when performed by experienced endocrine surgeons.³ However, given that 80% to 85% of patients will have only a solitary adenoma, a bilateral neck exploration subjects 15% to 20% of patients to unnecessarily extensive surgery, with the attendant risks of recurrent laryngeal nerve injury and postoperative hypocalcemia.

There has been an evolution in the approach to surgery in these patients since the 1980s because of an improvement in preoperative localization studies and the development of intraoperative PTH (IO-PTH) monitoring. By incorporating these tests into their algorithm, most endocrine surgeons have now adopted a focused or unilateral approach to parathyroidectomy, with exploration of the contralateral side if two normal or abnormal parathyroid glands are seen on the ipsilateral side, or if the IO-PTH fails to decrease. A bilateral approach is still indicated for those with familial or lithium-associated HPT. A retrospective study of 338 patients with sporadic primary HPT found that ultrasound alone had a sensitivity of 65% in detecting a parathyroid adenoma, sestamibi scan alone had a sensitivity of 80%, and the use of both techniques together increased

the sensitivity to 96%, which is similar to the success rate associated with a bilateral neck exploration.³³ The distribution of pathologies (81% single adenoma, 10% hyperplasia, 7% double adenoma, and 2% carcinoma) was similar to that generally reported in the literature.

The development of a rapid IO-PTH assay³⁴ further influenced the idea that unilateral neck exploration may be sufficient. However, a prospective study evaluating the use of ultrasound, sestamibi scan, and IO-PTH assay in 350 patients with sporadic primary HPT found that the combination of the 3 studies had a 9% failure rate if a unilateral approach was undertaken, though these data may be related to the lower number of solitary adenomas (69%) and higher number of double adenomas or hyperplasia (14% and 17% respectively) found than that generally reported in the literature.³⁵ As one might expect, a criticism of the unilateral approach is that it may underestimate the incidence of multiple-gland disease. A study of 45 patients who underwent bilateral neck exploration found an incidence of double adenoma or hyperplasia of 13% compared with 0% in 35 patients who underwent focal neck exploration.³⁶ All patients were normocalcemic at a mean follow-up point of 17 months. A larger review of the literature demonstrated similar findings. This review of 2095 patients in 31 studies who underwent a unilateral approach found that 92.5% had a single adenoma and only 5.3% had multiple-gland disease, compared with 79.7% and 20.6%, respectively, in a review of 2166 patients in 14 studies who underwent a bilateral neck exploration.³⁷ The difference in these data was statistically significant.

To better address the question, researchers conducted a prospec-

tive randomized trial of unilateral versus bilateral neck exploration in 91 patients in Sweden.³⁸ Unilateral neck explorations were guided by preoperative sestamibi subtraction scintigraphy and IO-PTH testing. There was no statistically significant difference in the incidence of multiglandular disease (5/41 vs 4/40), costs (\$2258 ± \$509 vs \$2097 ± \$505), or cure rate (95.1% vs 97.5%) between unilateral versus bilateral exploration. Patients who had a solitary adenoma, however, had a significantly shorter mean time in surgery (62 ± 29 vs 84 ± 38 minutes) when the surgeon used a unilateral versus a bilateral approach. Furthermore, patients in the bilateral group experienced a higher incidence of transient postoperative hypocalcemia and consumed more oral calcium than those in the unilateral exploration group. There were no cases of permanent recurrent laryngeal nerve paralysis in either group. Thus, this randomized trial demonstrated no difference in the incidence of multiglandular disease or cure rate between a unilateral versus a bilateral neck exploration.

Conclusion

Primary HPT is the most common cause of hypercalcemia in the outpatient setting. It is more common in women and more likely to be sporadic than familial. Most patients with primary HPT have symptoms or metabolic complications when carefully evaluated, and we recommend parathyroidectomy for virtually all patients, even for those who do not meet the NIH criteria for parathyroidectomy. This recommendation is based on studies documenting the natural history of untreated primary HPT and on multiple studies that show an improvement in quality-of-life measures, decreased future risk for

developing renal calculi, improved bone density and cardiovascular health, and decreased risk of premature death after parathyroidectomy. Because most patients with sporadic primary HPT have a single gland adenoma, preoperative localizing studies, IO-PTH testing, and a focused or unilateral approach is our preferred procedure when one tumor is identified preoperatively, with exploration of the contralateral side if two normal or abnormal parathyroid glands are seen on the ipsilateral side, or if the IO-PTH fails to decrease. This can be done with success rates similar to those of bilateral neck exploration. ♦

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Clarke's First Law

When a distinguished but elderly scientist states that something is possible,
he is almost certainly right.
When he states that something is impossible,
he is very probably wrong.

— Sir Arthur C Clarke, b 1917, British science fiction author and inventor



"Haleakala—The House of the Sun"

whole cloth quilt, painted with procion dyes; machine quilted
35" x 49"

By Charlene Hughes, RN

Ms Hughes is a nurse at the Wailuku Clinic, Maui, Hawaii. She began quilting in the 1970s and, in 1996, founded the Maui Quilt Guild. She has created and donated quilts to survivors of Hurricane Katrina, domestic and animal abuse shelters, hospitalized veterans of wars, residents of retirement homes, the AIDS Foundation and breast cancer research. Her quilts are featured in many venues: exhibits, books, magazines, including two pieces on exhibit at the Wailuku Clinic and the Kona Clinic.

“The Other Side of the Fence”: A Geriatric Surgical Case Study of Error Disclosure

By Robert Formanek, Jr, MD
Doug Bonacum, MBA, CSA

Introduction

Learning and continuous improvement are cornerstones of the profession of medicine. Learning methods available for physicians and other health care professionals include case study and peer review. Through their application in the examination of clinical care, insights are gained to improve the performance of individual clinicians and teams as well as the health care system at large.

This article includes panel discussion, commentary, and excerpts from a letter entitled *The Other Side of the Fence*,^a which was written by a patient's daughter to a Kaiser Permanente (KP) facility Healthcare Ombudsman/Mediator (HCOM) following her mother's death. It represents an actual case—a true story—that offers a number of dimensions from which to learn, including the unique point of view presented by the patient's daughter about her mother's course of care. In the letter, the daughter reflects on her mother's care experience, which involved an unanticipated adverse event.

Her disappointment regarding her relationship with and confidence in the health care team implores us to look deeply into the meaning of high-quality, patient-centered care. As individuals and as a health care organization we must ask: What can we do better to give our patients and their families the comfort of

knowing that their health care team is “on their side” and not “on the other side of the fence”?

Brent James, MD, a nationally renowned physician leader in clinical quality improvement at Intermountain Health Care in Utah, emphasizes the critical importance of trust in one's physicians and other health care professionals. This trust forms the basis for the therapeutic relationship—the trusting relationship—that is foundational to the provision of safe, high-quality health care. He argues^b that to achieve this trust and, thus, to be a complete physician, a complete nurse, a complete social worker, ie, a complete health care professional, one must effectively play the “caring role” in concert with the more familiar “curing role.” By skillfully manifesting both, patients will know their health care team is indeed on their side.

In this case study, the patient's daughter and attending surgeon share the story of the 90-year-old mother admitted to the hospital with a hip fracture. In addition to the “factual,” objective information related by the storytellers, there are critical subjective elements—particular beliefs, values, and emotions—that interplay with the clinical decision-making process. Following the story, three KP experts provide analytic commentary.

The article challenges us to:

1. distinguish between the “curing role” and the “caring role”
2. expand the “caring role” as professionals, as teams, and as a health care system
3. be mindful of and address conflict between our own values and those of our patients
4. affirm the importance of timely, honest, and empathetic communication as essential to the therapeutic relationship, and
5. identify local resources for advice and support, especially following an adverse event.

The Story

Daughter: My 90-year-old mom was on the frail side, but she lived independently in her own apartment. She played cards a couple times a week with her friends. She read three or four books a week, did a crossword puzzle every day, and watched one, and only one, TV show—*Jeopardy*. In December 2005, my mother fell at home and fractured her hip. She was taken by ambulance to the emergency room and I was informed that she would need to go to surgery. Her surgery had to be delayed for a day however, because she was in atrial fibrillation, which required medication control.

My mother wanted me to let everyone know about her advance directive and that the most important thing to her was the quality of her life, not the quantity. She didn't fear

Robert Formanek, Jr, MD, (left) is the Medical Director for Medical Directors' Quality Review (MDQR) at The Permanente Federation in Oakland, CA. E-mail: robert.formanek@kp.org.
Doug Bonacum, MBA, CSA, (right) is the Vice President, Safety Management, the Department of Care and Service Quality of Kaiser Foundation Health Plan and Hospitals in Oakland, CA. E-mail: doug.bonacum@kp.org.



death; she feared the process of getting there. So, I was very clear with everyone from day one that she had an advance directive, and I made sure that everyone had a copy.

On the following day we waited for her to go to surgery and nothing was happening. The nurses on the floor didn't seem to know what was going on. Finally, around 7:00 pm, they told me they couldn't fit her into the schedule and she would have to go the next day. On the following day she did eventually go to surgery. She did well during surgery and woke up normally.

On the day after surgery the physical therapist came in and we went to get her out of bed. When she stood up on that leg, she really screamed in pain. We were both surprised. Later, the therapist mentioned to me she may have been being a bit melodramatic, because it shouldn't have been that painful.

Attending Surgeon: The surgery went well except I had a little trouble inserting the implant after the fracture was in place, but I didn't question it because everything came together well. Afterwards I checked the x-ray and then moved her hip; the motion was fine, and it appeared stable. On the third day after surgery I came to see her—I had been off the weekend—and I noticed her increasing need for pain medicine. She was not very communicative herself, but her daughter was concerned and had good reason to be, because I too did not expect that much pain on the third day after I had fixed the fracture.

I repeated an x-ray and noticed that the two bottom screws had pulled out and the implant had displaced so there was no longer fracture reduction. This was obviously very upsetting. I went and told the daughter that the fracture had displaced, the implant wasn't in the right place, and that we should revise the surgery—do

it over—to get the best possible chance for her mother to heal the fracture and to walk again.

Daughter: The next day came and we weren't given a time for the surgery. When it got to be late in the afternoon I made a few calls and was asked to go to the recovery area to speak to the surgeon. When I arrived, another orthopedic surgeon and an anesthesiologist were there with my mother's doctor. The other orthopedic surgeon seemed to take the lead in talking to me and he said they had shown my mother's x-rays to nearly all the orthopedists in the department and the consensus was that they didn't want to take her back to surgery. There was a chance it could heal if she didn't weight-bear for 30 days and that she would be able to get up after that. They were very concerned about the risk of taking a 90-year-old back to surgery. I was very clear with him that my mother was 90, she had led a good life, and these were her words more than mine: What was important to her was some kind of quality of life and being as independent as possible. It would be okay if she passed away in surgery. Her biggest worry was suffering in her last days and not being independent. He told me, "If it was my mother, I would not risk taking her back to surgery."

Attending Surgeon: I hadn't spoken yet and the daughter turned and asked me directly "What do you think?" And I didn't give her my opinion. I deferred to the other surgeon, saying he had a lot more experience than I did. And maybe they're right that she will heal in time, that there won't be any adverse effects, and her pain will decrease, and it would be too risky to have the surgery. So she accepted that and went along with it.

Daughter: So the plan was we

would wait three days, repeat the x-ray and if it looked like the bone was healing in place, we would wait three more days, repeat the x-ray, and if it looked okay, then my mom would go to the skilled nursing facility (SNF) and not weight bear for 30 days. Time went along and I was told the x-rays were either improved or looking the same. On day 13 of my mother's hospitalization, it was time for her to go to the SNF and she was scheduled for discharge. The medical, hospital-based physician who was managing her care told me he had concerns that if she didn't get up soon, she would never get out of bed. He asked if I would mind if he called the orthopedists and ask them to reconsider, and I didn't mind, and he called, and they declined.

Attending Surgeon: At that point, we admitted her to the SNF and ordered as much pain medicine as necessary. Over the course of the next month, we had x-ray follow-ups and conversations over the phone; however the mother's pain wasn't decreasing much. She still required heavy sedation and pain medicine.

Daughter: She was unable to eat much of anything. During her entire three-week stay she ate less than a cup of food. She told me, "I just really want to be comfortable and pass away." Nearly a month after she fell, the SNF doctor called me to say that she was still requiring a tremendous amount of pain medication, much of the time she was unarousable, and when she wasn't, she was crying. He was concerned that this just wasn't a normal course and decided to get another x-ray. He called me following the x-ray to say it was bad. All five screws were out of place. Even the plate itself was misplaced. He said we absolutely could not leave her in this condition and that she would have to be taken back for surgery.

Attending Surgeon: My patient's

... there are critical subjective elements—particular beliefs, values, and emotions—that interplay with the clinical decision-making process.

daughter and I discussed the fact that another surgery may be the best option for her mother, even now, a month later.

Daughter: My mother did return to the hospital. She was so fragile by that time from not eating. I just didn't know whether she could make it through surgery. I didn't want her to suffer any more. I did say to the doctors again; please don't worry if she doesn't make it through the surgery—at this point, if she doesn't, she would consider it a blessing. And again, it seemed that people were very uncomfortable with me saying that.

They did take her back to surgery, and on her second day post-op, she said, "My hip feels better, but I really don't want anything else done. I don't want to go through this anymore." At that point, I asked for the palliative care physician and nurse to come and see my mother.

I am not only a daughter of a KP patient; I'm a 25-year employee with KP. I'm the associate medical group administrator for a facility in the Northern California Region. And I thought to myself how helpless I felt in all of this, in dealing with physicians and their lack of putting a priority on the patient's wishes, especially a 90 year old with a very clear advance directive who comes in alert and awake and clearly stating her wishes. She didn't fear dying. She feared the process of getting there. I feel like we all let her down. She went to a nursing home under palliative care—she was there four days and passed away. That was February 2005.

Two days later, my mother's doctor came to my office in administration to tell me how sorry she was that my mom had passed away. She sat down and she told me a possible reason for things not going well: the wrong-angled plate had been put in my mother. She had ordered one

angle, but when it was handed to her in surgery, neither the tech, nor the nurse, nor she had checked to make sure it was the right angle. When they took her back to surgery, they realized this. She felt terrible about it.

Attending Surgeon: And then I drew a picture for her of the fracture and the implant, and how close the two angles were, and how easy it was to mistake them if you hadn't a suspicion. And that this may have been a cause for her mother's surgery failing, although I wasn't at all certain that it was. But even if it wasn't, I thought it was certainly something that she should know about ... And I was very surprised that she thanked me after I told her.

Daughter: I did appreciate her coming to apologize and telling me the truth of the events, and for the tears we shared together. It showed me that my mother wasn't just a number; that her doctor did care about her, and she felt very badly about what had happened. As a nurse, I know that medicine isn't always perfect and that mistakes happen, but I am hopeful that some lessons will be learned from my mom's case. I'm sorry that she had to suffer so much during the last weeks of her life, but I think she would be happy to know that some changes have been made so that this won't happen to someone else, and that her story will help physicians (and all health care professionals) think about the bigger picture of a patient's life, and their values and wishes.

The Panel

Panel members are: Kate Scannell, MD, the Director of the Department of Medical Ethics for Kaiser Permanente Northern California; Sarah McCarthy, MD, the Assistant Physician-In-Chief (APIC) for Risk at a regional medical center; and Maureen Whitmore, the HCOM at

a regional medical center.

Michael Ralston, MD (MR) (retired Director of Quality Implementation from The Permanente Medical Group, the moderator): *What is KP's policy for communicating when an adverse event or outcome occurs?*

Sarah McCarthy, MD: When this happens, patients and their families want three things: first, they want an apology, if it's appropriate, or an expression of empathy for their experience; second, they want to know what occurred, how it occurred; and third, they want to know that we're doing something to prevent it from happening again to someone else.

We believe that it's our responsibility and our obligation to communicate with patients and their families, especially when an adverse event or outcome occurs. We also believe that it's the patient's right to have an explanation of what happened and to have that information in a timely, compassionate, and truthful manner. Using those three tenets, we train physicians and other practitioners to have these difficult conversations with patients. We also offer expertise through our HCOM, our Director of Risk Management, our APIC for Risk, and other physicians specially trained in communication techniques.

MR: *What is the role of the HCOM?*

Maureen Whitmore: The HCOM's role is to help resolve health care concerns and conflicts early, especially if an unanticipated adverse event occurs. An HCOM is an informal, impartial, neutral facilitator attempting to understand what happened—to understand the patients' and families' concerns—and to support physicians in communicating with patients and families when there's been an adverse outcome. In this case I coached the doctor, supporting her communication with the daughter. I offered to be present,

"... if she doesn't make it through the surgery ... she would consider it a blessing. ... people were very uncomfortable with me saying that."

if she wished. She felt comfortable making the communication without me, because of the strong relationship she had with the patient's daughter. After they met, she and I debriefed, and then I called the daughter to provide answers to any remaining questions and concerns. Our role is to support and advocate for the physicians, families, and patients, and for the organization; to understand and resolve the situation to the degree possible. Our role is also to highlight any system issues so these can be addressed in an effort to prevent something similar from happening to another patient in the future.

MR: *What is the role of the Ethics Committee or an ethics consultation?*

Kate Scannell, MD: When practitioners and patients feel they are on "opposite sides of a fence," that is a signal that the ethics committee or an ethics consultation could be helpful. I would like to think of that consultation as a search for a gate that opens opportunity for more effective communication, which reaches towards mutual and common understanding. The ethics committee would open the gate by opening a conversation in which different moral perspectives are aired and explored, and challenging ethical dilemmas are discussed in a

safe, reflective, nonjudgmental, and sensitive manner. This conversation often leads to decisions made with transparency, honesty, and inclusiveness, and it facilitates resolutions that people are committed to on a deep ethical and moral level.

The major reason an ethics consultation wasn't considered here was the lack of perception of moral conflict. The situation was viewed largely as a difference of opinion about the medical or surgical approach, rather than a difference in personal values. The mother professed certain deep and personal values about what mattered most in her life, and she made a concerted effort to express them. She also executed an advance directive in which she indicated her wishes and value priorities to inform medical decision making. The values of the practitioners differed from those of the patient. Her physicians may have prioritized a different value—quantity of life—over quality of life. An Ethics Committee consultation would have clarified these distinctions and framed the situation as an ethical conflict.

MR: *Since the initial focus was on the insertion of the wrong plate of a different angle than intended, was the issue of patient-centeredness overlooked?*

Dr McCarthy: As APIC for Risk and Patient Safety, my focus was to support the surgeon's communication with the daughter about the error that occurred. I was focused on how the error occurred, and what we could do to prevent this type of wrong device error in the future. At first, I didn't consider the more problematic issue, which was the patient's values and wishes not having been met and that this was an ethics issue. This makes it clear how readily available the Ethics Committee and consultants should be to practitioners.

MR: *What about the importance of understanding and respecting*

Perspective from an Orthopedic Surgeon

By Thomas C Barber, MD

1. When to defer to a senior partner. The knowledge and understanding of older, more experienced partners should be valued. One of the great things about KP is the ready availability of more experienced physicians, to consult, either at our own facility or at another facility. However, care must be taken when advice is given from a physician who does not have an in-depth knowledge of the patient or case: even the most experienced physician may not be able to give the best advice for a specific situation. In this case a more experienced surgeon took responsibility for a patient he did not know well. In general we need to take advice from experienced physicians, filter it with the knowledge of the patient that we have, and come to our own conclusions. A physician who knew and was sensitive to the patient's advance directive wishes may have come to a different conclusion, as implied by the discomfort that the physician had with the senior physician's recommendation.

2. When to discuss adverse events. The fact that the wrong angle plate was used may have nothing to do with the outcome of this case. On the other hand, it might have been a contributing factor. When a physician feels that an adverse event might be related to outcome, it is important that it be discussed with the patient and family as mentioned in this case. Some reviewing orthopedic surgeons felt the error with the plate was not related to the outcome in this case, yet we still support discussing the issue with the patient and her family because the intent of the surgeon was to use a different angle plate.

3. Physicians may sometimes confuse a conservative approach to a problem with a nonoperative approach. It has been shown that the risk of mortality and morbidity is greater in letting an elderly hip-fracture patient lie in bed than it is to operate even in a patient who is at high risk for surgical morbidity.¹ The more conservative approach in this case would have been to reoperate as soon as the failure of fixation was noted. The mortality rate within one year of a hip fracture is about 20%,² and the patients who do better are those who are able to get up and walk quickly after injury. Given these statistics and the patient's desire for quality of life, a decision to reoperate as soon as the fixation failed might have been appropriate. ♦

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Thomas C Barber, MD, Associate Physician in Chief for IT and Surgical Services for the East Bay Service Area of Kaiser Permanente Northern California Region.

patients' values during the medical decision-making process? How can we get better at doing this?

Dr Scannell: Any time there is a conflict in thinking or approach, first make an intellectual shift from a medical conflict, a scientific conflict, to a conflict of values. Medicine is values-laden. The decision-making process should always incorporate a process of eliciting and sorting through values of the patients and physicians involved in the decision. Generally, once the conflict is understood as a values conflict, practitioners entrusted with the patient's care should honor the patient's wishes, promoting patient-centric care in which the values of the patient take priority in the decision. At times, that may not be feasible if practitioners hold contrary, deep-seated claims of conscience—another situation in which an ethics consultation could be helpful.

Throughout, it's important that practitioners remain conscious of their own values and not project them onto the patient; not use them to supplant the patient's values. Quality-of-life evaluations and decisions can only be made by the person living that life. Use the metaphor of "the fence." If you think you and a patient stand on opposite sides of a fence, look for a gate by looking for conversation about the moral dimensions characterizing the opposition.

MR: *The daughter and the surgeon did seem to have a close, trusting relationship. Is there a broader message about the physician-patient relationship?*

Ms Whitmore: What Dr Scannell has been saying underscores the importance of the caring role—listening for values and creating a trusting relationship early on with each patient, in this case starting in the Emergency Department, dur-

ing admission, while going to the operating room (OR), whether it be the physicians, nurses, respiratory therapists, other staff, and then continuing that relationship throughout the hospitalization, even, and especially, during and after an adverse event. Although such relationship building can be a great source of satisfaction, it requires skill, hard work, and the courage to have difficult conversations when necessary. We all need to support our practitioners in having these conversations.

Discussion

KP enjoys a rich array of committed, competent, and hard-working physicians, nurses, other health care professionals, and staff who are highly trained and adept in the "curing" role. In addition, these individuals bring a wide array of abilities that serve them well in the "caring" role. Indeed, many patients experience a trusting, therapeutic relationship with their physician, their health care team, and the health care system.

Trust is established one "touch point"^c at a time. To the extent a trusting relationship exists, it is to the credit of each and every person who has effectively manifested the curing and the caring roles. Yet, there is a gap between the consistency with which trusting relationships are built with patients and what we would want. In the spirit of closing this gap, we turn to a patient's story for insights from which we can learn and change for the better.

The story reminds us that, given the demands, complexity, and invasive nature of health care today, even well-trained, highly competent and capable professionals, working with the best of intentions, are not immune to unintended dire consequences. While we constantly strive

to reduce or eliminate unwanted events and outcomes; failing this, especially if we have been mindful of the "caring" role, we can at least extend open communication and genuine empathy when an adverse event or outcome does occur.

After the occurrence of an adverse event, we are likely to ask—especially when closely involved in the care—"How could this have happened?" and "What does it say about me as a professional and as a person?" In the face of such questions, special courage is required to remain open to critical examination so that we and our colleagues can learn from what happened and make changes to prevent similar undesired results in the future.

When examining issues of clinical judgment and decision making related to the safety and quality of care, we cannot always reach definitive, straight-forward, or unequivocal answers, and that is in some ways the case here. On the other hand, unanswered or incompletely answered questions are more likely to remain vital for further consideration, which in the long run can be of greater value to self-discovery and beneficial change than arriving at an answer and thereby closing down further consideration.

The Caring Role

The panel provides us with an insightful discussion of key issues related to patient-centered care, including open communication, respect for values, and shared clinical decision making. We see that it is through the "caring" role that we recognize and respond effectively to personal values, especially when conflict exists between our values and those of our patient. This is a central lesson of the story. With that in mind, we proceed to additional issues raised in the story.

Open, timely, and empathetic communication is the foundation on which trusting, therapeutic relationships are based and on which the safety and quality of care depend.

The Long Delay

Most striking is the long delay in returning the patient to surgery after the loss of reduction of her fracture repair. Was this, as alluded to, related to fears (conscious or subconscious) that she would die in the OR? If so, and especially if this concern conflicted with the patient's desires, should the patient have been afforded a second opinion? This aside, one physician reviewer's dictum was: "Especially in the geriatric patient you get one chance, maybe two, never three. With each passing day, the patient grows increasingly frail and less resilient. When there's a complication, when something goes wrong, respond aggressively—don't delay!"

Still, several reviewers found the initial decision to delay the patient's return to the OR acceptable as "a short-term strategy," during which to assess for signs of positive progress. However, even the "other surgeon," upon whose advice the initial delay

was based, stated that knowing the patient's condition continued to deteriorate (which he did not) he would have recommended return to the OR. Decision making can often be a dynamic process. In this instance the team's communication was not managed across time. As a result, a one-point-in-time recommendation carried unintended weight going forward.

Ageism

Another question raised is ageism. Did this, perhaps unwittingly, prejudice the decision-making process toward an overly conservative approach? Yet another avenue for reflection is whether there were issues related to "psychological power imbalance" among members of the health care team and how this may have influenced the decision-making process. Are there similar overlooked risks in our own settings? How can we recognize and ameliorate them?

Pain Control

Then there is the issue of pain control. Typically, in the immediate post-op period following an acute surgical intervention, we expect to see an increase in the need for pain medication. However, over time it should steadily decline. In this case, the patient's escalating analgesic requirements (Figure 1) were a "red flag" that seems to have been missed. Again we can ask, what are the potential "red flags" in our setting? How can we be sure to recognize and act on them when present?

Wrong-Angle Plate

Finally, the surgeon's discovery during re-operation that the "wrong angle" plate had been used in the initial surgery focused attention on the case as a sentinel event. A sentinel event is defined by The Joint Commission as an unexpected occurrence involving death or serious physical or psychologic injury, or the risk thereof.¹ Regarding the "wrong angle" error, the majority of expert reviewers believed it did not contribute to the failed fracture repair. But even if this were so, should the surgeon still have communicated it to the daughter? How soon? KP has a policy of transparency and full disclosure.² What would you have done?

Summary

This is an unfortunate story of care that went wrong for an elderly patient, her daughter, and her surgeon. The daughter, in spite of a close relationship with the attending surgeon, was left questioning whether the health care team had been on "the other side of the fence." As the story unfolded, all experienced great pain in one way or another. In the aftermath, the daughter resolved to share her mother's story as a learning device with the aim of preventing

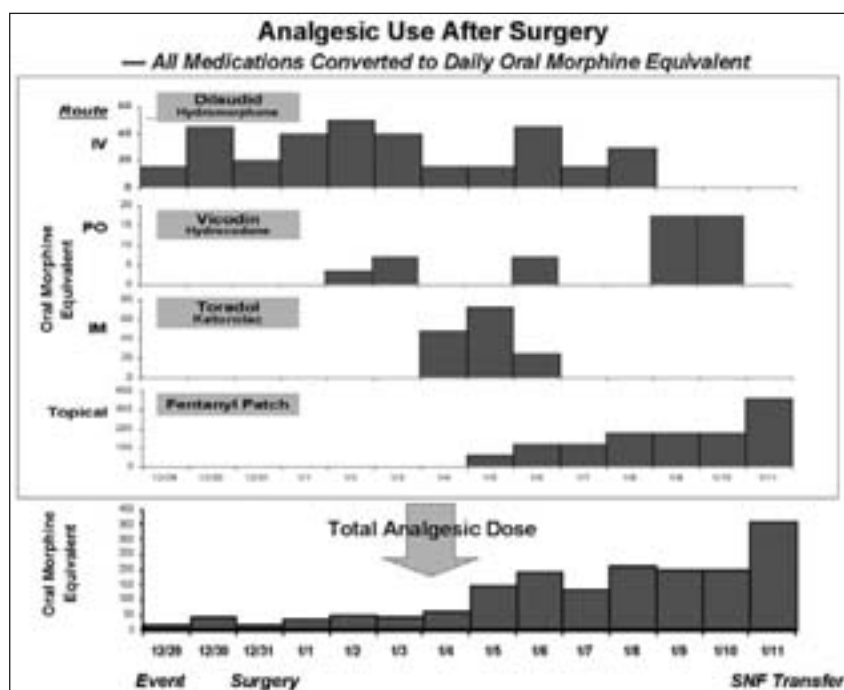


Figure 1. Chart of patient's analgesic use after surgery.

similar future occurrences.

The story is not unique because of its rarity, as most health care professionals can attest. In all likelihood it is not the "worst case we've ever encountered." Neither does it stand apart because it so perfectly illustrates a single point. It is special simply because it is available for our examination, not having been lost to the vagaries of the legal system or conveniently concealed as an embarrassment or threat.

In telling the story, the daughter and attending surgeon display great personal and professional courage, openness, and humanity as models for all of us to emulate when things go wrong. For this we are indebted to them. The issues involved were multiple and complex. We are invited to take the lessons, directly or by analogy, to our own clinical settings and apply them through the prism of the "curing" and "caring"

roles that we all strive to fulfill in our quest to be complete professionals in a complete and caring health care delivery system.

Open, timely, and empathetic communication is the foundation on which trusting, therapeutic relationships are based and on which the safety and quality of care depend. Our opportunity is to continuously improve the safety and quality of care for our patients by respecting their values and beliefs, and in this way to provide them, to the best of our ability, with the knowledge and confidence that their health care team is on their side. ♦

^a *The Other Side of the Fence* is based on transcripts from an educational session that includes videos. To inquire about using the session materials for training and education within KP, you may contact Robert Formanek, Jr, MD, by e-mail or at 510-271-5853.

- ^b Brent James, MD. Meet in the middle: Key infrastructure to drive organizational change. Presentation at the Institute for Healthcare Improvement (IHI) Quality Form 2005 Dec.
- ^c A "touch point" is created every time a member/patient experiences any involvement with the organization. When these experiences degrade confidence, rather than building it, the results can be devastating.

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Illusion

The greatest problem with communication is the illusion that it has been accomplished.

— George Bernard Shaw, 1856–1950, Irish poet and playwright, 1925 Nobel Laureate in Literature



"Out of Order"

photograph

By Denise Fuson, MD

Dr Fuson is an Internist at the Oakland Medical Center in CA. Dr Fuson, a lifelong photographer, became interested in night photography after discovering The Nocturnes, a Bay Area group dedicated to night photography. This photograph was taken from the roof of the parking garage at the Oakland Medical Center with ambient light at f8.0, 8 seconds. Dr Fuson uses minimal digital adjustments.

Giant Colonic Diverticulum: Endoscopic, Imaging, and Histopathologic Findings

By Pejvak Sassani, MD
Hardeep M Singh, MD
Donald Gerety, MD
Maher A Abbas, MD

Abstract

Giant colonic diverticulum is a rare manifestation of diverticular disease. Although this entity can be discovered incidentally on imaging studies, patients can present with a variety of symptoms. This report illustrates the clinical presentation, endoscopic imaging, and histologic findings for this disorder. Surgical resection is curative and in select cases can be carried out laparoscopically.

Introduction

Colonic diverticulosis is a prevalent condition in the Western world.¹ A rare manifestation of diverticulosis is the formation of a giant colonic diverticulum (GCD). Since GCD was first reported by Bonvin and Bonte² in 1946, only 130 cases have been described.³⁻¹⁹ The pathogenesis is not entirely clear. In most patients, only one diverticulum is found, usually in the sigmoid colon.³⁻¹⁹ The following two cases illustrate the clinical presentation, surgical management, and imaging, endoscopic, and histologic findings for this uncommon disorder.

Case Histories

Case 1

A man, age 55 years, presented to the Emergency Department with left lower quadrant abdominal pain. His medical history was unremarkable. He was afebrile and had localized tenderness. The patient was discharged and given oral antibiotics; the presumed diagnosis was diverticulitis. His symptoms did not resolve. An outpatient laboratory workup revealed occult blood in the stools and mild anemia. Endoscopic evaluation revealed a circumferential mass in the sigmoid colon with friable mucosa and a markedly narrowed lumen, limiting the extent of the examination. Biopsies revealed chronic inflammation and foreign-body giant-cell reaction without evidence of malignancy. The patient's car-



Figure 1. Acute mucosal ulceration and surrounding chronic inflammation found in the patient in case 1 on histologic evaluation.

cinoembryonic antigen level was normal. He underwent an uneventful laparoscopic sigmoidectomy and was discharged from the hospital on postoperative day one. Intraoperative findings revealed an inflammatory mass in the sigmoid. Histopathologic evaluation revealed a 5-cm diverticulum with acute mucosal ulceration and surrounding chronic inflammation without malignancy (Figure 1).

Case 2

A man, age 60 years, presented with a one-year history of an enlarging mass in the midabdomen. His medical

Pejvak Sassani, MD, is a Surgery Resident in the Section of Colon and Rectal Surgery in the Department of Surgery at Kaiser Permanente in Los Angeles, CA. E-mail: pejvak.x.sassani@kp.org.
Hardeep M Singh, MD, is a Gastroenterology Fellow in the Division of Gastroenterology at Kaiser Permanente in Los Angeles, CA. E-mail: hardeep.m.singh@kp.org.
Donald Gerety, MD, is a Gastroenterology Consultant in the Division of Gastroenterology at Kaiser Permanente in Los Angeles, CA. E-mail: donald.c.gerety@kp.org.
Maher A Abbas, MD, is Chief of the Section of Colon and Rectal Surgery in the Department of Surgery at Kaiser Permanente in Los Angeles, CA. E-mail: maher.a.abbas@kp.org.



Figure 2. Computed tomography scan of the patient in case 2 showing a well-defined cystic structure spanning from the mid to lower abdomen.

history was unremarkable, and he had no other symptoms. Computed tomography demonstrated a 10-cm well-defined, gas-filled cystic mass spanning from the mid- to lower abdomen (Figure 2). The lesion appeared to originate from the sigmoid colon. The patient underwent a laparoscopic sigmoidectomy, converted to open procedure. The giant diverticulum was found to be stuck to the mesocolon and adherent to loops of jejunum, precluding a safe laparoscopic resection. His recuperation was uneventful, and he was discharged from the hospital on postoperative day five. Histopathologic evaluation revealed a purple-tan shaggy-surfaced diverticulum, 11 cm × 10.5 cm (Figure 3), with acute mucosal ulceration and inflammation associated with underlying chronic inflammation (Figure 4).

Discussion

Colonic diverticular disease is common but rarely presents as a singular giant diverticulum.¹⁻¹⁹ Overall there is an equal sex distribution, with most cases involving patients who present in the seventh decade of life (reported range, 32–90 years).²⁻¹⁹ Choong and Frizelle³ proposed classification of GCD on the basis of size and histologic findings. A diverticulum >4 cm in diameter can be reported as a GCD. Histologically this entity can be divided into two types: pseudodiverticulum (type I) or true diverticulum (type II). Its pathogenesis is not well established. One postulated mechanism is the influx and trapping of gas into a diverticulum through a narrowed, chronically inflamed neck acting as a ball-valve, leading to gradual enlargement of the diverticulum.

The clinical presentation of GCD can vary from asymptomatic to vague abdominal pain, bloating, distension,

constipation, weight loss, fatigue, anemia, or bowel obstruction.²⁻¹⁹ An abdominal mass can be palpated in 60% to 70% of patients.¹⁹ Incidental GCD is diagnosed by findings from barium enema, plain radiograph, or computed tomography.²⁻¹⁹ Filling of the diverticulum during barium enema has been noted in 60% to 70% of cases.¹⁹ Colonoscopy can be helpful in some cases.⁴

Surgical resection is curative and can exclude an underlying malignancy. Adenocarcinoma arising from GCD has been reported.¹⁹ Although diverticulectomy with primary closure of the bowel has been described, we concur with many authors and favor surgical resection.²⁻¹⁹ In most cases, a segmental colonic resection and primary anastomosis is the first surgical option. A laparoscopic approach is feasible in some patients, as demonstrated by one of the cases reported above. Adherence to small bowel or a very large diverticulum that hinders visualization may preclude a laparoscopic approach.

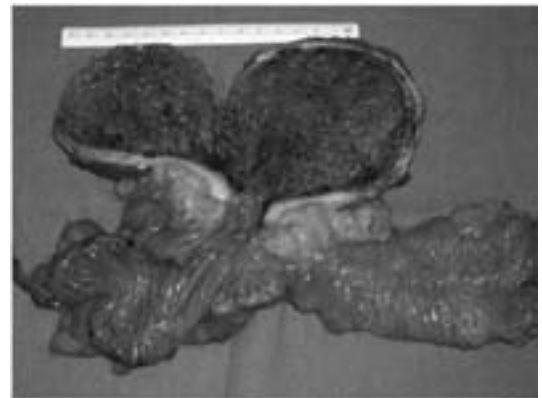


Figure 3. Gross surgical specimen from the patient in case 2 showing a purple-tan shaggy-surfaced diverticulum, 11 cm × 10.5 cm.

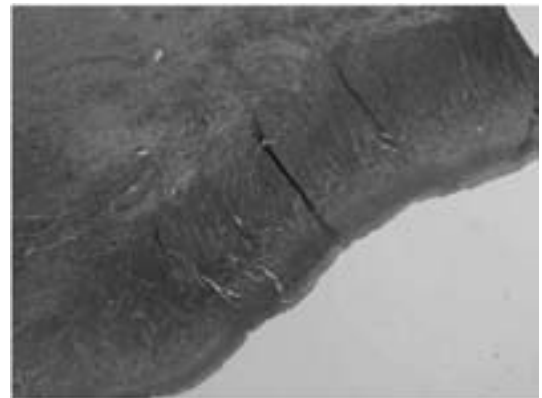


Figure 4. Pathology slide made for case 2 showing inflammation of the entire mucosal surface and underlying mixed chronic inflammation.

Conclusion

GCD is a rare form of diverticular disease. Imaging studies can be helpful in diagnosing it. Surgical resection is curative and can be accomplished laparoscopically in select patients. ❖

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Gathering Up Crumbs

Be careful with the crumbs. Do not overlook them.

Be care with the crumbs; the little changes to love,
the tiny gestures, the morsels that feed, the minims.

Take care of the crumbs; a look, a laugh, a smile,
a teardrop, an open hand.

Take care of the crumbs. They are food also.

Do not let them fall. Gather them. Cherish them.

— *Becoming Bread: Embracing the Spiritual in the Everyday*
by Gunilla Brodde Norris, author

Improving Chronic Care: The “Guided Care” Model

By Chad Boulton, MD, MPH, MBA
Lya Karm, MD
Carol Groves, RN, MPA

Introduction: What’s the Problem?

Everyone is working hard, but the quality of chronic care is still mediocre. Donald Berwick, MD, says “every system is designed perfectly to achieve the results that it achieves.”¹ The problem is the growing mismatch between the chronic care needs of the population and the acute care orientation of the health care system. Sixty-five million older people with multiple chronic conditions are trying to get health care from a system that is designed to treat acute illnesses and injuries. It’s as though we are trying to put a square peg in a round hole. We will continue to get the poor results we are now getting until we redesign the system.

Guided Care is a new model for “chronic care” that is now being tested by Kaiser Permanente (KP) in the Baltimore-Washington, DC area. Guided Care is primary health care infused with the operative principles of recent innovations to ensure optimal outcomes for patients with chronic conditions and complex health care needs. A registered nurse who has completed a supplemental educational curriculum works in a practice with several primary care physicians, conducting eight clinical processes for 50-60 multimorbid patients.

A Typical Case

Ms Marian Chen is a 79-year-old widow who lives alone. She receives Social Security benefits and a modest pension; she is enrolled in a KP Medicare Health Plan. Her daughter lives ten miles away and is busy dealing with her three teenagers. Ms Chen has five chronic conditions for which she sees three physicians and takes eight prescription medications every day. The patient has had a very busy and medically complex year. She has seen eight physicians, five physical therapists, four occupational therapists, 37 nurses, and six social workers. This was the result of her chronic conditions

flaring up and causing two hospitalizations, followed by inpatient postacute care and home care (Figure 1). At each transition, a new team of clinicians assessed the patient and created a new care plan.

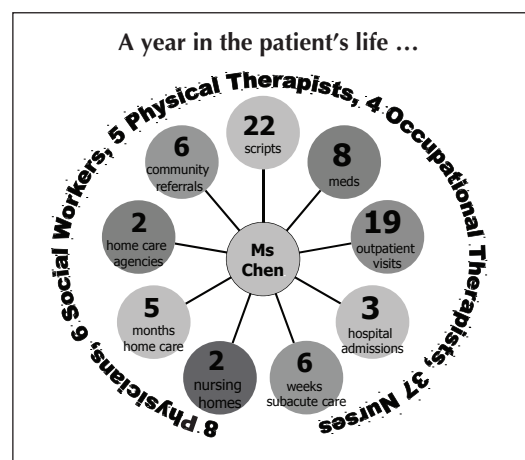


Figure 1. A year in the patient's life ...

Despite her insurance coverage, the patient has incurred significant out-of-pocket costs, increasing her stress level. The patient rates her quality of life as poor. Her daughter, to help, has reduced her workload to half-time, and is now considering nursing home options for her mother. She doesn't think she can keep doing this much longer.

The family's experiences, which are not unusual, show that chronic care is:

1. fragmented
2. discontinuous
3. difficult to access
4. inefficient
5. unsafe
6. expensive.



Chad Boulton, MD, MPH, MBA, (top) is Director, Lipitz Center for Integrated Health Care, and Professor in the Department of Health Policy and Management, Bloomberg School of Public Health, Johns Hopkins University; and a participant on the Advisory Panel of the Case Management Society of America's National Transitions of Care Coalition to improve the quality of care between health care settings. E-mail: cboulton@jhsph.edu.

Lya Karm, MD, (left) is an Internist at the West End Medical Center in Washington, DC, and Physician Director of Senior Services for the Kaiser Permanente Mid-Atlantic Region. E-mail: lya.karm@kp.org.

Carol Groves, RN, MPA, (right) is the Director of Senior Services for the Kaiser Permanente Mid-Atlantic States. E-mail: carol.groves@kp.org.

The Nightmare of Navigation

Not surprisingly, the patient is often confused by the complex care she has been getting from multiple clinicians—and by all the medications that she is supposed to be taking. She is discovering that health care for people with chronic conditions “... is a nightmare to navigate.”² We designed *Guided Care* to improve the quality of care and the quality of life for people like Ms Chen.

The Cost of Chronic Care

Figure 2 shows the nation’s Medicare expenditures for beneficiaries with different numbers of chronic conditions. Patients having four or more chronic conditions (about 25% of the older population) account for 80% of all Medicare spending. So chronic care stresses not only the patient, the patient’s family, and the employer, but also the budgets of health care organizations and the federal government. Today there are about 65 million older Americans with multiple chronic conditions; by 2010 there will be 70 million. Unless changes are made, the magnitude of the chronic care problem will grow every year for the next three decades.

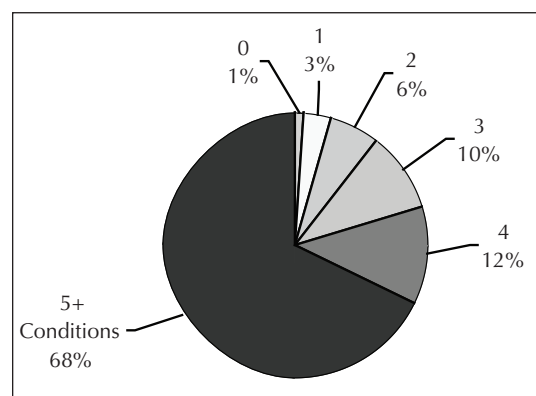


Figure 2. The 23% of older people who have >4 chronic conditions account for 80% of Medicare spending.

The Chronic Care Model

Wagner and Bodenheimer³ have proposed the “Chronic Care” model for improving chronic care (Figure 3). This model asserts that improving chronic care will require simultaneous improvements in support for self-management, design of practices, decision support, clinical information systems, and integration of community resources into health care. According to the model, improvements in these processes will foster more productive interactions between patients who are informed participants in their care, and practice teams that are prepared and proactive in providing

care. Ultimately, these productive interactions should improve the outcomes of chronic care.

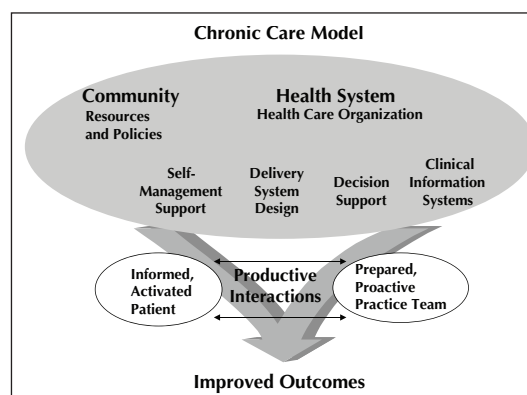


Figure 3. The Chronic Care model for improving outcomes.

The Guided Care Model

In designing *Guided Care*, we used the Chronic Care model to select several successful innovations in chronic care. We then combined these innovations to create the *Guided Care* model.

During the past 20 years, pioneers have created innovations capable of improving several of the individual processes of chronic care. Kate Lorig, RN, DrPH, for example, has shown that her chronic disease self-management course can empower patients to become more informed and active in their own health care, resulting in improved quality of life and lower health care costs.⁴ Similarly, Mary Naylor, RN, PhD, and Eric Coleman, MD, MPH, have developed approaches to transitional care that can reduce the need for readmission to hospitals.^{5,6} Others have conducted successful experiments with family caregivers, disease management, and case management.

To create the *Guided Care* model, we combined the principles underlying such innovations and integrated them with primary care. We hypothesize that this approach improves the quality of care, patients’ access to care, and their capacity for self care, thus resulting in improved health outcomes (Figure 4). Our goal is to develop a model of care that is sustainable and diffusible throughout the health care system. Therefore, we also designed *Guided Care* to be:

1. effective in practices throughout America
2. financially sustainable
3. attractive to physicians and nurses
4. valuable to health care organizations, and
5. popular with patients and caregivers.

Sixty-five million older people with multiple chronic conditions are trying to get health care from a system that is designed to treat acute illnesses and injuries.

What *Guided Care* Looks Like in Practice

Guided Care is driven by a highly skilled registered nurse in a primary care office. The *Guided Care* nurse assists three to four physicians in providing high-quality chronic care for their patients in need of good chronic care.

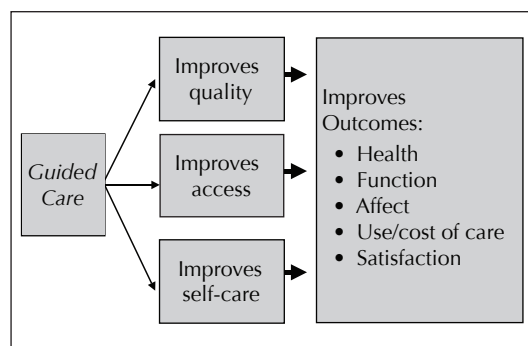


Figure 4. How *Guided Care* improves outcomes.

Who is Eligible for *Guided Care*?

Those eligible for *Guided Care* are high-risk patients with several chronic conditions and complex health care needs in a primary care practice. To select eligible patients, we use predictive modeling software to analyze patients' encounter data for the previous year. This "hierarchical condition category" (HCC) software^a assigns points to each diagnosis from each encounter and computes a risk rating for each patient. The 25% of patients with the highest risk of needing complex health care in the coming year are eligible to receive *Guided Care*.

Preparing the *Guided Care* Nurse Curricular Phase

Critical to the success of *Guided Care* is the preparation of the *Guided Care* nurse. We have designed a case-based, three-week curriculum that teaches RNs the special skills they will need to practice *Guided Care*, including the use of the *Guided Care* electronic health record (EHR), transitional care, motivational interviewing, evidence-based guidelines for managing chronic conditions, health insurance coverage, and working with family caregivers and community agencies. The curriculum includes self-learning material and interactive workshops with instructors and other nurses.

Integrative Phase

Following the three-week curricular phase in the classroom, the nurse completes a four- to five-month integration into the primary care practice. To become

an effective member of the practice, the nurse develops working relationships with the physicians, the other nurses, the support staff, and the receptionists, learning how each part of the practice functions. At the same time, the nurse acquaints each staff member with the role of the *Guided Care* nurse, while building a case-load of 50-60 patients.

Guided Care Services

For each patient, the *Guided Care* nurse provides eight services:⁷

1. Assessing

The nurse begins by performing a two-hour comprehensive assessment at the patient's home. This assessment covers medical conditions, medications, functional ability, mental status, exercise, nutrition, home safety, caregivers, other providers, and insurance. The nurse then reviews the patient's medical record and enters all the assessment data into the *Guided Care* EHR, which is separate from KP's "HealthConnect" electronic medical record.

2. Planning Care

On the basis of this assessment data and recent evidence-based guidelines, which are programmed into the EHR, the EHR generates the patient's individualized Care Guide. This Care Guide is an integrated compilation of all the recommendations for managing the patient's chronic conditions. The nurse and the primary care physician discuss and modify the Care Guide to meet the patient's unique circumstances. The nurse then discusses it with the patient and family, modifying it further to conform to their preferences and to obtain their "buy-in." The final result is an evidence-based, realistic plan that addresses medications, diet, physical activity, self-monitoring, targets, and follow-up. The Care Guide is placed in the medical record and shared with other clinicians, as needed. On the basis of the Care Guide, the nurse then drafts a patient-friendly *My Action Plan*, which is owned by the patient and displayed in a plastic jacket on the refrigerator or other obvious visible place in the home. This two-page summary reminds the patient when to take medicines, what diet to follow, what exercise to do, when to monitor weight and blood pressure, what to watch out for, and when to see the doctor.

3. Monitoring

The nurse then begins the proactive monitoring phase of *Guided Care*. Rather than waiting for a problem to

prompt the patient to access the health care system, the nurse reviews the *Action Plan* at least monthly with the patient. Most of these contacts are by telephone, but some are in person in the office, at the hospital, or in the home. If the patient doesn't call, the EHR reminds the nurse to call the patient or caregiver. The frequency of nurse's contacts with each patient fluctuates according to need.

4. Coaching

During the monitoring contacts, the nurse reviews the patient's self-management, point by point, making certain that all components of the plan are being followed. The nurse uses motivational interviewing techniques to help the patient overcome obstacles. The nurse confers with physicians as needed, making adjustments to the *Action Plan* and Care Guide.

5. Chronic Disease Self-Management

The *Guided Care* nurse refers most patients to a local “chronic disease self-management” (CDSM) course. The course consists of one two- to two-and-a-half-hour session per week for six weeks. At each session, a group of 10-15 patients meets with two trained, certified lay leaders, who lead a structured course that Stanford University has developed. The course aims to move people from passivity about their health care to a position of “mastery,” in which each person adopts an attitude of “I'm the master of my health; I'm primarily responsible.” Patients learn to set and attain health-related goals, interpret their own symptoms, and use the health care system appropriately.

6. Educating and Supporting Caregivers

Each *Guided Care* nurse leads a sequence of classes and support group sessions for 5-10 caregivers. The caregiver classes, which meet weekly for six weeks, provide general information on how to be a caregiver. Following this course, the nurse leads an ongoing monthly support group for caregivers and monitors their status quarterly by telephone.

7. Coordinating Transitions Between Providers and Sites of Care

To help coordinate complex care, the *Guided Care* nurse provides a brief but complete summary of the patient's health and health care (the Care Guide) to the patient's other providers, eg, hospitals, specialists, rehabilitation therapists, and home care nurses. One of the nurse's highest priorities is to smooth transitions between sites of care, especially into and out of

hospitals. The nurse monitors the patient and family through the hospital stay and prepares them for discharge before they go home. When they do go home, the nurse visits them on the first day, making sure they have what they need and that they understand how to care for themselves, how to take medications, what to watch for, and that they have necessary contact information—emergency phone numbers and e-mail addresses—should problems or questions arise.

8. Access to Community Services

The *Guided Care* nurse also facilitates patients' access to many services provided by community agencies, such as Meals-on-Wheels, transportation services, senior centers, adult day health centers, and the Alzheimer Association.

Pilot Study

We conducted a pilot study for one year to assess the feasibility of providing *Guided Care* in a community primary care practice. We prepared one nurse, who then worked with two internists and their high-risk older patients in a practice in urban Baltimore, MD.

Surveys of the patients who received *Guided Care* and similar patients who received “usual care” in the practice showed that *Guided Care* recipients experienced more improvement in the quality of their care than did the usual care group.⁸ Insurance claims revealed that the costs of health care were lower for the *Guided Care* patients than for the usual care patients.⁹

Cluster-Randomized Controlled Trial

We are now conducting an eight-site cluster-randomized controlled trial of *Guided Care* involving more than 850 older high-risk patients, 320 family caregivers and 49 community-based primary care physicians. As

Patients learn to set and attain health-related goals, interpret their own symptoms, and use the health care system appropriately.

Table 1. Outcome measurement at 18 months

(n ~ 580 survivors, complete data)	
Patient <ul style="list-style-type: none"> • Functional ability • Affect • General health • Satisfaction with care • Use/cost of health services • Mortality 	Informal caregivers <ul style="list-style-type: none"> • Burden/benefits of caregiving • Affect • Satisfaction with care • Use/cost of health services • Financial status
Providers <ul style="list-style-type: none"> • PCP satisfaction • PC office environment • GCN satisfaction 	Insurers <ul style="list-style-type: none"> • Volume of services • Cost of services • Quality of care

PCP = Primary Care Physician; PC = Primary Care; GCN = Guided Care Nurse

shown in Table 1, we will compare several outcomes after 6 months and 18 months of *Guided Care* and usual care. The results of this study will determine the future of *Guided Care*. This randomized trial of *Guided Care* is supported by funds from the Agency for Healthcare Research and Quality, the National Institute on Aging, the John A Hartford Foundation, and the Jacob and Valeria Langeloth Foundation. ♦

(Paper presented at the Kaiser Permanente National Geriatric and Palliative Care Conference, November 3, 2006.)

^a Public domain software available at: www.cms.hhs.gov/MedicareAdvgtgSpecRateStats/06_Risk_adjustment.asp#TopOfPage.

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Care

Care more particularly for the individual patient
than for the special features of the disease.

— Sir William Osler, 1849-1919, physician, professor of medicine, and author



"Twenty-five years and two days"

India ink, oil paint, and plastic pearls on Yupo paper
24" x 18"

By Marilyn Mitchell, RN

Ms Mitchell is a nurse in the Education and Consulting Department at the San Diego Mission Road Medical Office. She created this multimedia piece to commemorate her 25th wedding anniversary, which was celebrated on a train in Europe where her husband was reading the paper illustrated in the art piece.

The “Party Drug” Crystal Methamphetamine: Risk Factor for the Acquisition of HIV

By Michael Allerton, MS
William Blake, MD

Introduction

The abuse of crystal methamphetamine (CM) has reached epidemic proportions in the US, with widespread health consequences for a wide segment of the population. Of US residents older than 12 years, almost 5% (12 million) have reported using CM at least once. Between 1993 and 2003, the rate of admissions for treatment for CM abuse in the US increased from 13 to 56 admissions per 100,000 individuals.¹ CM, a stimulant street drug, is closely associated with party use in an attempt to increase the sociability of party participants. Its use is an independent risk factor for both acquisition of and propagation of HIV infection.²⁻⁴

To deal effectively with the effects of CM on patients, clinicians need to understand its use and its role in HIV risk, its neurobiologic effects, and some of the risk-intervention methods currently used with patients who abuse it.

Crystal Methamphetamine and Crack Cocaine

CM, known by a number of street names, including meth, speed, ice, Tina, crystal, tweak, crank, and glass, is a methamphetamine powder that can be white, yellow, orange, pink, or brown. Color variations are a result both of different contaminants or additives included by the preparer and of the preparer's expertise. Ice and glass are methamphetamine of a

higher purity (concentration). It is generally translucent to white, sometimes with a green, blue, or pink tinge. Methamphetamines are derived from the parent compound ephedrine or pseudoephedrine hydrochloride and pseudoephedrine sulfate. Methamphetamines of abuse potential are purchased on the street in the form of powder and then used by inhalation and smoking, by snorting into the nostril, or by solubilizing and injecting intravenously and even rectally.¹

Neurobiologic Effects

The brains of people addicted to methamphetamine are different from those of nonaddicts. The pleasure center of the brain is the nucleus accumbens, where the active neurotransmitter is dopamine. Both crack cocaine and methamphetamine prevent the reuptake of dopamine, which allows it to collect and thus prolongs and increases its effects. Although crack cocaine works only at the synapse level, methamphetamine can also penetrate the neuron, and thus cause permanent cell damage.⁵

A wide variety of stimuli affect dopamine levels. Natural rewards such as food and sex elevate dopamine output by 150% to 300% above basal output.⁴ Stimulant drugs, however, are more efficient than natural rewards at increasing the release of dopamine. Methamphetamine increases dopamine release

to >1000% above basal levels within the first hour of taking the drug, with levels returning to basal after three hours. Similar increases are seen with cocaine, nicotine, and ethanol, of >300%, >200%, and approximately 200%, respectively.^{6,7} Brain-imaging studies in both animals and humans show profound, long-lasting alterations of brain chemistry after relatively brief exposures to CM.⁸

Physical and Psychological Effects

The impact of altered brain chemistry is illustrated by a variety of cognitive impairments. One study focused on word and picture recognition and recall at baseline when study subjects stopped taking CM and thereafter.⁹ At three months and six months after stopping use of the drug, word recall and recognition continued to worsen, whereas picture recall and recognition began to improve slightly. This finding may have implications for communication strategies when interacting with current or recent methamphetamine users: A more pictorial approach to communication may be more effective.

The acute physical effects of CM mimic those of other stimulant drugs (Table 1). Heart rate increases, as do blood pressure, pupil size, respiratory activity, sensory acuity, and energy levels. Reaction time, the need for sleep, and appetite decrease. Acute psychological effects are increased confidence and alertness, elevations



Michael Allerton, MS, (left) is HIV Operations and Policy Leader for The Permanente Medical Group in Oakland, CA. E-mail: michael.allerton@kp.org.

William Blake, MD, (right) is a Specialist in the Department of Infectious Disease at the Cumberland Medical Offices in Atlanta, GA. E-mail: william.blake@kp.org.

of mood and sex drive, and increased energy level and talkativeness and a decreased sense of boredom, loneliness, and timidity, all effects that make the drug desirable. Chronically, the drug causes tremor, weakness, and dry mouth (Table 2). The anorexia and diarrhea it causes often lead to weight loss. Those who snort and inhale the drug are at increased risk for respiratory infections. Chronic psychologic effects include confusion, decreased concentration, irritability, and panic reactions (Table 3).

Patients taking the drug often have the sensation that they have bugs under their skin, leading to picking. This tendency contributes to ongoing and pronounced skin and soft tissue infections (Figure 1). Users engage in bruxism because of the hyperactivity produced by the drug. This and the decreased saliva production and toxic effects of the drug itself cause pronounced degradation of the teeth and "crystal meth mouth syndrome."

Prevention Strategies and Drug Treatment

It is evident that there is a severe need for preventing CM use. Use of the drug is a risk factor for HIV acquisition, especially for men who have sex with men.¹⁻³ In this population, the general probability of HIV positivity is 8%. The prevalence of HIV among recreational users of the drug is 26%, whereas it is 41% among untreated chronic users. The likelihood of HIV infection is 62% in individuals seeking detoxification in outpatient psychosocial clinics. Among those requiring residential treatment for their addiction, HIV prevalence is 90%. The longer someone is using CM, as seen by these indicators, the greater the likelihood of acquiring HIV.

Prevention of HIV in this population has been approached in a num-

ber of different ways. One strategy is postexposure prophylaxis with antiretroviral agents, which has been shown to be effective if done within 72 hours of exposure and is considered to be the standard of care, with numerous evidence-based guidelines available.¹⁰

Another approach centers on treatment of individuals known to be HIV positive. Those who are being successfully treated for HIV and have a low viral load are much less likely to transmit the virus to others. Also, when patients are in treatment for HIV, they are much more likely to receive appropriate risk-reduction counseling regarding both drug use and sex in addition to counseling about their medications.

Early work in developing prevention strategies for both patients without HIV and those already infected with it revolves around risk counseling and patients' and clinicians' perceptions of risk. Patients expect that if they are at risk because of a certain behavior, their clinicians will ask about that behavior. Conversely, the significant barriers on the part of clinicians are their general comfort level with discussing particular risks and the expectation that patients will initiate discussion if they are at risk. It is not difficult to see that this dynamic is ineffective. A key point to remember is that patients will disclose risk to their clinicians if given the opportunity.

As part of the "Prevention for Positives" program, one novel intervention tool has been developed: the "video doctor."¹¹ The video doctor was part of the prevention strategy, called Positive Choices, in which patients spend 10 to 15 minutes of discussion time with a computer-generated physician and receive risk-reduction counseling (unpublished data from Barbara Gerbert, PhD, et al).^a Each discus-

sion is oriented to patients' risk profiles as disclosed to the video doctor. The program also assesses patients' readiness to change and their sex. The system then generates a "cueing sheet" that is given to clinicians prior to patients' visits.

The Gerbert trial randomized 476 HIV-positive patients (376 men [79%] and 100 women [21%]) to either receive standard counseling by clinicians or spend time with the video doctor before seeing their clinician. Study retention was good, with 371 (78%) completing three months of follow-up care and 395 (83%) completing six months. Of the 476, 243 (51%) had the HIV risk factor of being men who had sex with men, 100 (21%) had other sexual risk factors, and 76 (16%) had the risk factor of intravenous drug use.

Clinical variables assessed in the study included antiretroviral use for

Table 1. Acute physical effects of methamphetamine

Increases	Decreases
Heart rate	Appetite
Blood pressure	Sleep
Pupil size	Reaction time
Respiration	
Sensory acuity	
Energy levels	

Table 2. Chronic physical effects of methamphetamine

Tremor	Sweating
Weakness	Burned lips; sore nose
Dry mouth	Oily skin/complexion
Weight loss	Headaches
Cough	Diarrhea
Sinus infections	Anorexia

Table 3. Chronic psychological effects of methamphetamine

Confusion	Irritability
Concentration	Paranoia
Hallucinations	Panic reactions
Fatigue	Depression
Memory loss	Anger
Insomnia	Psychosis



Figure 1. (upper) Example of skin and soft tissue changes after only three months of CM use. (lower) Example of appearance changes after several (2.5) years of CM use. www.facesofmeth.us [Web page on the Internet]. Portland (OR): Multnomah County Sheriff's Office; 2005 [cited 2007 Sep 24]. Available from: www.facesofmeth.us. Reprinted with permission from the Multnomah County Sheriff's Office.

treatment of HIV, which was at the level of 67% and 16%, respectively, for current and former users. Undetectable viral loads were found in 45%. Twenty-one percent had viral loads <10,000 copies/mL, 11% had between 10,001 and 50,000 copies/mL, and 6% had >50,000 copies/mL. Sixty-one percent reported having unprotected sex (45% with their main partners and 35% with casual partners). Forty-three percent reported some drug use, with crack cocaine and methamphetamine being most common at 24% and 15%, respectively. Thirty-nine percent reported heavy drinking of alcohol.

The Positive Choices intervention was found to significantly reduce high-risk behaviors. At three and six months, respectively, overall drug use decreased from 85% to 66% and from 88% to 59% of study subjects,

methamphetamine use decreased from 83% to 58% and from 73% to 48%, heavy drinking decreased from 78% to 53% from 51% to 43%, and unprotected sex with casual partners decreased from 87% to 69% and from 94% to 81%.

Conclusions

The recreational use of methamphetamine is highly prevalent among populations at risk for acquiring HIV infection, especially men who have sex with men. Although the health consequences, in addition to HIV infection and its subsequent morbidity, are serious and affect a great many people, there are significant barriers on the part of both clinicians and patients to assessing risk and providing appropriate risk-reduction counseling. Appropriate and novel screening tools for assessing risk help overcome these barriers and contribute to substantial reductions in high-risk behavior. ♦

Original presentation by Michael Allerton, MS, at the 2007 Fifth National Kaiser Permanente HIV/AIDS, STD, and Hepatitis Conference in Napa Valley, CA, April 2007.

^a The Positive Choices trial, Barbara Gerbert, PhD, University of California, San Francisco Division of Behavioral Sciences, principal investigator.

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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CLINICAL MEDICINE

Corridor Consult

When Is a Computed Tomography Angiogram Necessary to Rule Out Pulmonary Embolus in the Emergency Department?

By Joel Handler, MD

Case Examples

A previously healthy woman, age 25 years, presented in the Emergency Department (ED) with sudden onset of pleuritic chest pain. She said that she had had no cough, fever, or chills; she took birth-control pills. Physical examination showed the patient to be comfortable breathing room air and to have a pulse oximetry saturation of 92%, respiration rate of 18 breaths per minute, blood pressure of 118/62 mm Hg, and a heart rate of 74 beats per minute. There was no chest wall tenderness and no calf or popliteal tenderness or swelling. A telephone advice nurse had recommended that she go to the ED.

A man, age 68 years, who had a left upper lobectomy for cancer four years earlier presented with shortness of breath that began a few hours before his ED presentation. He said that he had no chest discomfort, cough, fever, or chills. Physical examination revealed that although he was not uncomfortable, he had modest tachypnea. His respiration rate while breathing room air was 22 breaths per minute; his blood pressure was 142/84 mm Hg and he had a heart rate of 88 beats per minute. Chest examination revealed reduced breath sounds bilaterally. There was no calf or popliteal tenderness or swelling.

Discussion

As illustrated by these two cases, the most common scenarios in the ED in which pulmonary embolus (PE) must be ruled out are otherwise unexplained pleuritic chest pain and dyspnea. However, the frequency of these complaints combined with the ready availability of expensive computed tomography angiography (CTA) has led to the procedure's being ordered too often. CTA is not innocuous; it exposes patients to significant radiation exposure. A single CTA carries a radiation exposure equivalent to that of 400 chest x-rays. Therefore, several careful clinical investigations have sought to define a low-risk population who do not need CTA. A multidisciplinary task force of Kaiser Permanente Southern California (KPSC) experts, supported by the regional Medical Technology Assessment Team, is promoting the use of an evidence-based diagnostic algorithm to rule out PE (Figure 1).

Identification of a low-risk population of patients for whom CTA does not add utility requires both an assessment of pretest probability and an assay of D-dimer, which is a breakdown product of cross-linked fibrin. Studies have shown that the D-dimer assay is not a good enough stand-alone test because of the risk of false negative assay results with high-probability patients.^{1,2} The generally accepted

standard for a noninvasive protocol to rule out PE in the absence of CTA is a sensitivity $\geq 98\%$. Of patients with normal findings on invasive pulmonary angiography, 1.6% develop PE within one year.³ There are also different pretest clinical probability scoring systems and D-dimer assays from which to choose.⁴⁻⁹ General estimates of low, medium, and high risk used in some studies work well in the hands of pulmonary and critical care experts who have more experience with PE. Specific probability scoring checkoffs on a numeric scale that are then summed have more general applicability at the front line of EDs. At the KPSC hospital laboratories, a rapid enzyme-linked immunosorbent D-dimer assay with a sensitivity of approximately 90% and a specificity of approximately 50% is used in assessing candidates for acute PE.

The algorithm chosen for KPSC is modeled on the Christopher study, a large multicenter prospective trial.⁴ That study was unique because of its prospective validation of a user-friendly pretest probability scale dividing patients into "PE likely" and "PE unlikely" groups, thereby eliminating the difficult middle ground of "moderate-probability" patients. A pretest clinical probability score ≤ 4 means that PE is unlikely. In the group of 1057 patients with a pretest probability assessment of "PE

Joel Handler, MD, is an Internist/Intensivist at the Orange County Medical Center in Anaheim, CA. Dr Handler is the Chairman of the Kaiser Permanente Orange County Critical Care Committee and the CMI Clinical Hypertension Lead. E-mail: joel.handler@kp.org.



Patient quality-of-care considerations with regard to radiation exposure are compromised when CTA reveals pneumonia, pneumothorax, or heart failure because a simple chest x-ray has not been performed.

unlikely” and negative D-dimer assay findings, nonfatal PE occurred in 0.5% (95% confidence interval, 0.2%–1.1%) at three months, well within the previously defined threshold of acceptability of <2%. No PE mortalities were observed. There probably is an additional measure of safety because the prevalence of deep venous thrombosis in a prospectively examined KPSC population was much lower than that in large multicenter trials using the same pretest probability scoring system.¹⁰ Moreover, in the Christopher study, the combination of “PE unlikely” and negative D-dimer assay findings occurred in 32% of the study population and safely avoided CTA in the diagnostic workup.

Our clinical algorithm demands an

emergency chest x-ray before pretest clinical probability scoring to rule out obvious alternative explanations for the chief complaint. Patient quality-of-care considerations with regard to radiation exposure are compromised when CTA reveals pneumonia, pneumothorax, or heart failure because a simple chest x-ray has not been performed. The requirement for a chest x-ray also has consequences for patient triage. Patients seen in an outpatient office setting with the possibility of acute PE must be referred to an ED or urgent care setting with chest x-ray availability, and therefore we have discouraged D-dimer assay availability at medical office building laboratories.

Though 18% of the patients in the Christopher study trial were inpa-

tients, we have also recommended that inpatient PE candidates be sent directly to undergo CTA because they generally are at higher risk, frequently have less cardiopulmonary reserve, and are more likely to have false positive D-dimer assay. False positive D-dimer results are related to being older and having concurrent comorbidities such as peripheral arterial disease, coronary artery disease, infection, or acute inflammation. Less than 10% of the inpatient subgroup in the Christopher study had the combination of an “unlikely” clinical probability score and negative D-dimer assay findings to preclude CTA.⁴

The patient in the first case discussed here had normal chest x-ray findings and a pretest clinical probability score of either zero or three depending on whether the clinician believed that PE was more likely than an alternative diagnosis. Younger individuals almost always have a myofascial cause for pleuritic chest pain even in the absence of a history of recent physical exertion or chest wall tenderness. If this patient had not been taking birth-control pills, she could have been sent home without further workup to use local heat and a nonsteroidal agent. Her chest pain could be reproduced with torso twist to the left in a sitting position, a maneuver occasionally helpful but unfortunately not routinely performed, strongly suggesting a myofascial etiology. Because of the worrisome pulse oximetry reading of 92%, a blood gas assessment was performed, showing a partial pressure of oxygen of 100 and a partial pressure of carbon dioxide of 38. A probability score of either three or zero would put her in the “unlikely” group, for which negative D-dimer assay findings would make CTA unnecessary. This patient had negative assay findings and was sent home.

The patient in the second case

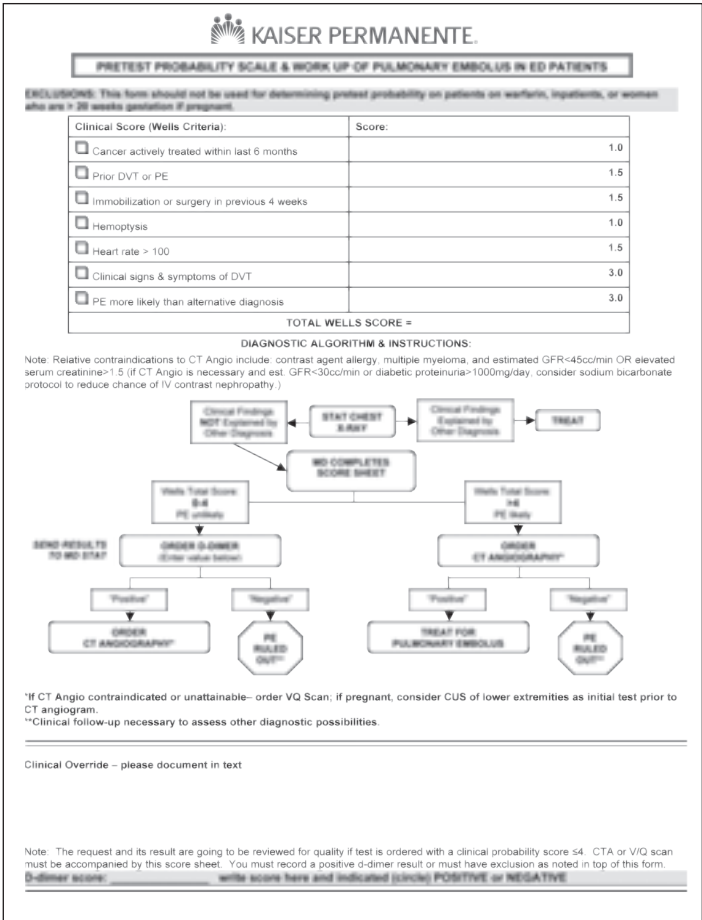


Figure 1. The Kaiser Permanente pretest probability scale and workup of pulmonary embolus in ED diagnostic algorithm.

discussed here also had negative chest x-ray findings, showing an old left upper lobectomy, and underwent pretest probability scoring. He scored zero on the cancer question because his lobectomy took place more than six months earlier and there was no ongoing disease. As with the first patient, the clinician could have given this man a score of either a three or zero on the "PE more likely than alternative diagnosis" question, though chronic obstructive airways disease was a reasonable alternative diagnosis in this former smoker with reduced bilateral breath sounds. With either diagnosis, a probability score ≤ 4 would put him in the "unlikely" category, eligible for a D-dimer assay. He was safely discharged from the ED.

On the basis of results of a small study for which patient consent and institutional review board approval was obtained, we have recommended using this protocol based on D-dimer assay findings for pregnancy ≤ 20 weeks' gestation because the rate of false positive results, 50%, approximates those of the nonpregnant healthy population.¹⁰ However, patients past 20 weeks' gestation were shown to have a prohibitive number of false positive D-dimer assay results (88%), and therefore these pregnant patients are sent to undergo compression ultrasonography (CUS) of the lower extremities when PE is a consideration. If CUS findings are negative, these patients are sent for CTA. Another group of patients in which diagnosis is problematic are those with glomerular filtration rate estimates between 30 and 45 mL/min. Depending on clinical necessity, these patients are eligible for a short course of hydration before and immediately after CTA, with follow-up renal function testing within two days. Pulmonary ventila-

tion-perfusion scanning, preceded by bilateral lower-extremity CUS, are considerations for creatinine clearance < 30 mL/min.

One barrier to use of the algorithm for ruling out PE in EDs has been the need to separate the chest x-ray from the commonly ordered chest pain/breathing difficulty biomarker panel, which usually includes D-dimer, troponin, and B-type natriuretic peptide assays. ED clinicians also must be convinced not to obtain CTA in the presence of an "unlikely" clinical estimate and a negative D-dimer assay result.¹¹ Another important issue is the D-dimer false positive rate, which leads to unnecessary performance of CTA.¹² Good clinical judgment, sometimes in short supply, should always be the driver for ordering any test, and when to initiate the PE rule-out algorithm incorporating the D-dimer assay is no exception.

These two patients, both of whose symptoms engendered a reasonable suspicion of acute PE, were properly treated, according to the evidence-based and expert-consensus rule-out algorithm. Both patients were found to be in a low-probability subgroup for which CTA was unnecessary, and both were safely discharged from the ED. ♦

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Nurse Lacasad Paints for Patients: A Service Credo Story to Improve Health Care

By Mia Medcalf

Nursing school was the hardest thing she ever did, but Sharon Lacasad, RN, saw it as a calling to become an oncology nurse; she likes to say, "It was destiny, oncology chose me."

Oncology chose Ms Lacasad as breast cancer had chosen her mother. It didn't sink in that her mom had cancer until one day when she was cutting her mom's hair and it was falling out due to the chemotherapy. It changed her life. She had been a physical therapist but she changed course, went back to school, and embarked on a path to become a nurse. She appreciated the care that her mother had received and wanted to be of service in return.

Many of the oncology patients in her unit are elderly and have few remaining family or friends. Ms Lacasad was concerned that the nursing staff was so busy and that the patients didn't really see how much the nurses cared. She knew it was important to demonstrate to her patients that the nursing staff cared about them deeply. She also had a sense that they weren't going to heal if they had no human interaction. Imagining herself as an oncology patient, she realized that it must be boring to stare at the blank walls in a room day in and day out. That was when she had the idea to brighten the walls by taking classes to learn how to paint and creating art for the patients.

Ms Lacasad takes time outside of regular work hours to get to know her patients and to create paintings that speak to who they are, what they care about, and what they like to look at. One of her patients loves to fish, so she painted a fishing scene for him. No flowers are allowed in her unit, so she has created scenes with flowers and landscapes. There are other scenes such as a



"Dif-fruit Points of View" Mixed Media: Watercolor and Ink (above)
by Sharon Lacasad (left).

serene woman holding an apple, a cathedral, and a row of colorful apples. A funny thing started to happen when the paintings were hung on patients' walls: the nurses started to slow down and engage in conversations with the patients in their care. Other people would notice the paintings and drop in to learn more about the pictures and their recipients. Patients and nurses became known to each other in a deeper manner with the paintings as a catalyst of something to share and enjoy.

Ms Lacasad is passionate in her belief that it is important to expose patients to more therapeutic modes of healing, such as the warmer care environments that she

promotes. She also speaks strongly about the need to educate the public about the relationship of environmental stressors and toxins to cancer. She shares that her mom never knew about everyday toxins that the average person encounters. Ms Lacasad is concerned that there is so little teaching about cancer prevention and would like to see free cancer prevention education courses in the future.

**"You do it
without any
thought of
recognition or
reward. You
do it because
you care ..."**

As for the paintings that she shares with her patients, these are her thoughts "You do it without any thought of recognition or reward. You do it because you care" ♦

Mia Medcalf is a National Service Quality Consultant with the Performance Improvement for Service for the Kaiser Foundation Health Plan, Inc.

Culture and Medicine: Reflections on Identity and Community in an Age of Pluralism

By Sylvestre Quevedo, MD, MPH

Labels of Identity— Race, Ethnicity and Culture

One of the great challenges in modern medicine is creating effective therapeutic relationships in an era of ever-increasing cultural diversity. Our hospitals and communities have become global villages where, daily, many languages, cultures, and customs intersect, clash, merge, and evolve. Yet in spite of this spiraling complexity, health caregivers, physicians, and patients visit and revisit this therapeutic encounter ever hopeful that it will provide solutions and solace. Beliefs, communication, and trust are the currency for a successful interchange. They are not the “stuff” of normal scientific discourse but they are every bit as real. How can we negotiate this uncertain terrain of relationship more effectively? Are there principles to guide us and stories to illustrate the pitfalls? Is there a “primer” for this?

I would like to relate a story that introduces the meeting that occurs between worlds when two people encounter each other *in all their particularity and richness and with the depth and intimacy* that Martin Buber referred to as a meeting of *I and Thou*.¹ Something is created in this—a new experience of Self and Other. Mr Buber wrote *I and Thou* in 1922 and it remains one of the most remarkable documents on relationship ever written. In it he said: “All real living is meeting”^{1p11} and “In the beginning is relation.”^{1p18} It is in this spirit that I engage in these deliberations with you.

Story of a Mexican-Indian Woman

I once took care of a 70-year-old woman—a Mexican-Indian from northern Michoacan near Patzcuaro, the homeland of the Tarascan people. The mountains and lakes in this part of Mexico participate with the people to create a beautiful serenity that surrounds the area and its towns. Towns with names like Tzintzuntzan. She was like the place that she came from and every month for a year, on the same day at the same time, she brought this serenity to me and to the medical clinic at the county hospital where I worked.

Medical clinic, in contrast, was squeezed into an afternoon of an already impossible schedule. It was supposed to be a break from the ICU and the wards, but it wasn't. The waiting room was wall-to-wall patients, and add-on and walk-in patients crowded the 20-minute appointments into 5-10 minute visits. The exam rooms, in a semi-circle, had two doors so the patients could be roomed from the hallway. We worked on the opposite side, “protected” from the waiting room and hallways and charting, on an open counter at a nurse's station that had more medical students, interns, and residents than nurses.

When I would see this woman's name on the chart I felt myself relax a bit. I always had the same picture of her in my mind. I knew she would be sitting quietly inside the exam room, peaceful and out of place against the institutional green walls. She always greeted me with a smile, and the kind, dignified look in her eyes calmed me. Her white hair, always pulled back, contrasted beautifully with the brown skin of her Indian face. We spoke in Spanish and I remember the old formal type of Spanish she spoke, a remnant of the colonial past. She had type-2 diabetes and hypertension, not too bad really. All of it came under easy control with a few medicines and I often spent our short time together simply reassuring her and enjoying her quiet demeanor while we talked about life (“cosas de la vida”).

One day there was quite a fuss at the front desk. One of the patients had come an hour late and the receptionist was trying to reschedule her for another day and time. The patient was adamant that she had to be seen and wouldn't reschedule. The receptionist came to me and asked me if I would add her on at the end of the day. I did and two hours later I saw the chart come up. I was very surprised to see that it was this same woman. It was so out of character for her to make any disturbance. When I came in the exam room she was distraught and tearful. I had never seen her lose her composure like this. I sat with her and asked her to tell me what was wrong. She told me that her husband who was in his late 70s had recently developed very bad congestive heart failure, had been in the Emergency Room

Our hospitals and communities have become global villages where, daily, many languages, cultures, and customs intersect, clash, merge, and evolve.

Sylvestre Quevedo, MD, MPH, is an Internist and Nephrologist in the Duke University Hospital and Health System; Associate Professor of Medicine at Duke University in Durham, NC; and Adjunct Faculty at the Osher Center for Integrative Medicine at the University of California, San Francisco. E-mail: sylvestre.quevedo@duke.edu.



and could no longer live at home. All of this had made her miss the bus, which she always took at the same time and at the same place. She then went on to tell me an amazing tale of traveling for five hours to get across town. She had to take a different bus, which left her at a corner she had never been to. She was illiterate and couldn't read any language, so the street signs were of no help. When she got off at a strange place and when people gave her instructions, even in Spanish, it was still very difficult for her to find her way. And she was very shy about letting anyone know that she couldn't read. This is so difficult for people—literacy. She and her husband were living in a garage with no heat or running water and because of his illness they were about to lose their place. This had upset her terribly.

I had seen her for a year, spoke to her in Spanish, and felt close to her, but in this moment I realized how much I didn't know the world in which she lived. She came every month into my world; I didn't enter hers—or maybe, truer yet, we came together between worlds.

A Terminology of Race, Ethnicity, Culture

As a foundation, it is necessary to work through some terms—race, ethnicity, and culture.

Race

Race is a troubled concept. It is now very much in dispute in biology. Genome studies have shown a remarkable degree of genetic similarity among races and a lack of correlation with phenotypic characteristics. There is much greater mixing between the races than was ever appreciated. For whatever differences people around the world have it appears that they are genetically more alike than different, about 99.9% worth. So race appears to be more of a social construct than a biological one.

In her book on *Cross-Cultural Medicine*, JudyAnn Bigby “recognizes race as a social construct that originates from societal efforts to separate people based on their looks and culture.”^{2p1-3}

Nevertheless, despite the ambiguities in the biology of race and its definitions there is no disputing the reality of racial prejudice in the world and the injustice and suffering it creates.

Ethnicity

Ethnicity describes certain subgroups that share ancestry, history, or culture. Factors that bind members of an ethnic group are diverse and include geographic origin—for example New England, the Deep South, the Southwest, Texas, or Hawaii—language or dialect, music, literature, cuisine, religion and gender roles. The

US government classifies Hispanics as an ethnic group that may be of any race.² More recently the term Latino has come into use to downplay the role of Spanish and the implication of origins in Spain.

My sister, who is a romance language scholar, tells me that “Latin” or Latino, as an origin, is a Western term that refers to the Roman Empire. So, of course, the French would be Latin by this definition—not helpful for the New World Latino. We will return to these troublesome labels.

Culture

Ms Bigby defines culture as “a shared system of values, beliefs, and learned patterns of behavior.”^{2p2} As defined, it can apply to ethnic groups, regional groups, and professional groups.

I find Clifford Geertz's comment more helpful. In his epochal work *The Interpretation of Cultures*,³ he says:

“... man is an animal suspended in webs of significance he himself has spun. I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning.”^{3p5}

He continues that culture does not cause behaviors, social events, or processes. Rather culture “is a context ... within which” those behaviors, social events or processes can be intelligibly described.^{3p14}

Jerome Bruner, in his characteristic brilliance, comments that to be part of a culture is to be “bound in a set of connecting stories, connecting even though the stories may *not* represent a consensus.”^{4p96}

Self and Community in Story and Image

In a fundamental sense culture is about identity or self in relationship or community. And community as a web of relationships surrounds self as a context. And context is culture, an interpretive community. Wittgenstein used the term “thought circle”⁵ and Ludwig Fleck used “thought collective”⁶ to describe these communities that we use for the social construction of reality.

The Self as a person is both being and acting in the world, ie the Self has both an ontologic and praxeologic status. Furthermore a person is not made (constructed) in isolation but rather in relationship. In other words the Self is “distributed, reflexive, and constructed.” Let me explain: A person is born with a history and into a culture and inculcated with this from conception. S/he therefore takes his/her existence from events distributed across history or time and space. S/he is reflexive (reflective) or consciously remaking him or herself, and constructed (both conservative [self-organizing] and creative [self-transcending]).^{4,7} Finally

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action is “situated” in the world, ie, in a context and that context is culture.

The Strange and Varied Experience of the Chicano

What’s in a name? Who is a Latino? When I was young the term Chicano was usually derogatory. The old people used to say “Chicano corriente” to point out the lower status that Chicanos seemed to occupy. If they were young Chicanos, I wasn’t supposed to be with them. It could also refer to tough guys—the Pachucos—also people I wasn’t supposed to associate with. And yet Chicanos were not Mejicanos. Mejicanos still knew Mexico, had ties there, went there; Chicanos rarely did. And when they did go to Mexico, Chicanos often felt out of place. Their Spanish wasn’t good, it was Spanglish or pocho—more terms that made you feel bad, even in Mexico. This is confusing when you are young. Later on, leaders of the Civil Rights Movement, like Martin Luther King, Jr, led us to a new awareness, and James Brown taught us: “Say it once, say it loud. I’m Black and I’m proud.”⁸ So Chicano became a term of pride.

In New Mexico, where my family originated, people pride themselves on being proper Hispanos. New Mexico was a Spanish colony and then part of Mexico for longer than it has been part of the United States. Some of the old people there still wear the traditional black suits or dresses with mantillas of colonial Spain on their heads. They didn’t want to associate with Chicanos or even Mejicanos. There you had to be a “Manito”—a true New Mexican—to attain preferred status. The history of New Mexico reaches back to the colonial period, the late 1500s. And in certain places your family was not even much Hispano but more Pueblo, or Mescalero, or Mimbreno. This is very much Indian country and in my own family there was Apache and Pueblo on both sides. During the Apache wars of the late 1800s it was unsafe to be Indian and worse to be Apache. So everyone had Spanish names and called him or herself “American” when the authorities asked. The authorities usually referred to them as Mexicans, even if they had never been in Mexico. I’m not sure what the “authorities” were, though they probably weren’t Chicano. I once asked my grandfather, who was Pueblo, what country he was from—he said he didn’t like either one very much.

If you are from Arizona you might be a Yaqui, who speaks Spanish, or Navajo or Papago (O’odham). And there was everything in between, like my friend Jesus.

Jesus

I met Jesus about ten years ago working on a project in Sonora, Mexico about 200 miles south of the Ari-

zona border. I was part of a group working with the Seri (Concaac) to record sacred songs, chants, healing ceremonies, and oral history. The Seri Indians are southern neighbors to the Pima and Papago (O’odham) of Arizona. Their homelands are on the Sonoran coast, about 100 miles north of Hermosillo. Jesus lives there in Mexico and speaks Spanish. I asked him about his parents. “Mi mama hablaba O’odham y nacio en Arizona, (My mother spoke O’odham and was born in Arizona)” he told me. His father was from the Mexican side of the border but also Seri. You wouldn’t call Jesus a Chicano, or a Hispano, nor a Mejicano (because the Seri regard themselves as a sovereign nation). He definitely is a Seri, and he is a Papago too, but not an Arizona Papago. You can see how these labels are confusing.

Choosing Categories

In the 2000 United States Census, for the first time, participants were allowed to choose more than one category. Among Native Americans in California almost 50% have mixed ancestry with Hispanic or Latino. This underscores the very close relationship between Latinos and indigenous peoples throughout the Americas.

Even if we clarify and apply these terms it can still be confusing. For example, Hawaiians are Native Americans even though they are also Pacific Islanders. This has been a problem for demographers. In Hawaii, where mixed racial ancestry is the norm, researchers regard racial identification as less important than language(s) spoken in the home and birthplace of parents.

Another example: Is a Spanish-speaking, black woman from the Dominican Republic (who lives in East Palo Alto) Latina, Hispanic, African-American, Afro-Caribbean, or all of these?

Rebeca

I have a good friend, Rebeca, whose family is European and Jewish. They found their way to Mexico during the diaspora of WWII. She grew up in Mexico, speaks Spanish to her children and either English or Spanish to her patients in her work as a nutritionist. Her parents now live in Israel. She embodies the beauty of Latino culture—the kindness or friendliness (*simpatia* and *personalismo*), politeness (*respeto*), importance of family—these qualities are hallmarks of Latino culture.⁹ To me, Rebeca is very much a Latina.

Two summers ago I was in Sao Paulo, Brazil, where 20 million people live. There I visited the famous Japanese community known as Liberdade, “Freedom.” I met third generation Japanese Brazilians who spoke Portuguese and only a little Japanese. They could be

... behind each label lies a real person with a very particular, indeed unique, story.

called Sansei, but are they Latin Americans, or Japanese Latin Americans, or Latinos?

Julian

Julian was born at Stanford hospital, grew up in California, and is a professional skateboarder. Recently he worked in a restaurant as a cook. His coworkers were Mexican and called him Bruce Lee because he looks Asian and doesn't speak much Spanish. His boss, who is white (EuroAmerican), tried to speak to him in Spanish because he didn't believe him. His mother is Sansei, third generation Japanese American, born in California to parents who are farmers in the Coachella Valley. I am his father. When I asked him if I could talk about him, he said, "Why?" and looked at me as if to ask, "Aren't I just like everyone else in California?" Well, yes.

These are all labels of identity and we all use them in various ways; sometimes they are necessary. We have to name the world in order to interact with it. The main point is to remind us that as we use these labels and categories, remember they are fictions at best, and behind each label lies a real person with a very particular, indeed unique, story.

Cultural Competence— What About The Term? Cultural Competence

The term originally derived from an institutional use where it describes the goal of having health caregivers who, in addition to other technical competencies, have a "cultural" competency. As such it implies the existence of an external standard against which competence is measured, for example proficiency in language for translators or professionals. In this usage it is understandable and the skills it implies are essential for the professional. But when used in wider parlance it implies that culture is monolithic and static and has a univocal interpretation. In this sense it is not useful, and can even be harmful, as it can lead to narrow reifications that pose as culture. So what should we do? Jettison the term? Take the dialogue beyond it to multiculturalism, or to local knowledge?

Local Knowledge

Local knowledge is a term used by Geertz to underscore the importance of context, situation, and local conditions in experience and behavior, local conditions that give rise to an endless range of possibilities in interpretation. He concludes, "the interpretative study of cultures represents an attempt to come to terms with the diversity of the ways human beings construct their lives in the act of leading them."¹⁰

Perspectivism

Perspectivism is a term used by Richard Tarnas¹¹ and Jerome Bruner⁴ among others to emphasize that all interpretation is done from some vantage point, someone's point of view, some perspective. And that perspective is neither neutral nor transparent.^{12,13}

Clinical Templates

LEARN¹⁵

- Listen to the patient's perspective
- Explain and share one's own perspective
- Acknowledge differences and similarities between two perspectives
- Recommend treatment
- Negotiate mutually agreed upon plan

Eliciting the Explanatory Model of Illness¹⁶

- What do you call your illness?
- When did your illness begin?
- Why do you think your illness started?
- What does your sickness do; how does it work?
- How severe is your illness?
- What do you fear most about your illness?
- What are the major problems your illness has caused?
- Do you have any ideas about what treatment you should receive?

The Ethnosphere, Language Loss, and the Value of Diversity

Let me end with a perspective on the value of cultural diversity. It comes from Wade Davis.¹⁷

"The ethnosphere is the sum total of all thoughts, dreams, ideas, myths, inspirations brought into being by the human imagination since the dawn of consciousness. The ethnosphere is humanity's great legacy, the symbol of all that we have achieved and all that we can achieve as a wildly creative and adaptive species. Yet, this rich and diverse legacy is threatened."

"The great indicator of this is language loss. When the oldest of us reading this article were born there were 6000 languages spoken on earth. A language isn't just a body of words and a set of grammatical rules; it's a flash of the human spirit, an encyclopedia of the human imagination. It is a vehicle through which the soul of each particular culture comes into the world. Every language is an old growth forest of the mind, a watershed of thought, and an ecosystem of spiritual

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possibility. And of those 6000 languages half are not being taught today, they are not being whispered into the ears of babies. Effectively, they are dead.

"Some view this as a good thing: one language so that everyone can communicate. Great idea, I say. Let's make it Lakota Sioux, or Cantonese, or Yoruba, or Tibetan, or Navajo, where nouns are scarce, everything is related and in motion. Suddenly you begin to see what it would be like to be enveloped in silence, to have no means to pass on the wisdom of your ancestors, to anticipate the promise of your children.

"And yet that dreadful plight is the fate of someone on earth roughly every fortnight because every two weeks some elder carries to their grave the last syllables of an ancient tongue."

Conclusion

As we dig more deeply into the topic of culture and medicine we see with new eyes the extraordinary complexity in the very notions of identity and community. And probably all people have multiple identities simultaneously.¹⁸ One can see how this leads to being a member of several, often very different, communities—all at the same time.¹⁹ We have explored this terrain here and, although sometimes a confusing excursion, I always come away with a renewed sense of wonder at the beauty and richness of the very diverse world that we live in. I wonder what your thoughts are? ♦

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Practical Advice

- Listen: Medical history taking is often more like an interrogation than listening to someone tell their story. Choose instead the approach being called *Reflective Engagement* or *Appreciative Inquiry* where the questioner assumes the posture of nonexpert learner.¹⁴
- Self-inquiry: What are your own hidden assumptions, implicit values, unstated goals?
- Language: Literacy and language create worlds, yet linguistic competence is not necessarily cultural competence. Remember that language can be used to control and confuse and that much communication is nonverbal.
- Nonverbal communication: recognize its importance.
- Attributes of a healer: The effective healer has certain attributes. Work to understand them from your own point of view and embody them in practice.
 1. Joyful
 2. Skill or skillful means
 3. Reverence for the work (awareness of participating in the mystery)
 4. Kindness
 5. Humility

Innovation in Our Nation's Public Hospitals: Interview with Five CEOs and Medical Directors

By Tom Janisse, MD
Winston F Wong, MD

What quality improvement strategies are the leaders of our nation's prominent public hospitals following at this critical time of American health care change? Even more burdened than community hospitals with care for the uninsured and immigrant populations and with scarcer resources, how can they prosper, let alone survive? At the Spring 2007 annual meeting of the National Association of Public Hospitals in Boston, we talked with five leaders (Table 1) and found surprising and hopeful answers, and offer this conversation so that we can learn from them and follow their lead.

The Permanente Journal (TPJ): Please briefly introduce yourself, your position, and give a brief description of your hospital health system.

Sandra Hullett, MD (SH): Cooper Green Mercy Hospital is a small community hospital in the medical center affiliated with the University

of Alabama at Birmingham, so we are a teaching facility. About 70% of the patients are uninsured; the other 30% are Medicaid, Medicare, and third party. We are a service provider for a large number of disadvantaged people. Fifty percent of our funding is from an indigent county tax. We've been there since 1972 and have been primarily a source for acute care though we are changing our image through more community-based work.

Gene Marie O'Connell, RN, MS (GO): San Francisco General Hospital (SFGH) is the only trauma center in the city, with a full array of services in the acute care hospital as well as primary care and specialties, and the only psychiatric emergency unit in the city with the most psychiatric and mental health services of any area hospital. We have a total of 550 beds. Through an affiliation with University of California, San Francisco, we provide a third of all the teaching for the university. Last year we saw over 100,000 unduplicated clients.

John W Buford, III (JB): Truman Medical Center (TMC)—a 501-C3, nonprofit entity that was originally the city hospital—is a two-hospital system that includes a long-term care facility, as well as a major behavioral health offering, and we oversee the Jackson County Public Health Department.

Alan D Aviles (AA): The New York City Health and Hospitals Corporation is the largest municipal health system in the country. We serve about 1.3 million New Yorkers every year, including about 400,000 uninsured. The system includes 11 acute care facilities and 4 long-term care facilities and more than 80 community-based primary care sites. We have 4500 acute care beds and another 3000 long-term care beds. We provide 5 million outpatient visits per year and 1 million emergency room visits per year. We also run a very large Medicaid-managed care plan with more than 275,000 enrollees.

Immigrant Care and Language Barriers

TPJ: Safety net hospitals have improved medical care outcomes despite the challenges of caring for patients who are often immigrants and whose primary language is not English. How have each of you accomplished that?

GO: We started working on this several years ago. Like the city of San Francisco, the hospital has a very diverse population—20% of all patients at SFGH do not speak English and we have an on-site language service department with 28 interpreters who provide interpreter services in approximately 20 languages. In response to demands

Table 1. The participants

Alan D Aviles: CEO, New York City Health and Hospitals Corporation, New York
John W Buford, III: CEO, Truman Medical Center, Kansas City, Missouri
Sandra Hullett, MD: CEO and Medical Director, Cooper Green Mercy Hospital, Birmingham, Alabama
Gene Marie O'Connell, RN, MS: CEO, San Francisco General Hospital, California
Ramanathan Raju, MD: Chief Medical Officer, New York City Health and Hospitals Corporation, New York

Tom Janisse, MD, is the Editor-In-Chief and Publisher of *The Permanente Journal*.
E-mail: tom.janisse@kp.org.

Winston F Wong, MD, is Medical Director, Community Benefit, and Director, Disparities Improvement and Quality Initiatives at The Permanente Federation in Oakland, CA.
E-mail: winston.f.wong@kp.org.

for linguistic services (over 75,000 requests yearly), we have recently implemented a VMI (Videoconference Medical Interpretation) system, through a collaborative grant from The California Endowment in which we partnered with Alameda County Medical Center. VMI refers to the conducting of medical interpretation through a videoconferenced call—the clinician and patient on one end (using a simple, mobile video unit) and the interpreter on the other end (using a stationary unit in the interpreter services call center). Videoconferencing equipment now has adequate visual and audio capabilities and is no longer cost prohibitive—making its application in public health venues feasible. The primary purpose is to improve the communication between limited English proficiency (LEP) patients and clinicians by increasing access to interpreter services and significantly shortening the wait time. Currently the clinicians using VMI can access an interpreter within several minutes, which has dramatically improved the efficient and timely delivery of interpreter services to our LEP patients.

JB: Many of our safety net institutions possess an outstanding set of qualities: high-caliber staff with passion and a commitment to the population that they serve. That makes a big difference, and that's reciprocal because the clientele, ie, the patients, respond to that passion and that caring, to which I attribute a large part of the results we get. In our environment at TMC, we have been almost singularly focused on two things: good customer service and good clinical outcomes. As we have worked on this mission and focus and strategy both technically and strategically, we've added the notion that it must be advanced through technology. Furthermore, we must be the employer of choice

for choice employees—if you hire the right people and keep the right people happy, other things will fall into place. Specifically to your question, the genesis of our institution was a segregated hospital, so its purpose was to address the disparities of the old segregated south. It's part of who we are—non-discriminatory, open and equal access, and equal service to all people, including all of the social service add-ons we provide beyond the clinical necessities, whether it be transportation, interpretation, or outreach and hand holding. Those additional social services are critical to the definition of a safety net. It's a much more holistic approach. Finally, one of the value systems that we adhere to lately is that we're better for everyone. I commonly say we do not discriminate against those who can pay because if you attract an upscale patient base, then service is going to be better for everybody. You don't want to become a poor people's hospital; you want to become a good hospital for everybody.

SH: Yes, we also have great diversity here. The problem is that small facilities become experimental places. Because Birmingham is in the south and people don't think much about southern states having issues with diversity, no one has prepared or tried to make any changes in the existing systems. I have lived in a community where the hospital's largest foreign language was Spanish—less than 1% six years ago. Now, overall in the hospital it's 15% and in our Obstetrics Department it's 67%. So, we have a rapid growth in the use of Spanish, which is not regularly taught in the school system. We depend on interpreters on a language-line, though inadequate. Because the need was so great I insisted the county support this. We

now have four full-time interpreters. We also addressed the issue by going to the community where there are four colleges that offer Spanish majors. We met with them and said, "We can do something for you and you can do something for us. Let us develop an internship for your students." That internship allows students to help us with navigating, enrollment, and registration of patients. We also worked with a Robert Wood Johnson Foundation Grant to teach certified medical language—Spanish. The result was a place in the county to become certified in medical language by Stanford University. Now we have four full-time interpreters to assist the clinic visit. Six years ago there were 2 qualified people, and now there are 25 people certified to interpret. Even though we have less money than other area hospitals, we address the language issue in a larger proportion. It's been an uphill battle because I live in the community where people, even on my staff, still say those people need to go back where they came from or learn to speak the language.

AA: For us, it's also a big challenge. Of course, New York City is an entry point for new immigrants from all over the world—the current estimate is 500,000 undocumented immigrants living in the city—and we're the major safety net for them. More than 100 different languages are spoken among our patient population. How do you address this diversity in the absence of dedicated funding to support the required infrastructure? We have a quite limited number of dedicated interpreters, so we address this mostly from a combination of a very diverse and bilingual staff, and we do rely on

More than 100 different languages are spoken among our patient population.

there is the issue of low literacy ... At what grade level should the communication occur?

telephonic interpretation services. All of our hospitals have dual-handset access to a language-line service. However, a small number of our facilities, including Bellevue Hospital, and Kings County Hospital in Brooklyn, are using a homegrown system called Team Electronic Medical Interpretation System (TEMIS), which was recognized as an exceptional innovation by the National Association of Public

Hospitals (NAPH), and won NAPH's safety net award. It's a remote simultaneous translation interpretation system for use in the exam room. The physician and patient put on a wireless headset and they connect to a centralized call center where highly trained interpreters perform simultaneous translation (as in the United Nations) so that the patient is literally hearing in his or her own language what the physician is saying, as if s/he is actually speaking the same language—it gives the impression that they're speaking to one another in the same language. We now have received special grant funding so that we have 28 interpreters with our TEMIS call center handling 8 languages. However, just those 2 major facilities and a couple of our diagnostic and treatment centers have access to it at this point. Many of our hospitals also rely on volunteers for interpretation services, which is fine for general interpretation, but we now require any staff or volunteers interpreting in the exam room to undergo a 40-hour interpretation training course intended to teach more precise interpretation that maintains the accuracy of the communication between the physician and the patient. A

couple of hundred people have completed that program, which represents a lot of investment in an important resource.

GO: Besides the language access that we have all addressed, there is the issue of low literacy. One of my doctors has been exploring the best way to communicate—one way is using pictures. And a major question is: At what grade level should the communication occur? Many patients may not understand what the doctor has said at all. Anybody who has gone to a doctor might have had that experience.

AA: Yes, that's very important. We're developing a tool that relies heavily on pictograms, especially for discharge medication instructions. Even when we generate instructions in the language of the patient, we still find many patients with illiteracy in their own language. Bellevue Hospital in particular pioneered work on materials for patients with low literacy that we now use more broadly in our system.

TPJ: A nodding patient isn't necessarily an understanding patient.

SH: We really struggle with having professional staff that speak different languages. We now put great emphasis in the school system on people becoming more competent in other languages. We're in the deep south, and we still had 18 different dialects documented in our hospital last year, with Spanish and Vietnamese the 2 most common. We have no physicians or nurses who speak those languages; the couple I had left or retired. We are working with the Spanish-speaking community to get nurses trained.

AA: Your question was about improving outcomes for the immigrant population. We have encountered another issue: for some communities, there are specific health issues not unique to them but that have a

disproportionate impact on them. For example, we have a large South Asian population in New York. South Asians, particularly from India, Pakistan, and Bangladesh, have a disproportionate incidence of cardiovascular disease at an early age—presenting with CV disease in their 30s that we are more accustomed to seeing in patients in their 50s—a result of both genetics and diet. We reach out to those communities to raise awareness of their heightened risk, and the need for early screening. Similarly, we find a high incidence of hepatitis B among the Asian immigrants seen at Bellevue Hospital, which serves a large Asian population, particularly Chinese, from the lower east side of Manhattan and other parts of the city. We reached out in those communities as well, and our screening has resulted in more than 20% of Asian immigrants testing positive for hepatitis B.

Connections to the Community and to the Community Clinics

TPJ: What is your perspective on community-based education and care, and your connection with community clinics, as it relates to your provision of care in either your public hospital or your health system?

GO: More people are discovering the value of community outreach to churches and other organized groups. They are happy to have you as a speaker, for example. However, what's our goal? Just to get to know people, to get people to come in for care, or delivering a specific message. The African-American diabetes project was with an organized group—people already working in the community, who knew so-and-so had diabetes. Sometimes word of mouth works really well. Kaiser

Permanente (KP) has done a lot for San Francisco General, for example different grants that we never would have been able to participate in, like with the Institute for Healthcare Improvement. One of the things KP has identified is that their patient population will be healthier if the whole community is healthier. This has been very helpful to our public health department, which I'm part of, because you can measure and measure our health disparity—it's not health care disparity—but then how do you do it in a more organized fashion? One of the things that helped us was getting all area hospitals and the African-American health disparity project to look at the same thing, for example hepatitis B. We got a number of the hospitals organized around this.

TPJ: Sandra, could you tell the story about this that you told me earlier?

SH: I worked in a community health center for 22 years before working in a public hospital. This gives me a different perspective of the community and how the community has been involved in their care. People see hospitals as a place to go when you're sick, when you need something done. Public hospitals often work with a group of community-based facilities practicing primary care and, when necessary, referring patients to the public hospital; therefore the community calls them community hospitals. These facilities just do primary care, they don't do community wellness programs, or go out into the community to listen to its needs. That's where, in the past, we erred: we came up with ideas that we think are important for the health care community. Now I actually work in the community on something that the community is

interested in. Before, our ideas were important to us, but in order for the community to buy into something, they must feel it's important. How do you get them to do that? You must first listen to their concerns. We started workshops: we invited the community in and shared the historical data: the health statistics of the area—the ten most-recorded health problems and the mortality rate associated with those problems. Then we asked them to pick what they thought was most important, something they wanted to work on. We would then develop it and see what the impact would be in the community. They picked breast cancer—in a community where cardiovascular (CV) disease was killing everybody. CV wasn't their interest; they were interested in breast cancer. They took it on; they learned about it and they came up with the framing process for getting the community involved. It was a project the hospital facilitated, but the community did the work. With the community and hospital working together, we created a forum in which lay women went into the community to educate women about mammograms and their importance. We then looked at the data to determine how many women had had mammograms before this project and then how many had one after our forum. The result was an 18% increase after six months—six months! Not just people who had talked to the doctor—because the emphasis was teaching people how to ask the questions, for example, “Why haven't you asked me about a mammogram?”—but people who actually had documented mammograms. I really think you can make a difference through hospitals—public hospitals especially—facilitating dialog—being there and listening to what those people know even though we think

we know what the issues are.

JB: Right. When people think about public hospitals, their first question is how many beds do you have? But it's really about the outpatient care volume—those 300,000 patient visits—the chronic diseases that embody societal ills, health care ills, and economic problems. Local communities can't absorb that. The question is: how are we going to substantiate the extremely valuable assets in our local communities that add to the quality of life in the community as a whole? Something's got to give. We've got to do it differently. Perhaps we need a payment mechanism that pays for the entire care continuum, expanded to include all health, including public health and mental health. It's all got to be rolled into chronic care and acute care services. There's a connection between inpatient and outpatient, first of all physically. Patients say they come into our hospitals but they may be coming to our clinics; they may be going to our diagnostic area but to them they're still coming to the hospital. And when things don't work out well, those outpatients become inpatients. We have to change how people think about the outpatient and inpatient settings and shift the emphasis to outpatient care. Because, on the other hand, if things work out well—in the case of prenatal care, for example—those outpatients become inpatients, then outpatients again after discharge, often seeing the same clinical team. And, a third thing, all outpatient and inpatient care should be connected by common medical record.

TPJ: Ramanathan Raju, MD, Executive Vice President and Chief Medical Officer for New York City Health and Hospitals Systems Corporation just joined in for Alan Aviles, who had to take an emergency call. Do

We have to change how people think about the outpatient and inpatient settings and shift the emphasis to outpatient care.

you have any comments about that, Dr Raju?

Ramanathan Raju, MD (RR): HHC is actively involved in many outreach public health programs with our colleagues at the Department of Health, all of which are targeted to meet community needs. These programs reflect our joint focus on important public health issues, and make readily available the tools and information that people need. For example, we have worked together on increasing access to HPV because it is one of the major public health issues confronting people ages 12 to 25. Also, the NYC Commissioner of Health is extremely interested in smoking cessation, and our coordinated cam-

... if a health problem exists in the community, then the solution can be found right there in that community.

paigns dispense smoking cessation medication and enroll people in smoking cessation programs. At our facilities, tobacco use assessment and counseling are now hardwired into the intake process. A last example is how we address community concerns has to do with the enactment of new immigration laws last year. We felt that people might be afraid to seek health care because of the concern that their information would be shared with federal government, which might lead to exposure and the threat of deportation. Mr Aviles and the New York City's Commissioner of Immigrant Affairs reached out to the community and reassured them that their information is always kept confidential and reiterated our mission that we treat all patients, irrespective of immigration status. The most important thing is to figure out what the community wants, because sometimes we have a paternalistic attitude that we know what's good for them and they should accept

whatever program we think they should have.

SH: I have a friend who says if a health problem exists in the community, then the solution can be found right there in that community. I know we've done a lot of work over the years—developing and distributing educational materials, for example—but we're still dealing with the same problems. My first research grant was from the National Institute of Heart, Lung, and Blood in 1982 on hypertension. I have a new grant to address cardiovascular disparity from the National Institute of Heart, Lung, and Blood. It's on hypertension again. So, something's wrong; we're not doing what we need to do.

RR: That is very interesting, because we have created a self-management tool for patients with hypertension and diabetes. However, with our old attitude of paternalism, we may say to patients that these are the food items that you can eat, and these are things you cannot eat. For ethnically diverse populations, that does not always make sense. Their cuisine and eating habits are so different that the normal dietary instructions do not always make sense to them. We have to figure out how to teach them healthy ways to cook and eat their own ethnic food, not teach them about X grams of carbohydrates and Y grams of fat and talk to them about food they rarely or never eat. They don't understand those calculations. So, one of the things we did was to build a working kitchen at Kings County Hospital. Now a dietician teaches them how to cook with their own ethnic food, making sure of right caloric intake. You cannot use a cookie-cutter methodology that does not work with some ethnic populations and then keep revisiting the same thing again and again

wondering why the outcomes are not optimal. I'm sure 20 years from today, there will still be hypertension grants because all that has been done so far is to institute very modest changes. Do we really engage the patient in an effective way? We talk to them, give them a piece of paper, and believe that they're going to follow our instructions when they go home. We call it engagement and get compensated for that encounter. Did we really achieve our goals during that encounter? We have the same issue with the flu vaccine. Some people do not believe in flu vaccines. They fear that the flu vaccine will give them the flu. So, unless we figure out their fear and deal with it, all our efforts to bombard them with flu vaccine campaign materials and incentives will yield only marginal results. We need to have a much more effective way of engaging patients—real engagement, not what we call engagement now. It is a flawed thinking ... that medications alone will get us the desired outcomes without enlisting patients' buy-in to make lifestyle changes—different communication styles and methods are needed for different groups of patients to get that buy-in.

SH: We believe in the education process, but we are working more to collaborate with communities, with health centers, and with other not-for-profit organizations. That is one of the things I like: we are collaborating more, not just doing our thing. Even so, we need to listen more to the community and we'll be much more effective.

GO: To follow Dr Hullett's point, the people at the San Francisco Department of Public Health came to the realization that there was always this push/pull between the hospital and the community people—that we were separate, serving different

populations, and the hospital used up all the money. A group of us now see the importance of support and giving to community programs, and recognize that their job is to keep people out of the hospital. I've proposed taking money out of acute beds to fund community programs, knowing that it's a real gamble in the first year, but in the long run, it can pay off. It's so important not to have a separation between the hospital and community providers. When they're linked, we can match the work in the communities I already mentioned.

RR: Public hospitals have done a much better job of this collaboration. We don't believe that the hospital's responsibility ends within the four walls around it. In fact we believe in the concept of "hospital without walls." Community providers are an extension of our delivery system. They are the hospital without walls. However Gene O'Connell is making a valid point. The present reimbursement system heavily favors inpatient stay, and does not pay adequately for disease management efforts. It is a real clash of mission and money at the end of the day.

Training Future Physicians in Quality Improvement

TPJ: Public hospitals characteristically train future physicians. How do you incorporate quality improvement awareness and methodology into your training programs so that residents are prepared for a future of not just gaining new knowledge, but improving the quality of their own practices?

SH: Cooper Green is a teaching facility with University of Alabama, Birmingham as our primary affiliate, though we work with many other organizations. Within the hospital

we build a culture where quality improvement is an essential part of what we do. Residents see physicians and nurses emphasize quality—it's our major focus—and a natural part of our culture. In our integrated model I see more residents taking on quality improvement themselves without us having to remind them of its importance. Quality has the same importance here as at the large university.

GO: That's interesting. I have to say we have rules here at SFGH too—many think it's the Wild West. The best thing that has happened to the whole quality discussion is changing it to patient safety. There is widespread awareness of patient safety, such as having ventilator-pneumonia posters everywhere, and holding chiefs accountable for improvement. A couple of years ago, a benchmark for us was our study of medical orders—people weren't signing and dating their verbal orders, so we got rid of verbal orders. We decided that at the Medical Executive Committee meeting, everybody said, "Oh, the patients are going to die," and "This is going to be awful." We haven't had verbal orders now for two years and no one has died. Making a dramatic change like that, which can really impact patients and staff, makes you realize you can improve things. As Dr Hullett said, it's not just for medical students; it's having a culture where everyone makes the patient safer. To collect quality data most public hospitals have to input manually. IT systems don't perform all the functions everybody wants. However, one of the positive things about manual data collection is that people open the medical records and actually read what people are writing. It would be great though if you could just push a button and get good data.

JB: I've been doing this work for over 30 years and have never seen a computer system that has lived up to the expectation, or the cost, that it has taken to bring it on. It would be nice for all of the great minds to get together and resolve the electronic health record technology with a common platform and perhaps a universal ID number so that the records can truly be transportable across multiple systems, and if there were federal funding to purchase these systems. They kill us.

RR: A couple of things are happening nationally that will firmly embed quality into practice, like Medicare pay-for-performance at the physician level. Residents are very smart, and quickly understand the marketplace and adjust how they have to practice. The second part of quality improvement is, how to get all stakeholders involved in quality? We started including the residents on the quality assurance committees, making them understand and be accountable for the results of what they do. The third thing we did was to create a robust physician support system with prompts and reminders—a medical record system that automatically tells you when and how to prophylax the patient for deep venous thrombosis, for example. This hardwires orders into practice. I agree with the panelists on this. This should become part of day-to-day life. When residents examine a patient with a mild heart attack, they should pick up a pen and order aspirin as automatically as they reach for a stethoscope. It's such a great tool—getting the medical student involved in patient care from the start—as opposed to spending years just reading books. Theory and practice are taught together.

JB: We always have this three-part focused mission on education,

It's such a great tool—getting the medical student involved in patient care from the start—as opposed to spending years just reading books. Theory and practice are taught together.

research, and clinical care. We are emphasizing clinical outcomes and clinical care, because these institutions should exist for the patient; not primarily for education. You can't have the teaching and training of physicians, students, nurses, and pharmacists take precedence over the patients and customer service. Patients are first. However, one of the benchmarks of any good institution is the application and the culture of innovation and creativity. We need to rethink old models because the rate of change is so fast—technologic advances have had a dramatic effect on our respective institutions—and, in fact, what we've been doing is not getting any of us to where we want to be in terms of quality and value.

Conclusion

What is perhaps most surprising to learn from prominent leaders of

our nation's public hospitals is that beyond the collaborative approaches they have implemented in their hospital departments, these leaders see the future as developing an integrated system with community clinics and with the neighborhoods and communities they serve, even in large, complex cities.

Secondly, the generative quality initiatives these leaders have implemented have been based on a scarcity of resources that necessitated collaborative solutions that not only reduce expenses but improve quality and satisfaction. For example, the increasing complexity of communication between people in an ever-larger and diverse population led to a simultaneous translation system—similar to that used in the United Nations—creating virtual direct dialogue between people with different primary languages.

The decision to better understand their patients' real needs led to better medical care, with much less time and money wasted on common wrong-headed, health care-expert approaches. Improved care is not about the number of hospital beds but about the number of outpatient visits that generate that need; teaching patients how to cook healthy foods is a superior educational tactic to developing better diet instruction sheets; and finally, that training future doctors by actually involving them in the hospital's quality improvement committees and clinical projects produces a more sustainable, long-term health care solution.

We hope this interview serves as a tribute to our nation's public hospital leaders, physicians, nurses, and caregivers, and their patients. ❖

Duty of Our Generation

This is the duty of our generation as we enter the twenty-first century—solidarity with the weak, the persecuted, the lonely, the sick, and those in despair.

It is expressed by the desire to give a noble and humanizing meaning to a community in which all members will define themselves not by their own identity but by that of others.

— Elie Wiesel, b 1928, Rumanian-born American writer, 1986 Nobel Laureate for Peace

Beyond Equal Care: How Health Systems Can Impact Racial and Ethnic Health Disparities

By Kate Meyers, MPP

Much has been written on the existence of racial and ethnic differences in health status and health care access and quality in the US. Researchers, think tanks, government entities, and advocacy organizations have worked to summarize many of the root causes, environmental and behavioral influences, and health system factors that play a role. Yet sustained and significant change has been elusive.

Many of the initiatives and efforts aimed at reducing health disparities have focused on the role of the health care system. In this context, potential solutions usually include approaches such as cultural competency training, access to linguistically appropriate care, expansion of insurance coverage, and support for consistent delivery of known best care practices to all patients.

However, factors outside traditional health care delivery—including community-based social determinants of health such as environmental pollution, job opportunities, education, income, and support for healthy lifestyles—play an equally if not more important role in disparities. Whereas at first blush it may seem that these factors are beyond the purview of health care organizations, there are in fact many ways in which they can influence—for better or for worse—these factors. Although equal care is a critical goal, if health care organizations' efforts to reduce disparities focus only on this goal, they will have limited impact on reducing overall differences in health status and outcomes.

What Are Health Disparities?

A voluminous literature, including the landmark 2003 Institute of Medicine report, "Unequal Treatment,"¹ documents the existence of disparities between whites and nonwhites in many different measures of health care access, quality, health status, and outcomes. Despite this attention, consensus is lacking on the definition, existence, or extent of the problem, let alone the causes and potential solutions.

Health disparities are generally described as differences in health care processes or health outcomes between different groups,^{2,3} but more specific criteria sometimes include whether those differences are avoidable or un-

just.⁴ Population groups are often defined by race and ethnicity, but can also be based on socioeconomic status (SES), sex, age, language preference, country of origin, or other characteristics. Some researchers describe SES (usually characterized by education, income, occupation, and/or wealth) as the most important determinant of racial and ethnic health disparities,⁵⁻⁸ and some have found that health differences between socioeconomic groups are often greater than differences between racial groups.^{6,9-11} At the same time, the majority of studies find that measured disparities between races are reduced but not eliminated after controlling for SES.¹ Whether disparities are an issue of race or of socioeconomic status is a false choice—there are disparities by race; there are disparities by SES; and these factors are intertwined but also likely play distinct, independent roles.

While the term "disparities" is frequently used in the US, many European countries refer to "inequities," a term that places greater emphasis on issues of morality and fairness. Though debate over the use of the term continues, this paper uses "disparities" for consistency with the bulk of work in the US.

Reducing Disparities: Influences and Arenas for Action

Disparities in health status and health care have been well documented, but solutions for reducing them are less clear. One reason is that the landscape of influences on health disparities is complex. The adapted version of the "ecological model"¹² presented here provides a framework for understanding that landscape, showing how individuals exist within, influence, and are influenced by their surrounding networks and environments (Figure 1). The model highlights the following key arenas for policy action, each with ample research connecting it to health:¹³

1. **Individual socioeconomic circumstances**—such as education, income, wealth, and occupation
2. **Physical and cultural community environment**—such as pollution, the built environment, public safety, access to services that support health, and social capital

Although equal care is a critical goal, if health care organizations' efforts to reduce disparities focus only on this goal, they will have limited impact on reducing overall differences in health status and outcomes.

Kate Meyers, MPP, is a Senior Policy Consultant at the Institute for Health Policy for Kaiser Permanente. E-mail: kate.meyers@kp.org.



3. Personal management of health—such as health behaviors, resources, and beliefs

4. Health care financing and delivery—such as geographic location of services, insurance status and type, provider payment rates, linguistic and cultural competency, provider bias, and adherence to known care standards.

A broad variety of actors have roles to play in addressing each of the four arenas. Because the first three arenas sit outside of traditional health care boundaries, health systems and providers may naturally gravitate toward addressing issues in Arena 4, health care financing and delivery. While there are critical equity deficiencies in the delivery of health care that do need to be addressed, health systems and providers also have important roles to play in impacting socioeconomic circumstances (Arena 1), the physical environment (Arena 2), and their patients' personal management of health (Arena 3) through their roles as employers, educators, community members, and health leaders. Health care delivery organizations, health insurers, and individual clinicians must move beyond current thinking that attention to health disparities means focusing only on care processes that patients do (or do not) receive and into a broader perspective on how their actions and decisions impact health more generally.

Investing in Communities

Health care organizations and providers have clear potential to impact health disparities beyond the usual realm of care processes by investing in the communities they serve. Such investment can take many forms, including providing insurance dues subsidies for low-income community members; providing no-cost screening and treatment services through specialized health fairs or clinics; developing community health worker programs that bring health education to the community and provide meaningful volunteer or job opportunities to the health workers themselves; supporting and partnering with local safety net institutions; and providing longer-term investments in communities to address their most pressing health needs. Some examples of how Kaiser Permanente (KP) has approached these investments follow:

- For more than a decade, KP has partnered with community health centers to “improve the quality and cost-effectiveness of care, to help build effective clinic management infrastructure, and to collaborate on projects that reduce health disparities and promote a community-based system of disease prevention and management.”¹⁴ These safety net partnerships are being strengthened by more recent work with local health departments and public hospitals. Current areas of support include investment

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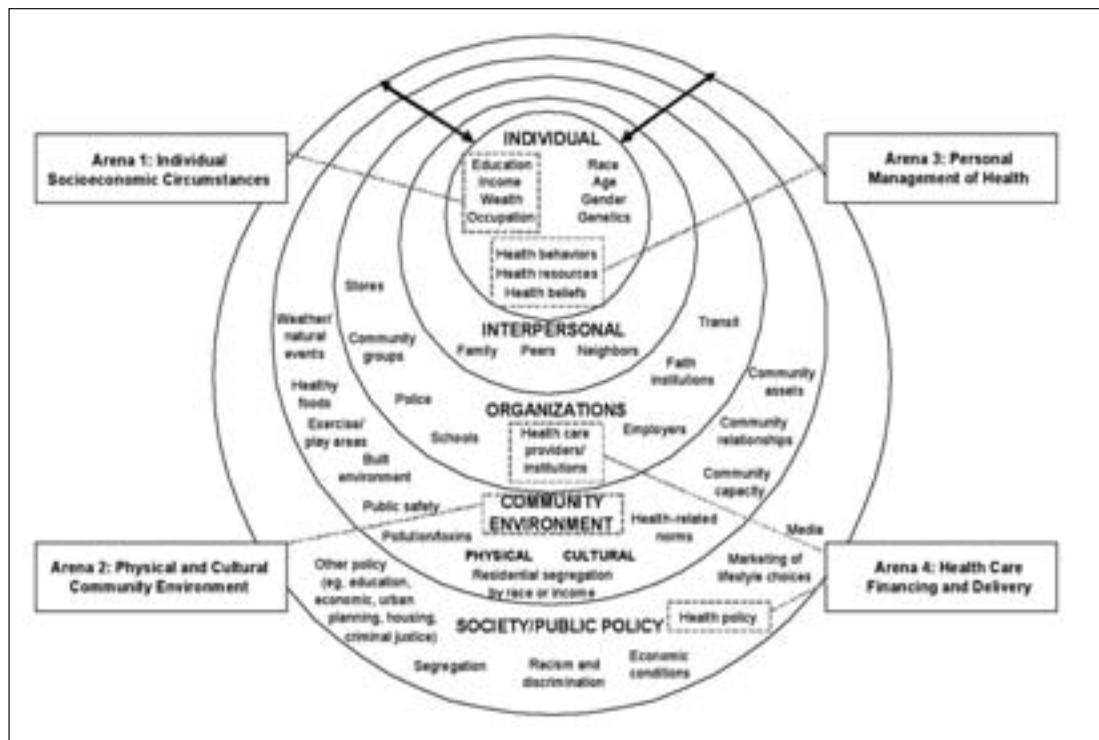


Figure 1: Landscape of influences on health disparities and arenas for policy action.

in health information technology; implementation of evidence-based treatment protocols for common chronic conditions; enabling KP physicians to deliver care and technical assistance in safety net settings; and connecting safety net health care teams to training in quality improvement processes through the Institute for Healthcare Improvement.¹⁵

- KP is developing Community Health Initiatives (CHIs) across its eight regions “by linking an evidence-based and prevention-oriented approach to medicine with community activism and proven public health interventions.” The focus of these CHIs is “Healthy Eating/Active Living” (HEAL) and the various health issues that can result from poor nutrition and inactivity. Some areas of emphasis within the CHIs are: focusing on small, defined geographic areas, working for change at multiple levels (eg, individuals, schools, workplaces, environment, policy); focusing on racial and ethnic disparities; committing to long-term partnerships (seven- to ten-year timeframe); and leveraging assets and strengths of the communities.¹⁶

Building Healthy Places

Despite advances in telemedicine, e-mail access to clinicians, and home care, the vast majority of health care delivery takes place within health care facilities such as hospitals, physicians' offices or clinics, and nursing homes. The continued dominance of “bricks and mortar” in health care means that opportunities abound to use more environmentally friendly practices in the materials and processes used in these medical and administrative facilities.

As capital investment in renovating and building health care facilities has increased in recent years, opportunities to use more environmentally friendly construction and design choices have grown. The *Green Guide for Health Care*, an educational resource for sustainable planning, design, construction, operations and maintenance of health care facilities, has helped provide health care systems with the tools they need to improve the health and impact of their buildings and practices.¹⁷ In recognition of some of the field's “early adopters” and innovators, National Geographic's *The Green Guide* newsletter has recognized America's top green hospitals based on 12 criteria: **siting** (locating facilities with consideration of impact on transportation, redevelopment, the surrounding environment); **water efficiency** (including landscaping, water use reduction, and waste water use); **energy use and air pollution**; **materials and resources** (using recycled or local building materials); **indoor environmental quality** (including ventilation,

use of toxics, and lighting); **healthy hospital food** (fresh, local, and organic options); **green education** (staff training); **procurement** (efficient and green products); **contaminants** (reducing toxins); **green cleaning** (use of cleaning products that do not release hazardous chemicals); **waste reduction**; and **healing gardens** (gardens, green roofs, low-water landscaping).¹⁸ These criteria demonstrate the variety of ways in which the decisions of health care providers impact their patients, the communities where they exist, and larger environmental and conservation concerns.

KP has been one of the leaders in such efforts to build healthier hospitals, medical office buildings, and administrative offices. The vision of its Environmental Stewardship initiative is, “to provide health care services in a manner that protects and enhances the environment and the health of communities now and for future generations.”¹⁹ To fulfill this vision, KP has focused on programs across the spectrum of environmentally responsible purchasing, green building, sustainable operations, chemical policies, and healthy foods. Some examples follow:

- For several years KP has been working to eliminate use of PVC (polyvinyl chloride) in its hospitals, due to the carcinogens created both in the production and incineration of this chemical. One major source of PVC is the backing used in carpeting, so when KP set out in 2002 to find PVC-free carpeting for its facilities, it used its purchasing power to encourage carpet manufacturers to pay attention to the contents of their carpets and how waste was disposed.²⁰ The national contracts were awarded to the vendor who was most responsive to KP's inquiries and requests, which ultimately led to the creation of PVC-free carpeting that is now being used across KP's facilities.²¹
- KP Colorado received the 2006 National Environmental Leadership award from Hospitals for a Healthy Environment for its work related to recycling, energy and water efficiency, reducing waste, and reducing the use of hazardous chemicals. Between 2002 and 2006, KP Colorado recycled more than 25,000 mercury-containing florescent lamps; recycled more than 1900 tons of paper and cardboard and 52 tons of plastic, and decreased the use and disposal of photo-processing chemicals by 70% by converting radiology to digital imaging in almost all cases.²²
- Starting with a pilot program in 1990, KP has implemented the use of reusable plastic totes instead of disposable cardboard boxes for distribution of medical supplies from its central supply ware-

As capital investment in renovating and building health care facilities has increased in recent years, opportunities to use more environmentally friendly construction and design choices have grown.

Access to healthy foods clearly impacts health, and differences in access by race make this an important factor in health disparities.

houses to each hospital and medical office building. Because cardboard and other paper materials make up almost half of a typical hospital's solid waste, KP's efforts to decrease the use of cardboard and minimizing the use of packing supplies (by having several sizes of plastic totes available) can serve as a model for similar programs in other health systems.²³

- In KP's renovation and construction of hospitals and medical office buildings, it is pilot testing innovative designs such as permeable paving and "green" roofs; reducing water use through landscaping design and use of urinals and toilets with lower water use; choosing nontoxic or less toxic building materials and cleaning products, and researching hazardous chemicals and working with vendors to identify suitable, safer alternatives.²⁴
- KP is also working to improve air quality in its communities by using more environmentally friendly fuels. For example, KP Northern California is in the process of switching from regular diesel fuel to biodiesel fuel (made from vegetable oil) for many of its supply transportation and courier trucks, aiming to reduce fossil-fuel emissions and air pollution. In addition, KP is now specifying cleaner thermal fluid boilers for its new facilities rather than smaller, more polluting "California specials" that have been a mainstay of the low-pressure boiler world for years.

These and other efforts to reduce air pollution, conserve resources, and reduce waste can provide broad benefit to the community and the environment. They

also have the potential to help reduce health disparities related to physical environmental factors such as pollution, toxins, or other harmful substances in the air and water, as people of color more have a much higher likelihood of living and working around such harmful substances compared to whites.²⁵ As health care organizations and providers conduct capital expansions and renovations, attention to the negative impact on their immediate (and the more global) environment and efforts to reduce that impact are important ways they can approach health disparities reduction beyond the financing and delivery of care itself.

Making it Easier to Eat Right

Media attention regarding what Americans eat and how that contributes to today's high rates of obesity is at an all-time high. Access to healthy foods clearly impacts health, and differences in access by race make this an important factor in health disparities. The greater prevalence of fast food outlets and liquor stores and lower prevalence of healthy food outlets in predominantly nonwhite or low-income neighborhoods have been documented repeatedly,²⁶ and are logical factors in greater overweight and obesity in those communities.

These differences in access to healthy foods can be addressed in part by actions and policies of health care organizations. For example:

- Since 2003, KP has established about 30 weekly farmers' markets at its hospitals and medical office buildings across the country.²⁷ As described by sponsor KP

Reaching Beyond the Clinic Walls to Address Obesity

By Jon Stewart, Health Policy Editor

Kaiser Permanente's (KP's) historic mission to serve not only its members, but the communities in which those members live, means that the organization has always looked for ways to reach beyond the medical setting and beyond clinical care to promote healthier communities. That has often meant working in the community to address health disparities related to minorities and socioeconomic status.

In Northern California, KP's Community Benefit program, for instance, is investing more than \$6 million to promote changes in public policy and community infrastructure related to the epidemic of childhood obesity in three lower-income, heavily minority communities in the Region. They include the predominantly Latino agricultural community of Modesto; the

heavily African-American city of Richmond, in the Bay Area; and the mainly Latino neighborhoods of south Santa Rosa. Called the Healthy Eating Active Living Community Health Initiative (HEAL-CHI), these five-year, \$1.5 million grants (plus additional funds for evaluation) are focused on promoting changes in four critical sectors in each community: schools, neighborhoods, workplaces, and health care.

Dana Williamson, KP project manager for the Santa Rosa grant, explains that the HEAL-CHI grants are specifically aimed at encouraging long-term, sustainable, and community-based strategies that go far beyond "merely educating people that they should eat more fruits and vegetables." To qualify for the grants, she says, community collaboratives were expected to

develop strategies to "make sure that those types of foods are available, affordable, and accessible in the communities. Similarly, it's not enough to tell people they have to get more exercise. Projects have to make sure that there are places in their community that provide and allow for safe physical activity."

The Santa Rosa collaborative provides a good example of how communities are taking advantage of the grants in this first year of funding. Lead by the Community Activity and Nutrition Coalition of Sonoma County and the Prevention and Planning Division of Sonoma County Department of Health Services, the collaborative has developed a detailed action plan that targets specific activities in all four sectors throughout the south fringe of the city,

Community Benefit, the markets were "... developed in collaboration with local health departments and community-based organizations ... to improve access to fresh, local foods for members, employees, and communities, and to provide a venue for health education and social marketing."²⁸

- KP has also focused on improving the health profile of food served in its facilities to patients, to employees, and to visitors, through catering, cafeterias, and vending machines. In addition to simply making more healthy options available and to revamping recipes to make them healthier, KP is piloting programs to serve more fresh, locally grown fruits and vegetables in its facilities. In Northern California, this focuses on small farms run primarily by ethnic minorities.²⁹

By helping to improve access to healthy foods—for patients, for employees, and for surrounding communities—health care organizations can help impact one of the critical aspects of personal management of health (Arena 2 in the model presented here).

Additional Opportunities

Although it is beyond the scope of this paper to explore in depth several other important opportunities for health care organizations to help reduce health disparities through the "nonhealth care arenas," they do warrant consideration. These include: employee wellness programs that encourage and support healthy behaviors and appropriate health-seeking behaviors; employee development programs that enable staff to learn new skills,

attain higher educational degrees, and potentially earn higher incomes in the future; and investing in internship or mentoring programs for students of color to help them learn about careers in the health fields.

Take-Aways

The complex nature of disparities means paying attention to only one policy arena is insufficient. Long-term solutions demand action to address factors in all of these arenas. The potential policy actors who could act to impact these arenas represent a broad swath of organizations and individuals, many of whom are already committed to working to address disparities—but who may have greater opportunities to address arenas currently seen as peripheral or beyond their scope.

Continued progress in the elimination of racial and ethnic disparities in health and health care will require integrated, interdisciplinary action from the affected communities and from the vast variety of organizations whose policies and actions impact their health and well-being. As health care organizations examine their current or future strategies, consideration of how they can positively impact the broad landscape of influences on disparities is essential to accomplish sustained, significant change. ♦

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which is a checkerboard of incorporated and unincorporated neighborhoods, most of which have major infrastructure gaps.

Already, funds have been allocated for two community garden projects and hiring a consultant to work with local restaurants and other food outlets to increase the availability of healthy food options. Project staff are also working with local residents on a "Photovoice" project—a social action strategy imported from China. Residents are given cameras and sent out to photograph what's working and what's not working in their communities, in terms of physical activity and access to healthy foods. They then share their pictures of things like streets with no sidewalks or crosswalks and stop signs, bike and pedestrian paths with poor or no lighting, and the shelves

of local mom-and-pop stores stocked with little more than canned goods, junk food, and alcohol. They pick several photos that they agree illustrate the most pressing needs, which they use as advocacy and communication tools in meetings with community leaders.

The project is also working in 11 local schools to implement nutrition and physical activity programs, including adding salad bars in five schools, starting three school garden programs, and training teachers to incorporate physical activity into their classroom curriculums. Worksite projects include working with two major employers in the area to pilot a worksite wellness program, and working with restaurants near major worksites to improve their menu choices. In the health care sector, the focus will be on

educating community physicians about BMI screening and training in communicating with families about obesity.

Anthony Taylor, a project coordinator with the Santa Rosa collaborative, says the involved residents there have already learned something important about how to maximize the impact of the KP grants. "We've discovered that there are a lot of people out there who are trying to do some of the same things we're doing, but for different reasons. They want more parks, they want community gardens, they want to fix the infrastructure. But they may be approaching these issues from very different directions and for different reasons—crime, personal security, recreation. But the end result is still the same—healthier communities." ♦

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Resources

- Kaiser Permanente Institute for Health Policy: www.kpihp.org/issueareas/improving/disparities.html
- Kaiser Family Foundation: www.kff.org/minorityhealth/disparities.cfm
- The Commonwealth Fund: www.cmwf.org/topics/topics.htm?attrib_id=12024
- Joint Center Health Policy Institute: www.jointcenter.org/new_site/index.htm
- RAND Center for Population Health and Health Disparities: www.rand.org/health/centers/pophealth/index.html
- PolicyLink: www.policylink.org/HealthAndPlace/default.html
- Prevention Institute: www.preventioninstitute.org/healthdis.html

Confronting the Uncomfortable: Health Plans and Health Disparities: A Moral Dilemma in a Morally Driven Industry

By Winston F Wong, MD

American medicine was traumatized when, in the 1970s, it was revealed that hundreds of African-American men were purposefully denied treatment for syphilis for decades at the Tuskegee Medical Institute.¹ For two centuries, American medicine had never confronted the mythology that the practice of medicine was above the fray of power structures that reinforced the status quo.

Historically, physicians have characterized their profession as the practice of the “art of medicine.” The Hippocratic oath inspires young doctors to apply biological knowledge to comfort and to help other human beings, regardless of their background. The complexity of human interactions leads to an infinite set of outcomes and expectations and, as an “artist,” a physician works earnestly to manage conditions resulting in comfort and wellness.

Health plans, in contrast, exist to efficiently organize thousands of individualized encounters by harnessing the power of technology and managing and parceling services to optimize health and mitigate the impact of illness for a defined group of individuals. In effect, health plans have become the invisible “third person” in the exam room, exerting a ubiquitous influence on what had been historically considered a hallowed relationship between physician and patient. Accordingly,

the predominant view of health plans (ie, insurers) is that of a necessary, but not altogether welcome third-party arbiter between patient and physician. The arbiter, in this case, has rarely been regarded as a positive force for change. (It should be noted that a number of health plans, eg Kaiser Permanente, are designed with the conviction that optimal outcomes are achieved when patient care incorporates “integrated” delivery, the result of a partnership between clinical provider and insurer. Nevertheless, physicians on one hand, and insurers on the other, represent dichotomous relationships to patients as *individuals*.)

In a generic sense, modern clinical outcomes are the result of physician-patient-health plan interactions. Indeed, thousands of hours and millions of dollars are expended annually to dissect the hidden factors that result in suboptimal population outcomes and adverse individual incidents. The resultant interplay between health plan and individual clinician ultimately defines the patient experience and the outcomes of the health care system as a whole. For the most part, America’s health care system, both heralded and maligned, examines itself through the lens of diagnosis, therapy, and delivery of care. Unfortunately, this

set of parameters falls short when applied to the *aggregate* impact of substandard care and outcomes provided to persons of color, ie health disparities. Our health care system, the composite product of health plans and clinicians, has yet rid “the damned spot” of discrimination and racial inequality and its concordant suffering.

The idea that clinical outcomes are bounded by the therapeutic relationship between patient and clinician results in physician-centric “solutions” to eliminate health disparities. But if we concede that health plans do indeed have a role in defining the clinical encounter, the “third person” in the exam room then might just have a major, if not decisive role in erasing the systematic failure to achieving equity in health care. Health plans wield powerful tools that can instigate positive health care outcomes. Health plans need to harness their assets, including the collection and analysis of copious data, the provision of incentives that accelerate the adoption of positive practices, and the establishment of benchmarks for standards and quality, to be effective change agents in eliminating health care disparities.

... diagnosis, therapy, and delivery of care. ... falls short when applied to the aggregate impact of substandard care and outcomes provided to persons of color, ie health disparities.

Winston F Wong, MD, is Medical Director, Community Benefit, and Director, Disparities Improvement and Quality Initiatives at The Permanente Federation in Oakland, CA. E-mail: winston.f.wong@kp.org.



Holding a System Accountable

In the landmark report, the Institute of Medicine's (IOM) "Crossing the Quality Chasm,"² six elements of quality were identified in health care; timeliness, safety, efficiency, efficacy, patient centeredness, and equity. The report concluded that our health care system consistently fails in all domains. Of note, the "equity" domain reflects a commitment wrapped in a core value of American democracy; a belief that all individuals are equal under law and are entitled to equal opportunity. In effect, calling out "equity" as an unaccomplished goal in health care, indicts not only the social conditions giving rise to disparate health, but also a health care system complicit in reproducing unequal access and outcomes. Thus, every instance in the continuum of providing health care, from accessing services to the patient-physician encounter, to referrals between providers, to obtaining emergency care and so on, can be examined as a contributor to inequity.

Elevating "equity" to a principle of an ideal health care system is an admission that disparate outcomes related to race and ethnicity are more than the aggregate impact of physician-patient encounters tainted by individual prejudice and stereotypes. There is no reason to suspect that American medicine has totally eradicated racist and xenophobic stereotypes from the profession, but the reproduction of disparities is much more likely related to a confluence of actions, decisions, and complacency within and by the organizations that deliver care. Thus data and research that paint a picture of disparate outcomes compel a thorough examination of the influences and decision processes that replicate unequal outcomes. Health plans have

the responsibility and accountability to evaluate their progress in achieving equity as diligently as any one of the IOM's other domains.

Data Paint a Sobering Picture

Race—A Social Construct

While science has thoroughly discounted "race" as a biologically defensible term, its influence on virtually every social interaction, particularly in the United States, is all but universally conceded.³ A purely biologic view of race would impute physiologic and biochemical causality for the more stark contrasts in disease burden and life expectancy. On the other hand, the recognition that racial categories are a social construct that continue to serve a particular role in defining power relations in American society implies that effective interventions that disrupt these associations are multitiered, residing above and beyond physiologic and linear solutions. Some observers suggest⁴ that racial categories, in essence, mask underlying class divisions in American society. Utilizing this framework, "race" is a proxy for "class," and health disparities are yet another by-product of economic and social inequality. As teleologically appealing as this theory is, it cannot explain why disparities persist between minorities and whites even when educational and income levels are adjusted to equilibrate socio-economic differences.

Persistence of poorer outcomes for any group of defined patients raises the specter⁵ of the usual suspects: that is, a disproportionate predilection to poor health, a lack of truly equal access to good care, and a breakdown in effective interactions between patients and the health care system. In the case of health care disparities, we find

that each of these factors is indeed operative and exacerbated by the confounding dynamics of race, power, and culture in the US.

Obesity

For example, Latino, African-American, Native-American, and Native-Hawaiian children are predicted⁶ to be two to four times more likely to develop diabetes in their lifetime compared with Caucasian children in the US. These predictions are based upon studies⁶ indicating a wide preponderance of elevated Body Mass Index ratios for children of these population groups, as well as current trends in diabetes rates among adults of these racial and ethnic groups. Whereas researchers grapple with understanding the complex interaction between genetic predisposition to insulin resistance and diet and lifestyle, there is also the cold social reality that children from these groups are less likely to have access to an array of food choices, recreational facilities and activities that stave off obesity and prevent the onset of disordered metabolism, the physiologic underpinning of diabetes.⁷⁻⁹ The pathogenesis of diabetes in America is arguably rooted in conditions resulting from unequal opportunity and deferred investments in community and economic development. Consequently, among young adults with the highest diabetic "risk factors" are those who grew up in poor minority neighborhoods.⁷⁻⁹

Nor does the influence of race on health outcomes confine itself to childhood. Recent studies examining hypertension among African-American men suggest that a lifetime of recurrent physiologic pulses of cortisol, one of the body's hormonal responses to stress and conceivably, responses to recurrent discrimination, could induce

Some observers suggest⁴ that racial categories, in essence, mask underlying class divisions in American society.

the development of persistent hypertension. When viewed as a precursor to hypertension, “African American” might be more accurately considered a condition related to a specific life experience, rather than simply a term associated with physical features or ancestry.

Lack of Access

Compounding the disproportionate prevalence of harbingers of poor health is the difficulty minority groups have in not only obtaining health insurance,¹⁰ but securing a reliable source of health care that meets their needs. Race and ethnicity are highly correlated with lack of health insurance in the United States.¹¹ Of the estimated 47 million Americans without health insurance, 15% are African American, and 29% are Latino, representing a disproportionate level relative to their percentage of the total American population.¹⁰ Moreover, in communities comprised of a high percentage of recent Asian immigrants, some studies have shown alarming rates of uninsured (eg, Alameda County, CA where 30% of Asians were uninsured).¹² Therefore, proponents of an American form of universal health insurance might foresee a future where inequities in health care on the basis of race wither away. This optimism should be tempered by another sobering aspect of unequal access. As the Agency for Healthcare Quality and Research has reported,¹³ even among African Americans and Latinos who have medical insurance, there are consistently higher levels of dissatisfaction in getting care for illness or injury in a timely fashion as compared to Caucasians. And, to make matters even worse, the gap regarding satisfaction with timely care actually increased among African Americans vs Whites as educational levels increased. For groups that have

a greater percentage of non-English speaking individuals, eg Asian Americans, adults reported a significant higher level of dissatisfaction with clinician communication, as exhibited by clear explanations and listening skills.¹³ Again, identifying lack of access to health care as a determining factor in health disparities requires a more detailed understanding of the nuances of obtaining care when one is minority, immigrant, and non-English speaking.

African-American Mortality

Among the most shocking indicators of health care inequities is the standardized mortality rate for African-American men over the last 50 years.¹⁴ That is, over the last 50 years, African-American men continue to experience a mortality ratio of 1.5 compared with European-American men.¹⁴ Put in another way, despite investments in addressing social inequality in our schools, housing, and environmental conditions, African Americans, as a group, exhibit a 50% higher mortality ratio than Caucasian Americans.¹⁴ Although great pains are made to emphasize that disparities exist in health status, as impacted by social determinants existing outside the health care system, it is also true that *even when African-American men receive health care, they die sooner*.¹⁵ David Satcher, MD, former Surgeon General of the United States, further elaborated that if mortality rates for African Americans were comparable to Caucasians, 80,000 fewer African Americans would die yearly.¹⁴ Numerous other studies¹⁶⁻¹⁸ illuminate apparent contributors to this failing report card: the disparity of African-American men compared with Caucasian men in terms of percentage receiving life-saving invasive interventions for myocardial infarctions,¹⁶ the rates

of kidney disease associated with poorly controlled diabetes,¹⁷ and the higher incidence of aggressive colon and prostate cancers.¹⁸

Obstacles

Studies¹⁸ confirming that African-American men are impacted by decision making or health care delivery design that renders suboptimal care raise ethical concerns that confront the very nature of healing and the practice of medicine. Faced with this sobering reality, clinicians are morally obligated to reflect whether the care they provide in each individualized encounter is characterized by inherent bias or stereotypes. Euphemistically referred as “clinical” thinking shortcuts, these subliminal, and occasionally explicit prejudices, work to embed unequal processes and outcomes in medicine.¹⁹⁻²² Furthermore, because all clinicians provide care within the context of a delivery system, the system itself becomes an accessory in replicating unequal processes resulting in disparate outcomes.

Even a relatively innocent and well-meaning directive, such as obtaining a mammogram at the local hospital or medical center, can become an insurmountable obstacle for a woman who does not speak English, relies on public transportation, and is uncomfortable with the notion of disrobing for what she considers a procedure with dubious intrinsic medical value.²³ A failure in obtaining such a procedure is conventionally (and conveniently) attributed to patient incompetence or noncompliance, but in fact, could be just as aptly attributed to a system’s inability or unwillingness to deliver care that is free from bias.

... clinicians are morally obligated to reflect whether the care they provide in each individualized encounter is characterized by inherent bias or stereotypes.

An assumption that care is provided without bias or discrimination may often be revealed as something other when seen from the eyes of groups who encounter recurrent patterns of care and service that reflect the values, capacities, and stereotypes of the dominant group.²⁴

The Role of Health Plans in Addressing Health Care Disparities

Faced with the daunting nature and complexity of health disparities in American medicine, health plans face an unsettling reality: variation in care and outcomes is not random. While unwanted variation is never good, variation associated with a demographic characteristic is worse, and worse yet when the defining demographic feature is increasing. Health plans and clinicians must adapt to providing health care to a population that is increasingly non-white, non-European, and non-native English speaking with diverse cultural and religious beliefs. A health plan must work with clinicians to minimize unwanted variation and manage resources to optimize care for a target population especially in wake of dramatic changes in its composition.

Data on Race

Faced with the uncertainty of persistent unacceptable variation in quality and outcomes most²⁵ health plans are at least evaluating the practicality of collecting racial, ethnic, and linguistic background of their members. In some instances, health plans are being required to report some rudimentary data on race and ethnicity by regulatory bodies as sanctioned by government. Operational challenges about

policy needs when plans evaluate how, when, and what data is to be elicited from members and subscribers. Nonetheless, groups such as the Hospital Research and Educational Trust and the Association of Health Insurance Plans have actively promulgated²⁶ responsible approaches to the collection of race, ethnicity, language, and socioeconomic status. There is currently no major health plan that can claim that a majority of their subscribers have been identified by race and ethnicity. Despite dispelling the misconception that the collection of race and ethnicity data among health plan describers is illegal, advocates of this data collection continue to face misgivings regarding the reliability and applicability, and thus, the inherent value of such data. Indeed, the “problem” of collecting data has begun to supersede the problem of health care disparities in the first place. Health plans, faced with the expectation from payers and consumers to demonstrate value as exhibited by performance and transparency, will inevitably confront race and ethnicity as a predictor of suboptimal outcomes. Those with capacity to aggregate data for race and ethnicity will be in the advantageous and enviable position of reducing risk among its subscribers, while at the same time delivering on their social contract to provide optimal health. Disease and population management approaches could be optimally designed utilizing data that illustrate characteristics of health care received by minority groups. Data likewise provides the opportunity for robust research and quality improvement initiatives regarding the epidemiology and health care of racial and ethnic groups, which can be shared among other health plans, resulting in improved care for all.

Cultural Humility

Cultural competence has emerged as a central component vital to effective care for patients and populations. The recognition that our health care system has been characterized by a historic lack of sensitivity and a certain callousness towards patients who are not of the Western European culture has propelled a greater appreciation for the diversity of America, and the need for health care organizations to not only accommodate, but indeed to embrace cultures from other global regions.²⁷ Thus, health plans are now employing a number of training programs to educate and to sensitize staff to issues and in skills necessary to care for patients of diverse cultures.²⁸ Health plans ought to play a critical role in both endorsing and promoting such activities. Yet it would behoove any plan not to equate cultural competence training as a commensurate response to the complexity of health care disparities. Although cultural competence can help decrease the communication barriers between patients and clinicians, it cannot, in isolation, address systematic issues that are rooted in unequal access and resource allocation that reproduce barriers to care.

Linguistics

Closely related to cultural competence is the provision of hospital and medical services in languages that meet the needs of both non-English-speaking and literacy-challenged populations. Across the continuum of patient care, compromises are continually endured by individuals who do not communicate using college-level English.²⁹ Health plans need to leverage their role in setting standards of care in clinical settings to provide services that assure safety and quality for all patients, regardless of their facility with English. Break-

Those with capacity to aggregate data for race and ethnicity will be in the advantageous and enviable position of reducing risk among its subscribers, while at the same time delivering on their social contract to provide optimal health.

downs in continuity of care, patient adherence to therapeutic regimens, safety precautions, transitions in care, patient education, and critical care interventions are often linked to poor communication stemming from linguistic barriers.^{30,31} Health plans need to invest in structures, systems, and processes that reduce communication barriers.

Entry Points

Access to care encompasses at least three entry points. From a macroeconomic view, health plans are accountable to consumers and purchasers to provide affordable health care and ideally to control the costs of health care. When costs spiral upwards more individuals—and disproportionately, more minorities, become medically uninsured. However, as stated earlier, providing affordable health insurance, and even ultimately providing universal coverage, would not dissipate issues related to the lack of a health care home and/or primary care clinician to a great proportion of minority patients. Plans must actively recruit physicians and other clinicians who are skilled and dedicated to the particular needs and interests of minority communities, and must actively reach out to communities that have not been engaged with health care institutions. Additionally, once health plans demonstrate capacity to involve patients from minority groups in shaping their health care needs, they need to assure that the systems and processes surrounding the provision of care are tailored to provide optimal service to diverse populations.

Leadership

Ultimately, the elimination of health disparities will coincide with great leaps in progress in addressing the social inequities of our society. To the extent we can identify and act upon the progeni-

tors of poor health and shortened life expectancy, ie the environment, the lack of social, economic, and educational opportunity, and the impact of racism experienced by communities and individuals, the perpetrators of disparate outcomes will regress. Health plans, by the very nature of their roles in facilitating the healing interaction between clinician and patient, can stand to either impede progress or catalyze actions that lead to the elimination of health disparities. Complacency is, in the final analysis, culpability. With that recognition, health plans, in fulfilling their obligation to provide a reliable, safe, and secure system of care to millions of users, must also assume a leading role in demonstrating a commitment to abrogate the destructive role of racism and social injustice upon the health care of all Americans. ♦

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Things That Matter

Our lives begin to end
the day we become silent
about things that matter.

— Reverend Martin Luther King, Jr, 1929-68,
Nobel Peace Prize winner and civil rights activist

HIV Today: What's Encouraging; What's Discouraging

By Lee Jacobs, MD

This and the next few issues of *The Permanente Journal* will have several excerpts from presentations at the 2007 Fifth National Kaiser Permanente (KP) HIV/AIDS, STD, and Hepatitis Conference held in April in Napa, CA.

I remember the first HIV meeting held in the mid1980s: it was the first interregional conference convened by KP on a clinical topic. I doubt anyone attending that meeting could have foreseen the tragic impact this virus would have on people throughout the world.

What's Encouraging

During the past few years, there has been real progress in controlling this infection—in the United States and in the developing world. Prenatal transmission in the US is now rare. Viral suppression can be effectively sustained with antiretroviral agents. With the use of antiretrovirals, opportunistic infections have decreased and subsequently the death rate from HIV has fallen dramatically. Rapid HIV tests provide immediate results in cases of occupational exposure and when women with undocumented HIV status arrive for delivery. In the developing world, there is availability of testing and antiretroviral therapy (ART).

What's Discouraging

Even though there is much to find encouraging, there is still much that is discouraging. There is still a steady

rate of HIV acquisition. There are over one million people infected with HIV, 25% of whom, between 250,000 and 300,000 people, are unaware of their HIV infection—and they are infectious! Despite probably being the most knowledgeable group, men having sex with men continue to represent the majority of new infections. Widespread opt-out HIV testing is not being done; thus, patients are only diagnosed when they present with a preventable opportunistic infection. Despite tremendously effective medications, poor adherence by patients results in viral mutation and subsequent failed suppression is all too common. The developing world still has ART acquisition and distribution problems. Although it remains promising, therapeutic and preventive vaccines probably will not be available in the near future. And still there is no cure for HIV infection.

Challenges for the Next Decade

Many perplexing questions highlight challenges for the next decade: Why would a person aware of the risks participate in risky behavior in the face of such a deadly disease? Why would a person who has engaged in risky behavior not present for testing while they are asymptomatic? Why would a person not take their ART medications when the risk-benefit ratio is clear? Take it correctly, you live; don't take it, you die. What will happen to developing countries

when the first wave of antiretrovirals lose effectiveness and newer, more expensive agents are needed?

What Can You Do?

All members of the care system need to be vigilant and to intervene to diagnose the unknown infected early and then take steps to encourage appropriate adherence with therapy.

Specifically, practitioners and other members of the health care team can:

1. Order HIV testing on all patients using the "opt out" approach
2. Take sexual histories as part of all general evaluations and educate as appropriate
3. Continue to emphasize the importance of never missing a dose of ART
4. Offer your professional services to agencies, churches, or other organizations assisting countries throughout the world devastated by this epidemic.

Conclusion

Yes, after 26 years, there is some very encouraging news; there have been major strides forward as a result of ART. However, there is still much to be done if this epidemic is to be slowed pending a future cure. As individual clinicians and health care organizations, we can adopt interventions that will decrease the incidence of new infections and improve the quality of life and longevity of those already infected with this virus. ♦

Lee Jacobs, MD, is an infectious disease consultant for The Southeast Permanente Medical Group in Atlanta, GA, and he is Associate Editor-in-Chief of *The Permanente Journal*. E-mail: lee.jacobs@kp.org.

Narrative Medicines: Challenge and Resistance

By David B Morris, PhD

"Take two short stories and call me in the morning."

—Anonymous

Narrative medicine as a relative newcomer continues to attract serious attention among health care professionals, despite the puzzlement of medical insiders who wonder what this alien creature is. Rita Charon, MD, PhD, founding director of the new program in narrative medicine at the Columbia University College of Physicians and Surgeons, offers a clear description: she uses the term *narrative medicine* to mean medicine practiced with "narrative skills."¹ This usage, although it entails further inquiries into the nature of narrative skills, clearly raises the question of what constitutes narrative. In her 2001 groundbreaking article "Narrative Medicine,"² Dr Charon offers a definition that parallels the account by novelist-philosopher Richard Kearney, who immediately puts nonphilosophers at ease with his plain-talk claim that all narrative shares the common function of "*someone telling something to someone about something*."^{3p5} Patients are always telling something to physicians, of course, and physicians are always telling something to patients—so maybe narrative isn't so alien to medicine after all. Lewis Mehl-Madrona, MD, reminds fellow physicians that their work, despite a biomedical emphasis on drugs and surgery, is saturated in narrative: "We may talk drugs while Bantu healers talk herbs. We may talk surgery while a Dene healer talks about a many-day Blessing Way ceremony, but there is a similarity: we are in dialogue. We are co-creating a shared story of healer and patients/families/communities wherever we go. We are immersed in the act of storytelling."⁴

Yes, but are power brokers in medicine actually *listening*? If listening, are they openly or secretly (in some inner sanctum of deep untouchable values) digging in their heels and *resisting*?

The Landscape of Resistance

It seems futile to deny that narrative medicine, despite impressive recent achievements, evokes strong resistance. Even if skeptics agree that both are telling stories, indigenous healers and science-oriented physicians engage in storytelling that proceeds from incommensurate systems of belief. Science-oriented physicians, that is, tell stories that resist identification as stories. Narrative

medicine needs to understand the resistances it evokes, including a resistance to identifying standard biomedical practices as narrative. It also needs to examine its own acts of narration. Dr Mehl-Madrona, for example, constructs an *us/us narrative* in which a doctor addresses his fellow doctors ("we"). The article constructs a nonfiction space of like-mindedness distinct from the conflict-torn arena that Mr Kearney calls *us/them narratives*: human vs alien or cowboy vs indian.^{3p79-121} As a writer-scholar affiliated with a medical school but without a degree in medicine, I am a semi-outsider, but as an outsider I feel a sharp dissonance between the fantasy of a medical consensus over narrative and the entrenched skepticism I meet when speaking to physicians about narrative medicine. "What you say about narrative is very interesting," I hear repeatedly. "Thanks so much for coming. But I have seven minutes per patient." End of story.

Medical resistance to narrative medicine taps into valid concerns about the management of time, but physicians are not the only resisters. Some patients say they prefer skilled technique to good bedside manner. A preference for brusque skill is not necessarily misguided, especially for well-informed patients as busy as their doctors, and many patients cling to the fix-it model of a no-nonsense physician who holds all the answers. A patient-centered resistance to dialogue reminds me of the comedian who complained that he went to his doctor for a sprained ankle and came out with diabetes. (Less talk equals less bad news.) Patients and physicians moreover meet within a system that defines their relation as asymmetrical—in power and knowledge—thus skewing a paradigm in which storytelling traditionally reduces the distance between narrator and listener. (Think of the bond reinforced when a parent reads a child to sleep or when suspense draws us closer: "Listen my children and you shall hear ..."). Biomedicine may resist narrative medicine in part because narrative implies a threatening erasure of professional distance and authority. Meanwhile, some patients will reject any medical outreach that looks like bogus intimacy or veiled paternalism.

Resistances to narrative medicine are real, both among patients and physicians, and cannot be wished away



David B Morris, PhD, is a Professor at the Center for Bioethics and Humanities at the University of Virginia School of Medicine in Charlottesville and the Founding Co-Director of the Taos Writing Retreat for Health Professionals in New Mexico. E-mail: dbm6e@virginia.edu.

in a dream of frictionless consensus. When George L. Engel, MD, first recommended the new biopsychosocial model, for example, he subtitled his famous 1977 essay “A Challenge for Biomedicine.”⁵ Resistances to a biopsychosocial model were—maybe still are—in part a response to the serious challenge it posed to biomedical principles and power. The challenge of narrative medicine, however, extends beyond patients and doctors, beyond even biomedicine. It also challenges proponents to clarify their basic concepts and to demonstrate their basic claims. Narrative medicine has in fact attained enough prominence that the time seems right to face even its own internal disagreements. This self-confrontation promises not only to clarify principles but also to reveal benefits (beyond better patient care) that narrative medicine holds for doctors.

Narrative Knowledge or Narrative Therapy?

The most influential discussion of narrative medicine, Dr Charon’s 2001 article in *The Journal of the American Medical Association (JAMA)*, insists that narrative is above all a form of knowledge. Narrative knowledge, in her account, complements (although it differs from) what she calls medical “logicoscientific” knowledge.² She sees two main roles for this narrative complement. First, narrative is a *source* of knowledge. It provides physicians with information as medically relevant as numerical data about pulse and respiration. Second, narrative is an *instrument* of knowledge. As an instrument, narrative requires skillful technique for its effective use, like a scalpel, and Dr Charon invokes an academic tradition of testable skills when she describes narrative (in the lexicon of medical education) as a “competence.” Narrative competence, in Dr Charon’s summary, implies the skill and experience necessary so that physicians may exercise the knowledge crucial to their profession. Narrative competence serves professional functions beyond the treatment of illness, from inspiring trust to promoting empathy, but the cultivation of a good bedside manner (preferable, surely, to a bad bedside manner, cultivated or not) isn’t among them.

Narrative knowledge differs significantly from narrative therapy. Clearly they can be related, and they are not inherently in conflict, but their differences matter. For example, Dr Mehl-Madrona tells several compelling stories—about Terry, cured after a 24-year history of irritable bowel syndrome, and about Bernard, a cancer patient now seven years cancer free—in which recovery accompanies both narrative intervention initiated by the physician/friend and life-changes initiated by the patient.

Narrative, in these cases, seems therapeutic. It accompanies, advances, or accomplishes a healing that Dr Mehl-Madrona describes as unresponsive to biomedicine. He also describes narrative skills in doctors and patients as mostly automatic. As moviegoers, theater buffs, and natural-born talkers, we are all experts in the understanding and creation of stories. “We have been doing it,” he writes, “for longer than we can remember.”⁴

Dr Charon, by contrast, wants certified professional competence and medical training in narrative. In fact, her account draws upon decades of scholarly analysis in the field of narratology, where competing theories abound.⁶⁻⁹ Narrative competence for Dr Charon implies that our native expertise is merely the starting point for extensive relearning: a process analogous to the relearning that occurs when medical students are taught professional skills at interviewing, even though they are natural-born questioners. Such learned and relearned narrative skills have uses extending far beyond therapeutic interventions that facilitate rare, if dramatic, recoveries or that indirectly improve quality of life. They encompass multiple everyday applications that provide doctors with medical knowledge—about behaviors and lifestyles and preferences—as vital as data on cholesterol levels or blood pressure.

The competence that Dr Charon recommends as indispensable for the professional use of narrative finds a clear illustration in the concept of *narrative situation*. A narrative situation shapes every story by governing who speaks about what, to whom, when, and where. Drs Charon and Mehl-Madrona, for example, both write to fellow doctors about narrative, but their narrative situations otherwise differ greatly. Dr Mehl-Madrona writing in *The Permanente Journal* is freer to pursue clinical storytelling in a memoir-like style. Dr Charon’s claim that narrative knowledge *complements* logicoscientific knowledge, by contrast, is an effective strategy for an article appearing in the citadel of biomedicine, *JAMA*. Her argument for narrative knowledge as a “complement” to logicoscientific knowledge does not directly challenge biomedical principles but rather appears to buttress them and (in shoring up any weaknesses) to assure their dominance.

Knowledge, even narrative knowledge, is power, but Dr Charon’s somewhat delicate narrative situation rules out the rude question of how far biomedicine, as a system of power, will accept a copartnership with narrative medicine. A new copartnership will change biomedicine, of course, much as yin changes yang, not least by redefining them as mutually incomplete and inseparable. A biomedicine possibly *changed* by nar-

Narrative competence, in Dr Charon’s summary, implies the skill and experience necessary so that physicians may exercise the knowledge crucial to their profession.

Unlike biomedicine, for example, narrative medicine utterly depends on the concept of intersubjectivity.

rative medicine is correct to see a threat to its identity and power. Dr Mehl-Madrona, in contrast to Dr Charon, writes from a narrative situation deeply informed by Native-American and indigenous traditions, within which stories (associated with knowledge and power) are not separable instruments of professional competence but rather inseparable signs of an entire worldview. This worldview understands health through concepts of living in balance with oneself and the world, including the local community and the spirit realm, and it understands stories as actively promoting or restoring balance. Here too a biomedicine that accepts or honors such a worldview, rather than simply adopting a few exotic therapeutic tools, is correct to see a threat to its professional identity and power.

Drs Charon and Mehl-Madrona both write from personal stances that defuse the potential threat posed by narrative medicine, but their recommendations imply ways of thinking about knowledge and about its legitimate sources that are bound to inspire resistance. Unlike biomedicine, for example, narrative medicine utterly depends on the concept of intersubjectivity.

An Intersubjective Model: Story as a Verb

For decades American medical students have memorized the familiar acronym that identifies the patient as subjective and the physician as objective, or at least as the official agent of objective fact: SOAP (*subjective, objective, assessment, plan*). Narrative medicine right at the start challenges this slippery assumption about a clean division between subject and object. True, common sense finds it hard to give up the reassuring binary division of the world into perceiving subjects and objects perceived. This ancient mind/body dualism—reinvented by Descartes to legitimize the body as a site for scientific knowledge—no longer coincides with what many patients understand about health and illness. (Their allegiance to conventional and alternative medicine—and to various mind/body practitioners—is well documented.) Quantum mechanics and narrative theory both renounce objective certainty as inapplicable to their fields of thought. Dr Charon, in this spirit of resistance, refuses to describe narrative knowledge as soft and subjective, in contrast to logiscientific knowledge in all its glittering hard objective truth. Narrative medicine is not practiced in some spongy nebulous province of unknowable subjectivities. The knowledge that narrative produces is not subjective or soft—ie, scientifically invalid—as opposed to objective hard data. Narrative medicine instead challenges the false binary of knowledge that is soft or hard. It asks what buried sexual

politics underlies medical metaphors of softness and hardness—and why doctors even *need* these worn-out tropes? It challenges biomedicine not to reject scientific method—it won't—but to rethink the concept of a knowledge that is neither purely objective nor purely subjective but, impurely and pragmatically, intersubjective.

Intersubjectivity does not translate into the moronic caricature that everything is relative. Everything *isn't* relative. Instead, it posits a knowledge constituted by a process of dialogue in which two or more subjectivities reach agreement (or reach a knowledge of their disagreement). Such knowledge, obviously, is not trouble free. Innumerable subjectivities once agreed that the world is flat, and they were flat-out wrong. Still, intersubjective knowledge is always open to change, and the process of change is far more complex than an intellectual morality play in which good science drives out bad science. From an intersubjective perspective, lab reports and numerical data both depend on multiple human subjects. They require consensus on methods for verification, on standard operating procedures, on legal and economic arrangements. Tests are open to false positives as well as to interpretation, fraud, or error. Yes, the truth claims implicit in lab reports don't resemble the claims of obvious fictions, such as, say, *Little Red Riding Hood*. To repeat, it *isn't* all relative. An intersubjective model nonetheless insists that its knowledge is constructed, and thus the grounds of its constructedness are always open for analysis. Despite its rejection of an illusory Cartesian mind/body split, which, incidentally, most pain specialists also reject, narrative knowledge is not cast adrift on a sea of relativism but navigates real variations among competing claims—patient, family, lab, intern, resident, attending physician, chief of staff, insurer, hospital attorney, and government agencies. The knowledge that emerges—provisional, inherently open to revision—embodies the dilemmas of an intersubjective model.

Over lunch, palliative care specialist Walter Forman, MD, and I tried to imagine an alternative to the medical-student indoctrination in SOAP. PLAN (*patient-lab-assess-negotiate*) is our new and improved SOAP. The patient/lab dyad replaces the misleading subjective/objective split, free from its loaded value-judgments. It does not label the patient as inherently less reliable than laboratory data. (The lab, on occasion, may be wrong and the patient right.) Both acronyms feature analysis and planning. Our strongest innovation was to add the imperative *negotiate*. The concept of negotiation recognizes that doctors do not plan alone, like a general laying out late-night strategy for tomorrow's campaign.

Wherever possible, patients must be consulted, but not simply as a matter of etiquette. Their bodies, their choices, their lives are at stake. They can undermine treatment with noncompliance, despite the best-laid medical plans, and they can aid recovery through a partnership that views medicine, like narrative, as inherently intersubjective.

Narrative requires full-body immersion in an intersubjective model because—as Mr Kearney observes—it “takes two to story.”³ *Story* for Mr Kearney resembles an action-verb more than a noun. Stories are less the work of individual authors, even if individual authors write them, than plural, coauthored events that depend also upon readers or listeners. Slippage appears as soon as you open *Hamlet*. “O that this too too solid flesh would melt.” Or: “... too too *sullied* flesh”? An editor decides. Experienced theater-goers may hear both adjectives in a ghostly duet. Moreover, *Hamlet* is rarely performed uncut. So *Hamlet* is the product of a collaboration among author, text, director, actor, audience, not to mention reviewers, critics, and scholars. This intersubjective matrix looks like the ninth circle of hell to orthodox proponents of the scientific method. Is it, however, really so alien to medicine? No physician could give a logicoscientific answer to the question of whether my father was an alcoholic. Chronic pain is notoriously hard to treat effectively. So too are depression and dementia. Doctors, to their credit, assist patients on this difficult, dangerous, uncertain ground—where the scientific method does not hold all the answers—but biomedicine resists (as if its life depended on it) the idea that such assistance involves narrative.

The verb-like quality of narrative is especially clear and troubling when stories change. Proponents of narrative sometimes speak about getting the patient’s story—as if narrative were an extractable unchanging nugget of data. Stories change depending on the narrative situation. A 50-year-old African-American woman may not tell the same story about sexual abuse to a 20-year-old white male intern that she tells to a 60-year-old African-American female gynecologist. Stories may alter with each retelling, as a hilarious joke may bomb in unfriendly circumstances. The inherent variation of narrative raises serious questions about its validity and credibility. It is hard to trust a story that tomorrow may take a 90-degree turn. Still, lives are like that. In the metaphor drawn from books and narratives, people do turn over new leaves. Physicians do not expect fevers to remain unchanged. Cancer and depression do not continue in a steady state. The verb-like variations implicit in narrative would seem relatively

unproblematic for physicians who deal every day with humans and diseases that unexpectedly change course. Narrative competence provides a framework for dealing even with certain stories that calcify into ritual recitations—like in-house myths about sickle cell patients and drug-seeking behavior—offering a way to identify and to critique troublesome sociocultural issues often invisibly at work in calcified medical behaviors or in static patient complaints. Stories, as Mr Kearney emphasizes about narratives of national identity, can trap as well as liberate. Illness narratives too can prove harmful or helpful, which is why they need to be examined. The variableness inherent in narrative includes, among its compensating benefits, the possibility to correct harmful illness narratives (such as the myths surrounding HIV/AIDS) and to replace professional narratives of identity that entrap physicians in a limiting conception of their own powers and competences.

Narrative competence, in short, offers guidance for negotiating the dilemmas of an intersubjective model. A biomedical corollary seems evident: “It takes two to doctor.” Resistance to this corollary may recognize that narrative medicine and its intersubjective model constitute a threat to the biomedical model. Resistance may also signal that the time is drawing closer for the emergence of a philosophy of medicine that integrates apparently contrary impulses in a new synthesis (rather than cobbles them together under the victory banner of biomedicine). Can Western health care forever accept a dual track system in which logicoscientific knowledge dances the old subject/object two-step while its young partners (narrative medicine and mind/body medicine) tango away into the new world of intersubjective doctoring?

Narrative Constructedness: Patients Are Stories

Rachel Naomi Remen, MD—pediatrician, therapist, medical educator, author—puts it this way: “Everybody is a story.”^{10pxxvii} Not everybody *has* a story—in the sense that everybody has a nose or a mother or a suitcase—but rather everybody *is* a story. Pediatrician and novelist Perri Klass, MD, medicalizes the same point. “Every person is a story,” she writes, “every patient is a story.” Doctors too. As Klass adds: “When I admit a new patient to the hospital, I start writing the endings in my head.”^{11p323} Minus story, that is, doctors are technicians in the dark, without a clue beyond textbook natural histories of disease, and patients are no more than mute featherless bipeds bearing signs and symptoms. If stories make us human, a medical encounter that subtracts narrative might as well

Stories are less the work of individual authors, even if individual authors write them, than plural, co-authored events that depend also upon readers or listeners.

subtract liver, heart, and respiratory system. As philosopher Alasdair MacIntyre contends, "... we all live out narratives in our lives ..." and "... we understand our own lives in terms of the narratives that we live out" ^{12p197} Other philosophers and neuroscientists now pursue good evidence that both human identity and human consciousness are fundamentally narrative constructions. ¹³ The relatively recent discipline of narrative psychology looks at all human life as inherently "storied." ^{14,15} In studying the life stories that people construct, psychologist Dan P McAdams, PhD, finds that these narratives guide behavior, framing how we see ourselves in the past, present, and future. ¹⁶

Narrative medicine is not, from this perspective, a time-intensive luxury gumming up the works with needless chatter or at best feel-good talk but an extension of medical practice crucial to getting and using knowledge needed for the care of patients. The key point is that narratives, like personal identities or postmodern cities, don't just exist or arise: they are *constructed*.

There are, as bioethicist Tod Chambers, PhD, summarizes the consensus among narratologists, "no artless narrations." ^{17p25} Every narrative, without exception, is *constructed*—through conscious or often largely nonconscious choices about what to include, exclude, highlight, or downplay. This *constructedness* is at issue (not aesthetic value) in the claim that no narrative is artless. Even nursery tales reflect choices about what is valued, marginalized, and excluded: *Little Red Riding Hood* exists in at least 17 different English versions since the 17th century. ¹⁸ Even a typical children's book, then, embodies a principle of constructedness, which is easy to confirm by imagining a 21st-century version in which Little Red Riding Hood actually possesses a name, tells her own story, dispatches the wolf, restores her grandmother, and ditches the trademark red cloak for outerwear with some style and attitude—like Princess Di in a Philadelphia Eagles jacket.

Every narrative, even absent an identifiable narrator, proceeds from a specific point-of-view or, as often in film, from multiple points-of-view. Screenwriters in scripts abbreviate the inescapable hyphenate as POV. ¹⁹ Although medical studies prefer a POV that aspires to seem impersonal, impersonality in language (like Swiss neutrality in geopolitics) is clearly a mode of constructedness. Television and newspaper reporters openly use the term *stories* for work that they regard as unbiased, impartial, balanced, or objective. Findings from randomized double-blind experiments regularly end up as teaser headlines. Even meteorological data, as novelist EL Doctorow observes, are reconstructed on television with

attention to narrative elements such as conflict (high-pressure areas *clashing* with lows) and suspense (tomorrow's prediction coming only *after* the commercial). "I am thus led to the proposition," he writes, "that there is no fiction or nonfiction as we commonly understand the distinction: there is only narrative." ^{20p26}

Narrative theorists claim that there is no God's-eye POV. Every text constructs the inherently limited standpoint from which it speaks, even when it ignores, confuses, or multiplies point-of-view. A specific POV necessarily entails blind spots, since a linear narrative can't see or say everything at once. A specific POV also embodies silent assumptions that influence not only what a narrative says but also, just as important, what it *can't* say. Western democracies, for example, silently assume that adults desire good health and personal autonomy, despite abundant evidence to the contrary. American media simply cannot say that the US health care system is not the finest in the world. ²¹ Stifled or silent speech similarly marks many Western medical encounters. Patients routinely withhold facts that they regard as irrelevant or shameful. Surely most physicians can think of statements they didn't make or deliberately withheld. Narrative medicine thus encourages physicians to consider not only what is said but also what is not said: what is silenced, excluded, marginalized, unsaid, or unsayable. ²² There is even evidence that POV influences health. When experimental subjects were asked to recall unpleasant memories, third-person scenes were significantly less upsetting than bad memories recalled in the first person. ²³ Psychologists studying the use of pronouns found that the ability to change perspectives is a potent indicator of how well the act of writing will predict improvement in health. ²⁴ All patients are stories, true, but their constructedness differs in ways that narrative competence helps to unfold. The patient as story contains fragments, inconsistencies, gaps, and shifts in POV that challenge the physician, above all, not just to listen, or listen actively, but to listen for significant elements of narrative.

Words Matter: One-Way Listening vs Two-Way Dialogue

Narrative (from Latin *narrare*—to tell) refers not simply to fictions, as we have seen, but to various forms of telling. These tellings include coherent narrative genres from epic poems to realist novels but also disjointed shards of discourse: TV sound bites, overheard phone sex, random blogs, you name it. While novels tend to lick up the social languages and speech genres that surround them, contemporary non-novelistic narratives equally absorb the fluid, shifting lingo and

The key point is that narratives, ... don't just exist or arise: they are constructed.

fractured consciousness of channel surfers, iPod-ites, and multitaskers. Narrative tellings are not necessarily verbal. Visual, musical, kinetic, and mixed-media forms of storytelling spin their familiar sagas from country songs and are-you-ready-for-some-football to *The Nutcracker Suite*. The body language that accompanies many spoken narratives is sometimes indispensable to full understanding. Narrative medicine nonetheless stresses—and it is hard in a medical context to overemphasize—that words matter.

Words are often slighted in a justified concern for larger narrative structures or patterns within medicine.²⁵⁻²⁷ Sociologist Arthur Frank, PhD, in *The Wounded Storyteller*, for example, sees narrative as the sign of a historic shift.²⁸ Until the 1950s, modern medicine was dominated by what he calls *the doctor's story*: tales of cure that feature physicians as heroes in the scientific conquest of disease. Contemporary postmodern culture, by contrast, celebrates *the patient's story*: tales that feature patients (wounded storytellers) reciting *chaos narratives* about lives falling apart or *restitution narratives* about the unexpected benefits that accompany illness. Today physicians too are wounded storytellers, such as Oliver Sacks, MD, recounting his severely injured leg or David Hilfiker, MD, breaking the physician's code of silence to describe his own professional fallibility.^{29,30} What matters most here is that individual stories—no matter how closely they resemble larger narrative patterns circulating within a culture—cannot be disentangled from the actual specific words in which they are told.

Narrative medicine in its attention to language promotes a shift from passive processing to (as the cliché goes) active listening, but it does more. Competence implies skills not only to recognize large narrative patterns (a disability narrative? a family-crisis narrative?) but also to focus on the fragmented, hesitant, half-coherent words that patients bring to physicians. Inside or outside larger narrative patterns, it implies an attention to even apparently innocuous words, words such as *soft* or *hard*, with their potent metaphoric implications about whose data matters, and why. Even a single word may function like a metaphor and constitute a compressed mini-narrative, such as the very unofficial crypto-acronym GOMER (Get-Out-of-My-Emergency-Room). GOMER reduces multiple troublesome patients to a single stock figure—a dim-witted sitcom character?—as if lifted from a private scripted medical revue. Attention to language equips doctors to identify such reductive mini-narratives, to critique them, and to pre-empt their possibly damaging impact upon treatment. An attention to words also holds out the promise of a more open dialogue between doc-

tor and patient. Dr Charon actually shares with a patient her written narrative of their initial encounter, asking for feedback in order to correct errors, to flesh out omissions, and to spark additions, so that patient and physician meet in an open-ended intersubjective narrative space where words matter because they constitute the ground (stable and shared but also changing and elusive) for improved understanding and continued exchange.

The importance of words in the medical encounter finds an embodiment in bilingual translators, whose role in medical communication goes beyond merely transposing words from, say, Spanish to English. Narrative knowledge implies a rejection of the error made in reducing words to transparent panes: an invisible medium through which meaning appears. This error encourages listeners to skip over words and leap directly to interpretation. Narrative medicine, by contrast, understands words as inescapably imprinted with sociohistorical contexts that alter meaning and trump interpretation. “This baby is poopy,” said medical student and young mother Perri Klass as a member of the neurology consult team called to examine a newborn, whose diaper stank. The otherwise all-male team ignored her. She adds: “I had used the wrong vocabulary. I tried again. ‘This baby has apparently had a bowel movement,’ I said.”^{31p161} No response. She finally elicited a response when she offered to change the diaper. The all-male physicians shook their heads no. The offer—like her earlier choice of “poopy”—indicated a descent from professional standards of behavior. Words matter in the same way that unprofessional actions matter. Too often, however, an interest in narrative remains fixed at the level of actions or events and ignores the equally powerful subdrama of language. Speech, from this point of view, is action. Spoken or written words, no matter how idle they appear, perform work in the world that is only more obvious when, in certain circumstances, we say “I do” or “shove off” or “so help me God.”

Words for narrative medicine belong to what anthropologists call thick description and local knowledge. Like a dialect or like stuttering, certain words in their thickness, opacity, cloudiness, or pure obfuscation may prove most significant when they temporarily stand in the way of meaning. Why, just here, do words fail the patient? Or fail the physician? Narrative, in short, is constructed out of words, multilayered in their significance, not interchangeable ciphers or synonyms. How does a patient hear the word *cancer*? Does the patient return to the physician who says that chronic pain is often *incurable*? Narrative medicine reminds physicians that patients *bang* on a doctor's words.

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Physicians' words are remembered, repeated to family and friends, analyzed for nuance like sacred writ. Narrative medicine prepares physicians to deal with words (speech-acts) as intrinsic to the medical encounter. It makes language—in addition to stories and disease states—a matter of professional competence.

Applications: Ask the Patient / Heal the Physician / Write Write Write

Narrative medicine is no panacea, nothing is, certainly not penicillin. Within medicine, narrative is an instrument suited to particular tasks, and its inability to meet hyperexaggerated expectations does not make it useless. As a tool, it must be matched to the tasks it performs well, so that we do not blame a stethoscope for its failure to turn a screw. Like any instrument, narrative must answer to questions of cost-effectiveness, but costs must be calculated fairly, with an awareness of externalities (or costs borne by parties not directly involved in the transaction). Medical economics cannot ignore costs associated, for example, with litigation, error, unneeded diagnostic procedures, and futile end-of-life intervention. Fairly calculated, an ounce or two of narrative prevention might pay big dividends. The economic language here, as narrative medicine would argue, is significant. Pragmatist philosopher and physician William James, MD, deliberately employed the metaphor "cash value" when appraising concepts.^{32p31-2} A Jamesian pragmatist philosopher focuses on practical consequences and asks about a concept not *is it true?* but *what work does it do? what is its cash value?* The cash value of narrative medicine may involve not only its benefit to patients but also (as crucial figures without whom there are no patients) to physicians.

First, however, a not-so-artful delay, recapitulation, and mark of constructedness. The strong version of narrative medicine entails several related claims: there is always story; the medical facts are not the whole story; the most important story may not be the story you hear. These claims bear qualification and discussion, but they add up to a significant change in medical thought and practice. When a patient presents to a physician, there may or may not be disease, but there is always story. The story is not identical with medical facts—virus, bacterium, or failed organ—because facts never speak entirely for themselves. They need a "storied" human voice. The most important story, in fact, may not be the story you hear because multiple stories often overlap. All the story-talk may serve as a screen to protect what is hidden in silence. Moreover, because stories change in the retelling, patients offer

differing narratives depending on the narrative situation or even on the location (home visit, grand rounds, private office). Truth is not the crucial feature of stories, as even false or misleading narratives offer useful evidence and do a certain kind of work. A patient narrative about drug-free living, if directly contradicted by a lab report, raises serious questions bearing on treatment and on the intersubjective physician-patient relationship. Narratives are sometimes pure fantasy, but not all fantasies are equal. Confabulation in fact is a symptom of significant brain damage.

Narratives are also vehicles of belief, and there is surely economic benefit in identifying and replacing counter-therapeutic beliefs about illness. A study of 100 patients, for example, showed that patient beliefs about pain correlated directly with treatment outcomes.³³ Some patient narratives expose beliefs that research proves to be truly harmful, such as beliefs about chronic pain that result in catastrophizing. A physician with skills in narrative medicine can help patients identify their commitment counter-therapeutic narratives that promote harm and prevent healing. The next step: to help patients replace harmful narratives with new narratives suited to a patient's culture and beliefs that promote health and sustain wellness. There are good reasons why physicians might want to share with patients (after a careful evidence-based review) a few individual "success stories."^{34p269-85} Patients, as cancer-survivor and Tour de France champion Lance Armstrong attests, want to hear how he beat the odds.³⁵ They want a narrative model for hope.

The economic benefit of narrative intervention may be even more basic and direct. Tests are expensive, often inconclusive, and sometimes downright unnecessary. Suppose a cheaper, surer method allowed doctors to collect certain kinds of relevant data. In a classic medical study of suffering, Eric Cassell, MD, confronted the difficult question of how a physician can know when the patient is suffering.³⁶ Dr Cassell, a pioneer in the study of physician-patient communication as well as an unusually wise clinician, offers a brief, sane, iconoclastic answer: "The only way to learn what damage is sufficient to cause suffering, or whether suffering is present, is to ask the sufferer."^{36p643}

Asking the patient, as Cassell knows, does not always supply correct, complete, or infallible data. Patients don't always tell the truth—especially if drugs or abuse are at issue—and sometimes they reply confidently despite false, flawed, or limited knowledge. They may repeat what they believe the physician wants to hear, or what the culture instructs them to say ("I'm fine").

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Asking the patient, however, is never without value. In addition to whatever information it produces, the question initiates a communicative process that may prove its value later. Like a serve in tennis, the physician's question launches a dialogic encounter whose outcome is (if not unpredictable) unknowable. A genuine inquiry—as distinct from a pro-forma checklist item—already implies that the physician has abandoned a detached, impossible God-like POV for a position of engagement that opens up a flexible space for human verbal interaction. It moves the physician, for however long the exchange continues in its narrative authenticity, off the script.

Here's the payoff for physicians. Physicians can be as frustrated as patients by the failures of biomedicine played out amid the maze of medical bureaucracies, insurance carriers, and multi-national pharmaceutical corporations. Physicians, in fact, bear a double load as they seek to treat increasingly frustrated patients. "Wherever I lectured," writes surgeon Lori Arviso Alvord, MD, "people would come up to me afterward and tell me stories of their impersonal treatment by doctors, of problems getting appropriate treatment through managed care programs, and of doctors or hospital staff who had treated them insensitively. They felt powerless, often miserable inside hospitals, stripped of their dignity."^{37p190} These are the stories that physicians would rather not hear, but there is worse. Physicians face unusually high rates of burn-out, alcoholism, and suicide.^{38,39} The highest suicide risk awaits women physicians.⁴⁰ What are the economic costs, even beyond personal tragedies, entailed in the loss of so many highly trained professionals?

"It's the humdrum, day-in, day-out, everyday work" explains pediatrician William Carlos Williams, MD, "that is the real satisfaction of the practice of medicine . . ."^{41p356} Dr Williams was certainly overworked, given his second job as the inventor of modern American poetry, but what sustained him through 40 years as physician to a poor immigrant community was not financial gain. As he continues: "I have never had a money practice; it would have been impossible for me. But the actual calling on people, at all times and under all conditions, the coming to grips with the intimate conditions of their lives, when they were being born, when they were dying, watching them die, watching them get well when they were ill, has always absorbed me."^{41p356} The demise of the house-call and the rise of the computer screen have separated physicians from patients, and it is worth speculating whether the separation has anything to do with physician discontent. Narrative medicine clearly isn't for everyone. Its role may be more important in certain

specialties. Nonetheless, stories reopen a space—flexible but not unbounded—where physician and patient may participate in an engagement that transforms the humdrum day-in/day-out diagnostic encounter into a source of truly sustaining, restorative satisfactions.

Writing has its satisfactions, not to mention frustrations, but its benefits radiate in some unexpected directions. Psychologist James Pennebaker, PhD, has shown across varied populations that the act of writing about traumatic experience provides measurable health benefits.⁴² The trauma, it turns out, need not be personal or even actual for writing about it over several days to produce measurable health benefits.⁴³ A research team unaffiliated with Dr Pennebaker has replicated his results among arthritis and asthma patients, for whom writing about trauma correlates with a measurable reduction in symptoms.⁴⁴ Dr Pennebaker has established that the benefit does not derive from mere "venting"—defined as the oral expression of feeling—nor is writing interchangeable with forms of nonverbal communication, such as dance. The health benefits seem to require the specific neural organization distinctive of writing, both syntactic and semantic. Nor is mere writing sufficient. "Using our computer analyses as a guide," Pennebaker explains, "we realized that the people who benefited from writing were constructing stories."^{42p103} Physicians not only treat trauma but also experience it as caregivers, and there is at least a possibility that, through narrative, they might just help to write themselves well.

Finale: Authorized Narratives vs Narrative Resistance

Narrative medicine, in order to merit space in *JAMA*, may need to emphasize its claims to knowledge. It may need to reaffirm the standard medical thumbnail case-study ("Mr X is a white male age 40 years"), which has its uses. The fact remains, however, that physicians are beginning to recognize the value of what's left out or neutered by the authorized biomedical narrative forms. New medical narrative forms are in development exploring new modes of engagement with patients, as the work of Dr Remen and Paul Farmer, MD, suggests. The therapeutic possibilities sketched by Dr Mehl-Madrona need to be explored seriously. Narrative medicine may prove most successful, however, because it offers some physicians a return to what drew them to medicine: something beyond facts, procedures, or logico-scientific knowledge. Such benefits include the restorative experience that Dr Williams found in a narrative-based immersion in the everyday lives of patients: "As I say, often after I have gone into my office harassed by personal perplexities of

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Such daily restoration seems indispensable to a professional labor as difficult, demanding, and dangerous as medicine.

whatever sort, fatigued physically and mentally, after two hours of intense application to the work, I came out at the finish completely rested (and I mean rested) ready to smile and to laugh as if the day were just starting."^{41p357} Such daily restoration seems indispensable to a professional labor as difficult, demanding, and dangerous as medicine. The national bean-counters might consider it money well spent if narrative medicine proves effective in promoting, as seems likely among the other benefits that it offers to patients, the long-term wellness and professional restoration of a growing subset of health care professionals receptive to the claims of story. ♦

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