

Health Policy NEWSLETTER

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FROM THE EDITORS

Activating Patient Involvement

“When patients and their families are educated and understand why and how they need to actively participate in their care, and when they feel empowered to do so, their involvement can help to prevent medical errors and enhance safety.”¹ This is the central theme of two important new books, *Patients as Partners: How to Involve Patients and Families in Their Own Care*, by Meghan McGreevey, and *You: The Smart Patient, An Insider’s Handbook for Getting the Best Treatment*, by Michael F. Roizen, MD and Mehmet C. Oz, MD.

Both books are quick to point out that countless medical errors occur and that a great majority of them are preventable. Roizen and Mehmet reveal that “you have a 1 in 25 chance of developing a serious unexpected complication (such as a fatal infection) when you check into the hospital...[and] your odds of being affected by that potentially deadly, unforeseen complication might be as high as 2 in 5.”² McGreevey asserts that “more than two in five, or 42%, of adults’ lives have been touched by a medical error in some way.”¹ Both also go on to report that about 70%-75% of these complications or medical errors are completely preventable. These books are unique and important because in addition to exposing many of the frailties that exist in the health care system, they take the next crucial step towards preventing these errors by providing people the knowledge they need to actively participate in their own care.

Patients as Partners is essentially a “how to” book for physicians to get their patients more involved in their own care. The book is written in the typical Joint Commission Resources (JCR) manuscript style, and is worth reading because it provides many relevant and provocative examples that illustrate its main point—why it’s so crucial to engage patients and how that goal can be achieved. The book covers everything from defining a culture of safety and explaining its importance; to learning how to communicate with patients, including specific techniques clinicians can use in their daily practice (e.g., putting patients at ease, initiating conversations, communicating with patients and their patient advocates, and gauging patient understanding); to current efforts aimed at getting patients more involved (e.g., the Speak Up campaign).

The strength of this book rests with the many examples it provides. It offers several informative case studies, such as the accidental death of a Boston Globe reporter at the Dana-Farber Cancer Institute and how this incident showed that “active patient involvement improves the quality of care, enhances patient self-esteem, increases patient safety, and reduces the potential for medical errors.”¹ The book also contains patient perspectives, like the story of how Roxanne Goeltz and her struggle to be an active participant in her own cancer treatment underlies the importance of effective communication skills. As the situation revealed, “when a patient feels mistrustful and afraid of medical institutions and physicians, yet wants to participate fully in his or her health care, not being able to do so may be frustrating, demoralizing, and anxiety provoking.”¹ The book also offers many genuinely useful tips, such as specific steps one can take to be an effective patient advocate, specific strategies for effectively communicating with patients, and methods of teaching patients to get involved (e.g., tell patients that it is okay to ask whether caregivers/healthcare providers have washed their hands). And finally, the book provides helpful references to web sites of organizations that provide valuable information about patient safety and patient-centered care.

Every provider should read this book; the examples are simply too good and too poignant to pass up. And considering that the book is also such a quick read, we think many patients would benefit from reading this book. The only real shortcoming is that some patients might not easily see its relevance as it focuses more on ways providers can engage patients and not on specific things patients can do to help themselves. That job is accomplished by *You: The Smart Patient*.

continued p.2



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You: The Smart Patient is similar to *Patients as Partners* in that it highlights many of health care's problems, and it strives to get patients more involved. This book, however, is geared more towards patients, not clinicians. It is also a worthwhile read because it offers patients concrete examples and guidance for taking control of their own care and navigating the often complex health care system. It does so while using humor and entertaining illustrations. Specific topics include choosing the right doctor; choosing the right hospital; choosing the right insurance company; understanding prescription drugs, dealing with clinicians; and understanding treatment options and alternative medicines and pain management.

The strength of this book rests with its easy readability and comprehensiveness. The book starts off with a simple quiz to "help you gauge how much you really know about taking control of your health care." It includes questions like "what's the most important thing to bring with you to the doctor's office," "when is the best time to schedule a doctor appointment," "how often does getting a second opinion change treatment substantially," "what is the biggest advantage most HMO insurance plans have over current indemnity health-insurance plans." The book then goes on to systematically tackle many of these questions. The book offers a handy glossary of medical jargon, which is translated into layman's terms, and sample forms from health journals, living wills, power of attorney, "do not resuscitate" orders. Overall, this book is an excellent "how to" guide for patients who "in clear, easy steps [want] to take

control of their own health care and deal with all matters that may come up when facing a medical [problem]." To be frank, every person should read this book, providers and patients alike, as we all will be patients one day.

Regardless of whether you're a patient or a provider, both books are a great read. They probably won't change your core beliefs about the health care system. What they will do, and what makes them so novel, is that they provide numerous ways to effectively get patients more involved in their own care. In our view, this level of patient activation is what real patient centered care is all about. As usual, you can reach me at David.Nash@jefferson.edu.

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Letters to the Editor

I read with great interest the articles by Maio et al. and Brixner et al. in the March, 2007 issue of the Health Policy Newsletter, concerning impact of publication of ALLHAT study results on physician behavior. Both authors conducted retrospective studies of large datasets – Maio, claims data for a region in Italy, and Brixner, for a large electronic medical record primary care database – in order to examine whether the ALLHAT recommendations regarding first line use of thiazide-type diuretics (THZDs) led to changing prescribing patterns. These analyses both observe relatively small changes in prescribing behavior and conclude that physicians are slow to adopt practice changes based on published evidence.

Although there is a wealth of published evidence of significant time lags in physician uptake of evidence-based guidelines and research findings, I question whether this conclusion can be drawn from the Maio and Brixner studies. From the limited methodologic information available in the Newsletter reports, it appears that neither study was able to clearly identify cases of first line use (i.e., newly diagnosed hypertensives started on an initial pharmacotherapy). As your own published work with PhRMA has pointed out, by the end of the ALLHAT study period, approximately 70 % of patients required multiple medications to control their blood pressure. So, even if physicians read ALLHAT reports and agreed with the findings, they would not see the results as applicable to treatment for their own well-established hypertensive populations, and would not discontinue therapies if blood pressure was being adequately controlled. In addition, as you know, ALLHAT findings were extremely controversial and have been challenged by many providers, professional societies, and academics.

If the evidence is reported, but not widely agreed upon or accepted, we would not expect to see major changes in prescribing behavior. This is very different than saying that physicians do not change behaviors in the face of evidence.

Neil Goldfarb

Department of Health Policy, Jefferson Medical College

I just wanted to take a minute to send you an email on your “Sunshine is the Best Disinfectant” article. I found it to be very educational and informative. HAI has always been something that I’ve run into over the course of my career in employee benefits with shock claimants on employer groups that have had complications and deaths due to infections happening in the hospitals. I have also been involved in worker’s compensation claims where job related injuries progressed into hospitalization stays where limbs were lost as result of HAI. Your article is something that I am passing on to some of my partners who deal with physicians and hospital groups in our area. Take care.

Raymond E. Rice

Williams-Manny Midwest

Please note: The comments expressed by the authors in this publication do not necessarily represent the views of the Editorial Board, Thomas Jefferson University, Jefferson Medical College or of the Department of Health Policy.

Welcome the 2007-2008 Delaware Valley Schweitzer Fellows

We are pleased to announce the selection of our inaugural group of Delaware Valley Schweitzer Fellows. As has been reported in previous issues of Health Policy Newsletter, the Albert Schweitzer Fellowship is a national program which provides students in health-related disciplines an opportunity to design and implement projects intended to improve the health of underserved communities. Jefferson’s Department of Health Policy (DHP) serves as administrative home for the recently-launched Delaware Valley program, one of the first expansion sites for this national initiative.

Applicants were invited from over 80 graduate programs in the Philadelphia region, southern New Jersey, and Delaware. With assistance of DHP faculty and members of the Program Advisory Board, 22 applicants were screened, and 12 selected:

- Betty Chung, UMDNJ medical student, will provide Hepatitis B education and screening in the Asian community
- Gillian Farrelly and Ivania Quesada, Drexel University dance movement therapy students, will employ choreography and dance to address psychosocial development of adolescents
- Rachel Kadakia and Melessa Yee, Drexel University medical students, will help uninsured clients of the 11th Street Family Health Clinic apply for health insurance
- Devra Noily, a divinity student at Reconstructionist Rabbinical College, will provide spiritual/pastoral care to trans-gender and intersex individuals

- SuJung Park, a Drexel University medical student, will provide health education and schoolwork assistance to youths in homeless shelters
- Michael Rovito and Julie Tippens, in Temple University’s Public Health program, will facilitate development of a school-based community garden, to empower youth and neighborhoods and promote community health and environmental justice
- Sheila Salvant-Valentine, a physician and Widener University health law student, will develop cardiovascular disease education and risk reduction programs for Delaware’s Haitian immigrant community
- Behnaz Sarrami, a Temple University podiatry student, will provide podiatric screenings and related health services to homeless shelter residents
- Alana Wright-Benton, studying health administration and health education at St. Joseph’s University, will provide education on SIDS prevention and child CPR to mothers of newborns in community shelters

The Fellows will conduct their projects over the next year, devoting at least 200 hours to community service over the course of the year.

Opportunities to sponsor a Fellow are available. Please contact Nicole Cobb, MAOM, Program Coordinator (nicole.cobb@jefferson.edu) for more information.

Update on Screening for Colorectal Cancer

In July 2006, the National Commission on Prevention Priorities reported that it had ranked colorectal cancer (CRC) screening as one of the top four prevention priorities¹⁻³, based on the burden of clinical disease that could be prevented and cost-effectiveness.

The report of the Commission highlighted the importance of prevention, and challenged those interested to head efforts to improve quality in the delivery of preventive services.

In March 2007, legislation was introduced in Congress that would establish a national CRC screening program. It would be supported by the Centers for Disease Control and Prevention (CDC) through grants to states and other entities that could reach the target populations. If established, this new federal effort would increase access to screening for the low-income uninsured and under-insured. Five demonstration programs funded by the CDC and three statewide programs that have provided free screening to low-income uninsured individuals are providing trial runs for this program.

Recognition of the importance of CRC screening has inspired initiation of several successful efforts to improve screening rates over the last decade. In 2002, only seven states had screening rates > 60%; by 2004, only two years later, 15 states were at that level, seven had surpassed 65%.⁴ During the same time period, 11 states experienced increases in endoscopy screening rates of 7% or greater; two had increases of 12%.^{5,6} Nationwide, overall screening rates increased by 3%.⁴ Medicare screening rates also demonstrated significant increases as measured in 2000 and 2003.⁷ And, between 2003 and 2005, rates in Medicare managed care plan increased from 49.5% to 53.9%; rates in commercial managed care plans increased from 47.4% to 52.3%.⁸

Significant efforts have been mounted by private and public groups to improve screening rates. The National Colorectal Cancer Roundtable supports progress of these groups with its strategic planning and networking activities. The Roundtable was founded as a collaborative endeavor between the CDC and the American Cancer Society (ACS) in 1997. Influential groups like the Cancer Research and Prevention Foundation (www.preventcancer.org), the Entertainment Industry Foundation (www.eif.org), well-known cancer centers, physician associations, and voluntary health organizations have played major roles. The Roundtable and its nearly 50 member organizations focus on policy, professional education, and public awareness. Activities in each area contribute to the improving screening rates.

The Roundtable members with a policy focus have worked on policies that promote screening, including coverage by third-party payers and employer purchasing of health benefits that include CRC screening. They worked with National Committee for Quality Assurance (NCQA) to include a measure on CRC screening in the Health Employer Data and Information Set (HEDIS). As of 2006, managed care plans now report CRC screening rates.

The Roundtable members focusing on professional education and practice sought to stimulate interventions among providers that increase screening. They urged associations of health professionals to include continuing education on CRC in

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accreditation, certification, and recertification procedures. The work group embraced the well-documented conclusion that provider recommendation is pivotal in persuading individuals to undergo screening.⁹

The Roundtable published a toolbox and guide to assist primary care physicians to improve screening rates.

The third group of Roundtable members focus on public awareness, promoting CRC screening in general rather than by a particular test. They recommended public education campaigns coupled with carefully designed interventions to target subgroups at greater risk. They endorsed the delivery of messages by role models, celebrities, and television personalities who could get public attention and influence behavior. In 2002, they achieved a designation of Colorectal Cancer Awareness Month for the month of March and developed the campaign slogan, "preventable, treatable, beatable." Polyp Man™ was created and appeared in televised public service announcements. In 2006, the Warner Brothers' Foghorn Leghorn cartoon character spoke to the television audience ("I say, I say, don't be a chicken, get screened"). Many groups have taken a leadership role in these and other public awareness initiatives, including the Cancer Research and Prevention Foundation, the Colorectal Cancer Alliance, the STOP Colorectal Cancer Foundation, Hadassah, the EIF, the Jay Monahan Center, and the Eric Davis Foundation.

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A Study of Colorectal Cancer Screening in Pennsylvania

In January 2006, Senate Resolution 212 directed the Pennsylvania Legislative Budget and Finance Committee: A Joint Committee of the Pennsylvania General Assembly to conduct a study of various aspects of colorectal screening. Researchers at Thomas Jefferson University were funded to determine the state's colorectal cancer burden, describe screening options and their cost-effectiveness, determine insurance coverage for screening, and assess screening capacity. The research team completed this policy study using data collected through reviews of the scientific literature, contact with leading experts in the field, administration of three statewide surveys, collection of data from the Pennsylvania Department of Health, and the Pennsylvania Health Care Cost Containment Council. Findings are summarized below.

Colorectal Cancer Burden and Risk

The burden of colorectal cancer (CRC) is substantial in the Commonwealth of Pennsylvania. The state will experience an estimated 8,000 new cases and 2,970 deaths from this disease in 2006.¹ Pennsylvania colorectal cancer incidence and mortality rates are higher than those expected in the nation. Further, incidence and mortality rates vary considerably across the state. The lifetime risk of being diagnosed with colorectal cancer in the general population is approximately 6%. More than 90% of colorectal cancer cases are diagnosed in persons 50 years of age or older. The risk of being diagnosed with colorectal cancer is greater among individuals with a personal or family history of colorectal cancer and or colorectal polyps, a personal history of inflammatory bowel disease and certain inherited genetic characteristics, (e.g., familial adenomatous polyposis (FAP) and hereditary nonpolyposis colorectal cancer (HNPCC)).²

Screening and Cost-Effectiveness

Screening for colorectal cancer in the absence of symptoms offers the potential for both primary prevention (incidence reduction) by removing pre-cancerous polyps and secondary prevention (mortality reduction) by detecting and treating the disease at an early stage. The recommended screening modalities are stool blood testing (SBT) every year, flexible sigmoidoscopy every five years, annual SBT plus flexible sigmoidoscopy every five years, colonoscopy every 10 years, or double contrast barium enema every five years. Screening with colonoscopy is recommended for those at increased risk at age 40, or 10 years before the age at which a member of the person's family was diagnosed with colorectal cancer.³

The standard threshold in economic outcomes research holds that an average cost-effectiveness ratio (ACER) of less than \$50,000 signals a relatively worthwhile economic investment. An ACER compares the total cost of screening to the total number of life years saved. ACERs for the most cost-effective screening strategies are as follows: ACER for stool blood testing every year ranges from \$5,980 to \$11,632; ACER for combined annual stool blood testing and flexible sigmoidoscopy every five years ranges from \$13,922 to \$24,570; ACER for colonoscopy every ten years ranges from \$14,181 to \$23,570.⁴ Thus, the use of colorectal

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cancer screening by recommended means is more cost-effective than not screening. Further, an annual SBT is the most cost-effective screening approach, followed by a combination of SBT and flexible sigmoidoscopy. Colonoscopy is less cost-effective than the other two alternatives, although it is certainly objectively cost-effective by the standards

of economic outcomes research.

Insurance Coverage for Screening

Insurance coverage for colorectal cancer screening is not uniform in Pennsylvania. The majority of insurers reported "always" covering the recommended colorectal cancer screening tests. The remaining insurers, however, reported that the screening tests were covered "sometimes." A small number of insurers restricted coverage for colonoscopy screening to enrollees who are at increased risk. Deductibles and co-payment varied considerably by type of screening test.⁵

Colorectal Cancer Treatment Costs

In 2005, there were 9,287 hospital admissions in Pennsylvania for which colorectal cancer was the *primary* diagnosis. Admissions by disease stage were as follows: Stage 1 (1%), Stage 2 (54%), Stage 3 and expired (45%). Treatment costs related to these admissions totaled \$540,533,844. Average treatment costs increased in accordance with disease stage: Stage 1 (\$36,395), Stage 2 (\$54,938), Stage 3 and expired (\$62,845). In 2005, there were also 5,327 hospital admissions in Pennsylvania for which colorectal cancer was a *secondary* diagnosis. Admissions by disease stage were as follows: Stage 1 and reported history of colorectal cancer (1%), Stage 2 (57%), Stage 3 and expired (42%). Treatment charges related to these admissions totaled \$222,256,770. Average treatment charges increased in accordance with disease stage: Stage 1 and reported history of CRC (\$28,400), Stage 2 (\$40,248), and Stage 3 and expired (\$43,944). Overall, there were a total of 14,614 hospital admissions for which colorectal cancer was the primary or secondary diagnosis. Treatment charges increased in accordance with disease stage. Total charges related to these admissions were \$762,790,614.⁵

Capacity and Demand for Colorectal Cancer Screening

A statewide survey of hospitals and ambulatory surgery centers showed that there is excess capacity in the state for the performance of colonoscopy procedures. Analysis of the survey data also indicates that flexible sigmoidoscopy screening is not commonly recommended or performed but there is substantial excess capacity for the performance of this procedure. Stool blood testing is relatively inexpensive and widely available. Screening capacity does not present a problem. Using three scenarios, we estimate that if the demand for all colorectal cancer screening procedures increased by 2.5%, 5%, or 10% per year, there would still be no capacity problem.⁵

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Domestic Violence in Same-Sex Couples

Research on domestic violence consistently demonstrates the need for services in the areas of prevention, screening, and treatment of abuse. However, the populations sampled for these studies are almost exclusively heterosexual, and the typical victim was female. Consequently, services, legislation, and public opinion of who is affected by domestic violence tend to neglect same-sex couples. Further, this skewed perspective often dismisses the possibilities that gay men can be victims or that lesbian women may be batterers. Existing literature suggests that rates of abuse in these populations range from 9%-41% depending on the definition of abuse.¹

Although broad, this range is comparable to that of heterosexual couples, reportedly between 2%-30% depending on several socioeconomic factors.^{2,3} This article aims to quantify the number of lesbian, gay, bisexual, and transgender (LGBT) people in Philadelphia who report to be victims of domestic violence.

To assess the problem, anonymous, self-report surveys were collected and analyzed over a 3-week period at the Mazzone Center for LGBT Health and Well-Being in Center City Philadelphia. The Mazzone Center sees a broad range of patients, 50% of whom are insured and 80% of who are non-heterosexual identified. The survey asked if participants had been victims of physical, psychological, sexual, and "I am scared for my safety" types of abuse. Also collected were the gender of the abuser, relationship between abuser and victim, and services sought for treatment or help. The survey was adapted from the George Washington University *Universal Violence Prevention Screening Protocol* and a study of heterosexual male domestic violence victims.⁴

Of the 99 people participating in the survey, 64 were male, 22 were female, eight were male-to-female (MTF) transgender, and six were female-to-male (FTM) transgender. The sexual orientation of the participants was predominantly gay (47), with three lesbian, 14 bisexual, 22 heterosexual, and seven people unsure of their orientation. Additionally, six participants left the sexual orientation component blank. The mean age of respondents was 31 years, with a range from 17 to 52. Six people refused to take a survey and none of these people knew the survey was about domestic violence at the time of refusal.

Overall, 24 respondents reported at least one type of abuse in the past 12 months; 14 of these specifically reported partner abuse. Abuse was reported by individuals across all sexual orientations and gender identities, with the highest percent reported by bisexual and transgender people. Seven of the 78 LGBT individuals said they had been threatened with a weapon. Of this group, five were female. Thirteen LGBT individuals reported that someone had choked, kicked, bitten, punched, slapped, grabbed, or shoved them in the past 12 months. Seven had had someone throw an object at them in an attempt to hurt them, with half of this group being male and a quarter being male transgender. Eleven of the total sample had been afraid a current or former intimate partner would hurt them physically. Five of individuals in this sample had been forced to have sex and all of these respondents were women. Interestingly, two were bisexual and three were heterosexual women, with no lesbians reporting forced sex. Current or past intimate partner abuse was the most common type of abuser-victim

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relationship and almost none of the individuals sought treatment or services related to their abuse incident.

This study indicates that domestic violence is at least as common in LGBT couples as in heterosexual couples and suggests that regardless of the sex of one's partner, providers should screen for domestic violence. Furthermore, few of these victims report incidents to police, physicians, counselors, or lawyers. While this may suggest that the abuse is not severe enough to warrant treatment or help, it is possible that the LGBT community's reluctance to disclose incidents of abuse is because of fear of a homophobic response.⁵

A majority of the victims in this study identified abusers as either current or past intimate partners, emphasizing that partner violence is of greater prevalence than family, acquaintance, or stranger abuse in this population. This has significant implications for health care providers in the screening and treatment of abuse incidents in this population. For example, it is important to make sure that a patient is safe to return home after discovering abusive behavior, as they likely have an ongoing relationship with their abuser.

The results indicate a significant rate of partner abuse in the LGBT community, and highlight the need for future research in this area. This study is one step toward understanding the magnitude of this problem and figuring out how best to reach this overlooked community in terms of prevention, screening, and treatment of partner abuse. The number of respondents and minimal refusals to participate in this survey (less than 6% of those asked) are suggestive of the LGBT community's cooperation and willingness to participate in research. This will hopefully encourage other researchers to study this population in order to better serve their needs. The scarcity of available abuse resources targeted toward the LGBT communities underscores the importance for all LGBT centers and programs to be aware of this issue and to work toward improving these services.

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Department of Health Policy Meeting Notes

The 16th Annual Dr. Raymond C. Grandon Lecture May 3, 2007

Patient Safety: The Impact of Facility Design

This year's speaker was John G. Reiling, PhD, MHA, MBA, President and CEO of Safe by Design. His message was clear and compelling. "See the harm, think 'human,' and seek techniques and technologies to design around preventing errors."

See the harm. The opportunity for harm in ambulatory and inpatient care is high. There are 15 million events of harm annually. One of 10 drugs administered is incorrect at the point of service and, last year, 90,000 people died of hospital acquired infections—one in 300 admissions. To appreciate the magnitude of these statistics, compare them to deaths on domestic airline flights (1 in 8 million flights) or the much publicized problem of lost airline luggage (7.5 problems per 1000 passengers).

Think "human." The Institute of Medicine report, "To Err is Human," acknowledged the fallacy in the belief that good doctors and good nurses do not make mistakes. All humans make mistakes. There are conditions under which mistakes are more likely (e.g., fatigue, noise, multitasking) and there are conditions that can be created to catch mistakes before they cause harm.

Seek techniques and technologies to design around preventing errors. Fewer patients will be harmed through good hospital design. Facilities, equipment, and technologies to support safety begin with standardization and simplification. Many normal hospital activities—e.g., looking for things in patient rooms and nursing stations that vary from one to another—use up considerable amounts of short-term memory and lead to making errors in more important processes. "Standardization is one of the most effective tools for creating a safe environment."

Across the country, safe design features are being incorporated into new and renovated facilities. Examples include:

- New inpatient facility designs feature a glass-windowed alcove with a computer in each patient room. This allows nurses to complete all tasks pertaining to one patient (e.g., post orders and enter clinical data) within view of that patient and before moving to the next. Studies show that "one-at-a-time" is more efficient and less error prone than "batching."
- Some hospital systems no longer use vinyl coverings on exterior walls because the material attracts infection-causing mold.
- Some facilities have begun to use windows that enclose blinds within the glass to reduce the surface areas that breed germs.

An organization must see harm in order to effect necessary changes. A culture of safety that permeates the entire organization must be created—and facility design makes it concrete.

Health Policy Forums

Pennsylvania 2020 Vision

Secretary Nora Dowd Eisenhower
Pennsylvania Department of Aging
March 14, 2007

In 2020, it is estimated that 20% of Pennsylvanians will be over 65 and 20% will be under 18. Secretary Dowd Eisenhower relayed this unusual statistic during her presentation on the Pennsylvania Department of Aging (DOA) and the Pennsylvania 2020 Vision project.

The DOA was created in 1978 to provide a greater focus on issues surrounding the aging population. Under the DOA, the Pharmaceutical Assistance Contract for the Elderly (PACE)

program was developed and managed. One of the first of its kind in the country, PACE has been providing income-based assistance for over 20 years. Funding for this and many other Department programs comes from the profits from the PA Lottery. Beyond the prescription assistance, as a rich data resource, PACE provides important drug detailing information for providers and allows for targeted improvement efforts for doctors.

Long Term Living (LTL) management also comes under the auspices of the DOA. Nearly 80% of PA state dollars for LTL goes toward institutional care, with the remaining 20% spent on care in the home or community. This breakdown is markedly different than that in other states, such as Oregon, which uses only 20% of state funds on institutional care. The Governor has set a goal of balancing these expenditures, using waivers. Additionally, the Governor's LTL Council, consisting of various state departments such as Transportation, Welfare, Health, and Economic Development, is looking at how we can better provide care and allow elderly to live in community settings versus institutions.

Secretary Dowd Eisenhower went into detail about the changing demographics of Pennsylvania residents and described the goals of the Pennsylvania 2020 Vision as being:

- 1) Assess challenges and opportunities presented by these shifts and
- 2) Develop Agency Response Plan (ARP) to plan for programmatic and fiscal impacts of these changes.

To view slides or listen to Secretary's Dowd Eisenhower's presentation in its entirety, please visit: http://www.jefferson.edu/dhp/education_ls.cfm

Strengthening the Mid-Atlantic Region for Tomorrow (SMART)

Bob Carullo
Executive Director, SMART
April 11, 2007

SMART, a grassroots organization that sprung from the technology community in the mid-1990's, pulls together a congressional caucus, the federal executive branch, states and regional technology communities. Currently a 4-state science and technology authority, SMART is working to expand to at least 4 additional states across the nation. SMART has federal budget line items through the Departments of Commerce and Defense.

Recognizing that there are limited national assets for technology, SMART developed its mission: *Integrated collaboration on science and technology issues that lead to regional technology enterprise and intellectual vitality.*

Members of SMART understand that you get out of the organization what you put into it. Its primary purpose is to help facilitate regional solutions for national and international issues. For example, the congressional caucus provides legislative support and can assist in gaining government endorsement for science and technology advancements.

SMART supports a variety of activities including:

- Annual Conventions: Tech Trends, Capital Forums, and SMART PROC (Procurements)
- Technology fairs in local congressional regions.
- Staffer series: quarterly technology topics requested by staffers, e.g., stem cell research
- State-Wide Meetings

For more detailed information on SMART visit:
<http://www.smartstates.com/>

To learn more about the SMART PROC meeting visit:
<http://www.smartproc.com/>

Potential Impact of Advance Directive Law Act 169 on Decisions and Care for Patients at End of Life: Reflections of Ethics Consultants

Patients' participation in end of life treatment decisions has received increasing attention in recent years as legal, ethical, and social pressures combine to support a more active role for patients. Despite overwhelming societal support for the view that individual patients should be involved in treatment decisions at the end of life, many problems remain in implementing this perspective.

Ethical and legal guidelines support the individual's role in medical decision making at end of life, including decisions to forgo life-sustaining treatment, even when it may result in death. Advance directives, such as living wills, were legislated in 1991 with the Patient Self-Determination Act (PSDA) and were aimed at strengthening the rights of patients to continue to express their wishes regarding the use of life-sustaining measures should they become terminally-ill or permanently unconscious.^{1,2} In the years since that legislation was enacted, however, a number of studies have demonstrated that only a small percentage of patients have advance directives, and these percentages are even smaller among minority patients.^{3,4} However, Teno, in a national mortality follow-back survey (N=1587) 10 years after the enactment of PSDA, found that a huge 71% of the 1,587 people who died (at home, in nursing home, or in hospital) were said to have had an advance directive. Further, individuals who had an advance directive were less likely to have a feeding tube, or use a respirator in the last month of life compared with those who did not.⁵

On November 30, 2006, Act 169 (The General Assembly of Pennsylvania Senate Bill No. 628 session of 2005) was signed into law by Pennsylvania Governor Ed Rendell. This Act, like most laws, is the culmination of a process of negotiation and compromise. It includes some changes designed to assist providers, specifically around advance health care directives and health care decision making for patients incapable of directing care.

In the new law, advance directives are valid now when the patient is determined to be incompetent, is permanently unconscious, or has an end-stage medical condition. Incompetency is defined as: A condition in which an individual—despite being provided appropriate medical information, communication supports, and technical assistance—is documented by a health care provider to be unable to: 1) understand the potential material benefits, risks, and alternatives involved in a specific proposed health care decision; 2) make that health care decision on his own behalf; or 3) communicate that health care decision to any other person. In the past, the term “terminal” was linked to a 6-month prognosis, which meant that some patients with stroke and Alzheimer's patients did not meet that requirement and thus were excluded from “benefiting” from having their documented wishes followed. To its credit, the new law streamlines the process for declaring a patient to be permanently unconscious or for being in an end-stage condition, no longer requiring confirmation by a second physician.

Of distinction in the PA law is that artificial nutrition and hydration (AN/H) are given heightened attention. Rather than

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consider this on equal terms with other life-sustaining treatments that can be foregone, AN/H are not considered as a presumed treatment to be withheld or withdrawn unless the patient specifically states otherwise in writing. Thus, the new law seems to imply a legal obligation to continue AN/H unless stipulated by the advance directive. At the same time, the text indicates that families and providers

may be able to discern a patient's wishes regarding AN/H, if it can be derived from other information about that patient, and withheld or withdrawn based on those inferences.

In another notable aspect of the law, the new term “health care representative” is introduced to refer to a class of potential decisionmakers for decisionally-incapable patients. These are individuals who do not need to be formally designated (unlike a health care power of attorney), but are assumed to be determined through family lines to close friends. These individuals can also consent to ongoing treatment and forgoing of medical care. However, unlike the health care agent with a health care power of attorney document, health care representatives, according to this law, can only provide consent to forgo medical care when the patient meets the living will requirements; that is permanently unconscious and in end stage disease.

The obligation of health providers to offer care that is more beneficial than burdensome and to provide comfort care at end of life is one that challenges many of us involved in ethics consultation and care of patients at end of life. Futile care is highly controversial because of the lack of consensus about whom or what defines futile care. The current Act reiterates that health care providers are not required to provide futile care but should “in general” have consent to withhold or withdraw care considered to be futile.

Where the new statute falls short of meeting the ethical needs of patients and health care providers “in the trenches” relates to its silence about serving the needs of the most vulnerable cohort of patients, those lacking decision making ability and having no advance directive or available family members or others who know their values.

There are no easy answers; as Veatch has described, “alone, incompetent and dying” is as bad as it gets.⁶ Ideally for these patients, a court appointed guardian seems reasonable, but is impractical due to expense and time. Too often a patient dies before a guardian can decide and advocate for the patient. Further, the guardians appointed often assume the minimalist role of merely giving consent for continued treatment and intervention without any consideration of whether that for which they consent serves any human need for the patient. Patients lacking decision makers cannot be enrolled in hospice programs, where such high quality end-of-life care would be delivered. The law would be far more valuable to these patients lacking decision making ability were it to acknowledge the reality that where no judgment can be made of the patient's values, including looking for substitute markers of values such as

continued p. 9


religious preference, retreat to a 'best interest' standard, with balance of proportionate benefits to burdens for the patient, is more likely to result in improved quality care at the end of life.

While the notion of autonomous decision making is one that is challenged daily in clinical settings across the country as decisions are made for dying patients by others, there is still an underlying societal belief in the importance of individual dignity and the rights of individuals to have a say in their medical treatment. Ensuring that medical care at end of life reflects respect for persons and supports a peaceful and dignified death remains a formidable challenge for policy makers and health care providers.

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Thomas Jefferson and Widener Universities Announce Joint Degree Program in Law and Public Health

Thomas Jefferson University (TJU) and Widener University have established two new joint degree programs in law and public health. The programs were approved last month by the TJU Board of Trustees. Candidates for the joint degree may enter the program from the Master in Public Health (MPH) program at Jefferson or from the Widener Law School and may start in the next academic year. Enrollees in this program will obtain one of two joint degrees, a Doctor of Jurisprudence-Master of Public Health degree (JD-MPH) or a Master of Jurisprudence-Master of Public Health degree (MJ-MPH).

Individuals with joint degrees are being sought after by hospitals, health departments, health associations, voluntary organizations, and other health institutions. MJ-MPH candidates are typically individuals who seek a career in health administration and will benefit from expertise in legal topics like confidentiality, bioethics, risk management, disability law, etc. Many MJ

graduates are nurses. JD-MPH candidates are typically individuals who sit for the bar exam and become legal counsels to medical institutions, businesses, and organizations. They may choose private law practice. The combination of a legal education with public health core subjects like biostatistics, epidemiology, health behavior, management and policy, and environmental health is of high value to health associations and institutions.

Joint degree students will study at both TJU in Philadelphia and Widener University in Delaware over the course of several years. The MPH may be completed in a little over a year and a joint degree will require 3-7 years, depending on which degree the student chooses and whether the student studies on a full- or part-time basis. Students will apply to both schools. Information may be obtained from the admissions office at Widener Law School or through Jefferson College of Graduate Studies. For more information, contact Jennifer Ravelli at 215-503-0174.

Transforming Healthcare: Themes from the 5th Annual National MD/MBA Conference

The 5th Annual MD/MBA Conference for program directors, faculty, students, and alumni was held on April 13-15, 2007 in Houston, TX. Sponsored this year by Baylor College of Medicine and Jones Graduate School of Management, Rice University, the conference focused on physician leadership in academic medical centers and hospitals. Speakers detailed how they utilized their combined medical and business training to positively impact their organizations and patients. The diverse examples include activities such as leading department and hospital-wide quality improvement efforts, planning system-wide resource allocation, and bringing promising technologies to market.

In his keynote address, Stephen Spann, MD, MBA, professor and chairman of the Department of Family and Community Medicine at the Baylor College of Medicine, stressed the need for physician-led transformation of health care given the high costs and quality gaps of the U.S. health care system. There was general consensus that physicians with business training are primed to lead this transformation, given their enhanced leadership and management skills. However, there was much debate about the specifics of how students could lead this transformation and how to monitor the impact of MD/MBAs. Students voiced concerns about opportunities to use and demonstrate the value of business education throughout their medical training and early careers. Faculty stressed the need to track MD/MBA students to demonstrate and optimize the impact of these programs.

Maria Chandler, MD, MBA, president of the national organization of MD/MBA programs and faculty advisor for the

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School of Medicine and the Paul Merage School of Business at the University of California – Irvine, provided the annual update of MD/MBA programs. The number of MD/MBA programs remains constant at 54, as reported in at the 2006 meeting. However, the total number of

MD/MBA students is unknown, since no formal reporting/tracking system is currently in place. Dr. Chandler expressed a desire to engage all of the programs in the organization's efforts to accurately determine the size and characteristics of these programs. She encouraged program directors, as well as students, to provide her with updated contact information, enrollment statistics, and ideas for the future of the organization, (mchandle@uci.edu).

Several actionable steps emerged from the conference. Merilee Perkins of Dartmouth Medical School presented a revamped version of the National Association of MD/MBA Students website (<http://dms.dartmouth.edu/mdmbas/>). The site contains regularly updated information such as MD/MBA profiles and a discussion forum. The Dartmouth Medical School/Tuck School of Business MD/MBA program maintains the site, with support from other programs. Current and past students are encouraged to upload their information to the site. Another goal of the student association is to develop a database of current and former students from all joint MD/MBA programs. Jefferson Medical College has volunteered to serve as an administrative home for this database. Results from these tracking efforts will be reported at the next year's conference to be held spring 2008 in Washington, DC.

New Publications from the Department of Health Policy

Blackstone EA, Fuhr JP, Jr. Generic biopharmaceutical drugs: an economic and policy analysis. *Biotechnology Healthcare*. 2007;4(1):43-48.

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Conclusions

Primary care physicians serve a basic role in facilitating population use of recommended colorectal cancer screening tests and follow up of abnormal screening test findings. Physicians most commonly recommend stool blood tests and colonoscopy screening. Hospitals and ambulatory surgery centers routinely provide flexible sigmoidoscopy and colonoscopy screening. It appears that sigmoidoscopy is currently used infrequently for colorectal cancer screening purposes in Pennsylvania. The capacity for endoscopy (flexible sigmoidoscopy and colonoscopy) screening in the state is substantial, however, and should accommodate increased demand without placing a strain on institutions that provide these procedures.

Any increase in demand for colorectal cancer screening resulting from these efforts is not expected to have a significant impact on the pricing structure or safety profile of colonoscopy or other screening procedures. Increases in screening rates can be expected to reduce both the incidence and mortality from colorectal cancer. Higher levels of screening use would be expected to reduce the costs of medical care for colorectal cancer. Increased colorectal cancer screening use could substantially reduce the personal and economic burden of colorectal cancer for citizens of the Commonwealth.

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HEALTH POLICY FORUM: FALL 2007

The Forum meets on the second Wednesday of each month (September-June) from 8:30 a.m. to 9:30 a.m. in Conference Room 218, Curtis Building, 1015 Walnut Street, Philadelphia, PA. A light breakfast will be served.

September 12, 2007

Household Survey and Consumer Driven Health Care

Cindy Fillman

*Director, Office of Consumer Liaison
Commonwealth of Pennsylvania*

October 10, 2007

Pharmaceutical Management Program & Business Strategy with Science and Technology

Kevin Caviston

*Director, Drexel MBA Pharmaceutical Management
Drexel University*

Department of Health Policy Presentations

Gagne JJ, Maio V, Rabinowitz C, Louis DZ. *Prevalence of Clinically Important Potential Drug-Drug Interactions in Regione Emila Romagna, Italy.* 12th Annual Meeting of the International Society Pharmacoeconomics and Outcomes Research, May 21, 2007, Washington, DC.

Lee SP, Bunz T, Gagne JJ, Maio V, Goldfarb NI. *Determinants of Total Hospital Costs Among Inpatients with Candidemia.* 12th Annual Meeting of the International Society Pharmacoeconomics and Outcomes Research, May 22, 2007, Washington, DC.

Short J, Talati A, Maio V, Pizzi L, Lagermasini C, Goldfarb NI. *Evaluation of the Impact of the Philadelphia Community Pharmacy Network Program.* American Pharmacists Association 2007 Annual Meeting, March 18, 2007, Atlanta, GA.

Benefits College Update

Now in its third year, the College for Advanced Management of Health Benefits is a national Value-Based Purchasing training program for employee benefit managers, other health benefit purchasers, and their agents. The program, developed by the Department of Health Policy in collaboration with the HealthCare21 Business Coalition in Tennessee, and the National Business Coalition on Health, seeks to provide benefit purchasers with the latest information on how to effectively purchase and manage

benefits so as to promote value and quality in health care. So far this year programs were held in mid-March in Las Vegas and early June in Nashville.

The remaining program of the year is scheduled for: September 24-26 in Columbus, OH.

For more information, or to request a brochure, please contact: neil.goldfarb@jefferson.edu.

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