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Healthcare Disparities Series:

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An Eye-Catching Vision: Patients and the Cost of Advanced Technology
From Patient to Partner - Engaging Patients in Population Health Management

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EDITOR'S LETTER

The April issue is Jay Mohr's last as the Column Contributor to the President's Desk, as his tenure as President of the WHCMAA and 7 years of service on the Association's Board come to a close in June. One of Benjamin Franklin's quotes is "Well done is better than well said." In the case of the WHCMAA, we are lucky enough to have had a leader who has not only done well by us but has also been a tremendously effective communicator. We wish him well as he passes the baton to Jeff Voigt, but make no mistake he will not be off the hook for remaining involved for years to come!

Much appreciation goes to our sponsors, Duane Morris, Locust Walk Partners, and Bristol Myers Squibb. And, as always, thanks to Jeff Voigt (the "executive sponsor" from the Board) and Gabriela Sanchez, who provides administrative support, and finally to you, our readers, without whom the WHQ has no life.

So spread the word outside the Wharton community, keep on reading, continue to contribute articles, and be vigilant about letting us know what you think and want from the WHQ.

Z. Colette Edwards, WG'84, MD'85
Managing Editor



Z. Colette Edwards, WG'84, MD'85
Managing Editor
To learn more about Colette,
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THE PRESIDENT'S DESK

Fellow Alumni, Friends and Colleagues:

"The more things change, the more they stay the same" is a quote that seems particularly appropriate as I summarize the past 7 years serving as a Board member and executive officer.

So, what's changed these past few years?

- We have steadily increased the variety and quantity of programming-related activities. Each year we organize, execute and sponsor at least 30 events for alumni. All of these events underscore our own commitment to the Wharton Lifelong Learning (L3) initiative.
- We have embraced technology and social media. Webinar-based events allow us to better reach our most remote members and offer a host of catalogued materials for future reference. We are now present on Facebook, LinkedIn, and Twitter, and, together with the *WHQ*, these tools enhance our connectivity.
- We have doubled-down on our commitment to the WHCM student community. Beyond the on-campus lunches, career advisory panels, and guest lectures, we now offer a substantial \$15,000 scholarship to 1st year students who choose to pursue an entrepreneurial, non-profit, or policy-oriented internship.
- We have expanded our offering and relationships within the broader Wharton and Penn Communities. Our joint membership initiative with the Wharton Clubs of Boston and New Jersey have been a tremendous success, both in terms of offering added value to our respective members, but also accretive numbers of new members. Further, we have extended WHCMAA benefits to other healthcare executives who are alumni of other University of Pennsylvania schools, including Medicine, Nursing, Law, College, Engineering, Public Policy and more.
- We have instilled a philosophy of productive decision-making at the Board level. Each interaction is designed to achieve a well-informed and vetted outcome. The results of our efforts are reflected in many of the accomplishments noted above.
- We have become more engaged with the Wharton healthcare faculty and will continue to work with them in order to provide L3 content.

And, what has remained the same?

- We remain the pre-eminent alumni organization for the business of healthcare.
- We continue to offer tremendous value to our members.
- We are one of, if not the most engaged alumni organization within the Wharton Alumni Association. Our organization maintains a strong sense of community, fostering collaboration between our members, students, faculty, and other clubs.
- We are a financially sound organization with a strong commitment to our by-laws, governance, and operating principles.



Column Editor: Jay Mohr, WG '91,
Managing Director and Co-Founder,
[Locust Walk Partners](#)
To learn more about Jay, [click here](#).

THE PRESIDENT'S DESK

continued

- We have a tireless program director, June Kinney, who continues to fill our pipeline each year with the highest caliber students. Despite our technological advances, June also remains the glue that keeps the WHCMAA organization so well connected.
- Finally, we have a dedicated Board of Directors who volunteers time, energies, and talents to ensure we keep pace with industry trends, stay committed to innovation, and remain a close-knit entity.

In conclusion, it has been an honor and a real pleasure to serve on this Board alongside such a tremendous group of professionals, and wish Jeff Voigt and the team continued success in the coming years. I have formed many relationships as a Board member, including some great, lifelong friends, and look forward to remaining involved in the Association for years to come.

Respectfully,

Jay Mohr (WG'91)
President, WHCMAA

OPEN WIDE: SOUTH FROM ALASKA

Here, There, Why Not Everywhere?

In the January 2013 issue I talked about how an innovation in dental care delivery, born of necessity, was addressing the problem of very poor dental health status among Alaska Natives, many of whom live in remote villages accessible only by air or water. Thus far, the Alaska program has proven to be successful in terms of quality of care, acceptance by the various communities, workability, and improvement in oral health status. The economics of the program are currently being evaluated.

I then asked the question, “If this innovation was working across the hundreds, if not thousands, of miles of expanse in Alaska to get care to populations that very much need it, why can’t the same model be applied across the river in Camden, New Jersey, or for that matter, in Aroostook County, Maine or the farmlands of Kansas?” But since pondering that question, I’ve come to realize there’s a conceit in my approach, but, to be fair, it’s not just my conceit.

My new question is, “If an advanced innovation has come about because of the lack of access to care for vulnerable populations, why can’t it be extended to the non-vulnerable population, and not just children but to adults as well? Why not see a ‘virtual dental office’ in venues such as suburban shopping malls, ambulatory care centers, and physician offices, all locales where access and awareness can be made even easier for those who aren’t traditionally considered to have a problem with access to care?”

Again, with the Alaska model, quality has already been demonstrated, management systems and practices have been developed and instituted, access to care is being markedly improved, and now the economics are being evaluated. What if it turns out this model of care, which centers upon making the most of appropriately trained providers in a true “system” of care, turns out to be cheaper than what traditional dentistry has to offer? You may recall a quotation I borrowed from a dental school dean, “If you live in the suburbs, have a car, plenty of money, dental insurance, and no dental disease, we have the perfect delivery system for you.”

Well, what if that implied “gold standard” of care is outperformed by one meant to address the needs of those outside that “perfect delivery system?” What if the geographic and conceptual far reaches of the oral health universe actually provide the vantage point from which to showcase there is a different sun around which to revolve?

As George Bernard Shaw said, “Some men see things as they are and ask why. Others dream things that never were and ask why not.” In the next issue I’ll present some ideas on the future of dental care delivery and say, “Why not?”



Column Editor: Harris Contos,
DMD, WG'80, Asclepius Consulting
To learn more about Harris,
[click here.](#)

THE PHILOSOPHER'S CORNER

This eclectic standing column features insightful musings, words of wisdom, life lessons, and stepping stones to business success. We'd love to hear from you, so [click here](#) to participate in future editions.

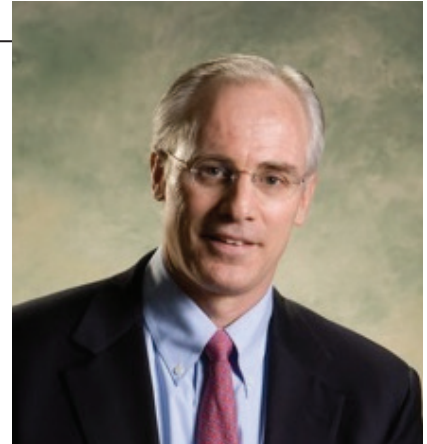
Life Lessons:

If I knew then what I know now, I would have given more than taken.

If I knew then what I know now, I would have been much more humble.

If I knew then what I know now, I would have thanked many more people along the way.

If I knew then what I know now, I would not have stayed at large companies for so long.



This month's philosopher is Jeff Voigt. To learn more about Jeff, [click here](#).

Favorite Quotes:

- "Pray for rain but don't stop hoeing."
- Irish proverb
- "Whether you think you can or can't, you are usually right."
- Henry Ford
- "God gave you two ears and a mouth for a reason."
- Unknown

Recommended Reading:

- *Medicare Prospective Payment and the Shaping of US Healthcare*; Mayes & Berenson (2006). How Medicare's payment system has shaped our healthcare system for good and bad.
- *Master of the Senate: The Years of Lyndon Johnson*, Robert Caro (2003). This is a great read on use and abuse of power as it is acquired along the way by then Senator Lyndon Johnson.
- *The Greatest Generation*, Tom Brokaw (1998). How ordinary citizens saved the world, became heroes and returned to everyday life (without ever talking about it.) (Story of my father.)
- *Team of Rivals, The Political Genius of Abraham Lincoln*, Doris Kearns Goodwin (2005). How Lincoln was able to "mold" his rivals (for the presidency) for the good of the country.

Column Editor:
Z. Colette Edwards, WG'84, MD'85
To learn more about Colette,
[click here](#).

ALUMNI NEWS

Safia Riza, WG'03

I have taken a new challenge by moving to India for the first time in my life and leading India business for a multinational pharmaceutical company. One of the many ways my job was made interesting was remote management of this business for 9 months while living in Brussels due to visa reasons.

Follow [this link](#) to the interview *Pharmaceutical Executive* conducted and published.

Ben Katz, WH/NU/WG'02

Ben Katz, along with Ron Lin (SEAS'01) and Greg Knaddison (WH'01), recently launched [CARD.com](#), an online bank that is fair, fun and fashionable.

Ben Katz (WH/NU/WG'02) lives in Santa Monica, CA with his wife Jessica and two daughters, Ila and Ava

Harris Contos, DMD, WG'80

Harris Contos will be part of a panel on updates on the dental care provisions in the Affordable Care Act at the National Oral Health Conference, April 20-24, Huntsville, AL and part of a panel "Has Dentistry Failed the American People" on May 10, part of Alumni Weekend at Penn Dental.

Bonnie Henry, MBA, WG'79

Bonnie, CEO of GameMetrix Solutions, announces they have just launched its new website with more descriptive insight into the company's offerings and more interactive tools, such as live demos and videos. Check it out at: www.gamemetrixsolutions.com.

We have also added a new member to our team, Bob Welch. He has been involved in designing and producing interactive games for over 20 years, including games for health. He works across multiple platforms having launched mobile, online, PC, and video games as well as traditional toys & games. Bob has worked with small development teams and international brands/publishers, including Hasbro, Atari, Fisher-Price, Mattel, Sony, Parker Brothers, Super-Ego Games, and Viximo. Bob's expertise ensures we have the best in game entertainment to sustain consumers' engagement.

Elayne Howard, WG'76

Elayne Howard will be speaking on "It All Starts with the Board" at the Franklin Forum of the Association of Fundraising Professionals, Greater Philadelphia Chapter, on May 10, 2013. This will be a great opportunity for those of you who sit on boards of not-for-profit organizations.

STUDENT HEALTHCARE CONFERENCE A RESOUNDING SUCCESS!

The Wharton Healthcare students held their annual conference on Friday, February 15, 2013 at the Bellevue Hotel in downtown Philadelphia. With over 500 attendees and 80 Wharton MBA healthcare alum attending, it was a resounding success. Additionally, 7 of the presenters/panelists were graduates of the healthcare program, and 2 were graduates of other Wharton programs as well. This degree of participation speaks volumes to the quality of the Wharton Healthcare Program and the effect its graduates are having in shaping our healthcare system.

Speakers included: Mitchell Blutt, MD, WG'87, CEO Consonance Capital; Gary Gottlieb, MD, WG'85, President & CEO Partners Healthcare (the largest healthcare system in Massachusetts); Julian Harris, MD, WG'08, Medical Director, Medicaid, Commonwealth of MA; Joseph Leveque, MD, WG'92, Vice President, Head of US Medical Oncology of Bristol Myers, Squibb; Bryan Bushick, MD, WG'89, Managing Director of Ansley Capitol Group, LLC; Craig Tanio, MD, WG'95, Chief Medical Officer of Chen Med; Vikas Goyal, WG'10, Senior Associate at SR One; Vincent Forlenza, WG'80, Chairman of the Board, CEO, and President, Becton Dickinson, and Mitchell Higashi, PhD, AMP'05, Chief Economist at GE Healthcare.

The theme of the conference, “Reshaping Healthcare – Emerging Trends Changing the Face of Our Industry,” brought together an engaged group of people involved in moving healthcare in the direction of increased efficiency and access. The industry is actively “decapitalizing” more intensive care settings and moving these resources to settings where it makes more economic (cost-effective) sense. Further, concepts such as incremental cost-effectiveness (e.g., value) are creeping into the equation, as providers and payers are examining new products and services and whether or not they add value. These concepts were discussed in detail by WG panelists Gary Gottlieb, Mitch Blutt, and Julian Harris (Strategic Impacts of An Aging Population), and Joe Leveque (Health Care Policy: Paying Less, Covering More) in each of the sessions in which they participated.

The keynote speakers included, Kent Thiry, Co-Chairman and CEO, DaVita; Bruce Broussard, CEO, Humana; Adam Grant, Associate Professor of Management at Wharton, and Vincent Forlenza, CEO Becton Dickinson. Kent discussed DaVita's unique culture and its rather “zealous” employees, which he identified as major contributors to its success. Bruce Broussard provided an overview of Humana's ever more holistic approach to health and wellness. Adam Grant presented an illuminating and often funny overview of “givers and takers” in business. He provided the example of Adam Rifkin, a very shy, networking genius who is a classic giver and lives by his “five-minute” rule: “You should be willing to do something that will take you five minutes or less for anybody.” Adam's giving helped him to raise \$50 million in capital for one of his successful start-up companies. It appears those who continually take without giving back create adversarial relationships with others and can end up losing out. However, while givers end up being ultimate winners in the game of business, they also need to ensure they do not burn themselves out. Vincent Forlenza, CEO of Becton Dickinson, outlined the challenges facing the medical products industry and indicated success moving forward will depend upon demonstrated cost-effective innovation and a favorable business environment.

As providers look to take costs out of the system by lowering labor costs and engaging patients in their care less expensively, approaches such as mobile health are moving to the forefront and were discussed by a third panel. Personalized medicine has been one of the more actively debated “futures for medicine,” and a panel outlined some of the challenges encountered when incorporating this strategy into real-life practice. While many feel personalized medicine may be a way for the healthcare system to improve overall care and lower costs, Sam Nussbaum, MD, Chief Medical Officer of Wellpoint (the largest private payer in the U.S.), cautioned the audience it may increase costs even as it improves care. The question will then ultimately be its value to the system. Wharton

Contributor:
Jeff Voigt, WG'85
To learn more about Jeff,
[click here.](#)

STUDENT HEALTHCARE CONFERENCE A RESOUNDING SUCCESS!

continued

grad Vik Goyal, representing the investor perspective, stated “value” is the key metric by which personalized treatments will ultimately be assessed by the market, relative to both financing and, ultimately purchase, by consumers/payers.

The student chairs who organized the conference included: Ana Crespo, Rebecca Heinrich, Vivian Hsu, and Gil Kerbs. Each deserves our congratulations for putting on a very informative and engaging conference. We look forward to all the 2nd year healthcare MBA students joining the WHCMAA upon graduation and contributing to our mission of lifelong learning!

DEVELOPING A SHARED LANGUAGE FOR SHARED WORK — COLLABORATION IN INTERPROFESSIONAL TEAMS

This is the last in a series of four articles on improving collaboration in healthcare. We will describe practical tools to enhance institutional performance through better collaboration—toward the primary goal of providing better patient care.

Earlier in the series, we defined collaboration as an ongoing, systematic, strategic process that results in a whole that is greater than the sum of its parts — a process fast becoming a business imperative as our country redesigns healthcare delivery. Clinical teams in hospitals have always worked together on patient care. But today, the push for value-based care and new metrics for clinical quality, appropriate care, cost, access, and patient satisfaction are combining to raise the bar for effective collaboration. As a result, interprofessional teams are becoming more common in acute care hospitals, and clinicians are increasingly communicating across departmental silos and between and among the various parts of the care continuum.

While team-based care can be better care, there is more risk associated with teams. Team dysfunction on units can ripple through healthcare organizations and impact outcomes at all levels, especially when new systems complicate traditional roles, accountability, and responsibility. So how can teams learn how to collaborate to move beyond the time-honored systems that historically dictated who does what?

Improving the Effectiveness and Performance of Interprofessional Teams

In diagnosing and treating patients, interprofessional teams can bring a potent combination of individual expertise directed toward a collective end — coordinated, high-quality care. The same set of core competencies are required of interprofessional teams regardless of whether they are utilized in a hospital or by a physician group. Clinical, financial, and operational skills are all essential to ensure that the institution functions as a whole that is greater than the sum of its individual parts. Consider the following example:

- An academic medical center developed a strategic plan to differentiate itself in cancer care. The problem: the pillar of its cancer service was a poorly functioning Breast Care Clinic (BCC). The issues in the Center showed up in several ways: patients were frustrated by wait times, clinicians were disengaged, performance metrics were low, and leadership disagreed about what needed to be done to reorganize. The unifying goal driving the team's work was, as the Associate Medical Director said, "My mother and my wife should actually want to come here for their breast care."

An analysis of the BCC showed a significant lack of clarity around authority and accountability. This uncertainty left BCC staff confused and frustrated. Who does the BCC Director report to? What is the authority of the Chair of Radiology? These and other questions drove the work to improve the performance of the leadership team and the entire BCC.

Teams fail when it is unclear whether or how they should participate in a process. In complex situations in a hospital, uncertainty about substance (What is clinically needed at this point?) can get mixed with uncertainty about process (Whose patient is this?). In such situations, either politics dominate substance (I am not senior enough to "call out" the Attending) or conflict is avoided and suboptimal choices are made.

Contributors:
Carey Huntington and
Jennifer Tomasik

To learn more about Carey and
Jennifer, [click here](#).

DEVELOPING A SHARED LANGUAGE FOR SHARED WORK — COLLABORATION IN INTERPROFESSIONAL TEAMS

continued

A Tool for Productive Collaboration: Decision Charting

Decision Charting has been proven to exponentially improve team collaboration and performance. The process begins by identifying critical decisions where confusion exists, and assigning the following roles to each team member in a “Decision Chart”:

A – Approve the decision

R – Responsible for staffing the decision (pull together people and resources to make a recommendation)

C – Consult to the decision before it is made

I – Informed about the decision after it is made

Team members complete charts independently, based on how they see each individual as being currently involved in a decision, and how they should be involved in that decision in the future. The data is compiled and analyzed. The group reviews the most critical decisions where disagreement exists, and builds a shared view of who should be involved and how going forward. This process streamlines teamwork by creating a common shorthand for future decisions (*I have the “R” here*) and depersonalizes conflicts by using roles instead of names. It ensures accountability and increases effective communication among individuals and team members.

Below is an abbreviated example of a completed and analyzed Decision Chart from the BCC. Two decisions are listed on the left, with six “roles” at the top. The percentage represents respondents who assigned a role to a stakeholder:

	Enterprise Chief Nursing Officer	Dean of Finance	Hospital Chief Nursing Officer	EVP of Health Affairs	Dept. Chair	CCO
Continue or discontinue the Neuroscience Service Line	C 56%	C 63%	I 69%	A 100%	C 44%	R 63%
Hire a new Cancer Director	C 56%	C 69%	I 81%	A 81%	C 56%	C 50%

In the second decision, “the decision to hire a new Cancer Director,” it’s clear who has the ‘A,’ but no one has the ‘R’ — which meant no one knew who would recruit, review, and nominate a candidate for the EVP of Health Affairs to consider.

Decision Charting became a shared language to build interprofessional relationships and clarify roles for the entire BCC. Debating and mapping out potential roles made potentially difficult conversations more concrete, transparent, and less interpersonally risky. The Decision Charting work improved both patient care and bottom line performance for the BCC. Wait times for diagnostic mammogram appointments improved, decreasing the number of days to a visit by 89%. Outpatient revenue increased by 44%. More effective collaboration was credited for producing these results, and the BCC is now a major contributor to the institution’s success.

DEVELOPING A SHARED LANGUAGE FOR SHARED WORK — COLLABORATION IN INTERPROFESSIONAL TEAMS

continued

Conclusion

In this four-part series, we identified attributes of effective collaboration, then examined how partnerships at different levels within and among healthcare organizations can create a whole greater than the sum of its parts.

- Our first segment introduced “**the collaboration dilemma**” — the fact that the very differences that can create value can also destroy it. When parties commit to understanding and integrating different points of view, the results are a better overall outcome.
- The second installment focused on **collaboration across institutions**, a growing imperative with the increase in mergers, acquisitions, joint ventures, and alliances. Identifying “gives” and “gets” — what an organization needs and what they can offer in return — will help partners more quickly assess the long-term viability of arrangements and shape collective goals.
- In the third segment, we discussed how to foster **collaboration between physicians and administrators**: by listening to and understanding physician resistance and using it to shape effective strategy, and by creating “productive pairs” that rely on mutual influence and ensure institutional support for change. With methods like these, health systems can shift to delivering quality and value together.
- This piece described how to build a shared language to clarify decision-making in **interprofessional teams**, laying the groundwork for more complex and fluid collaboration.

We hope the stories and resources we shared in this series will help you collaborate more effectively in the emerging healthcare landscape, whether it be with clinical partners, within your institution, or across alliances.

For more information on this topic or related materials, contact CFAR at info@cfar.com or 215.320.3200, or visit our website at <http://www.cfar.com>.

THE ROLE AND IMPACT OF THE NURSE PRACTITIONER AT WALGREENS AND IN THE U.S. DELIVERY SYSTEM

In a relatively short period of time, the role of the advanced practice nurse has been conceptualized and established, evolved into a heavily relied-upon but still supporting position, and finally today, matured into one of leadership and growing responsibility. This most recent development has come particularly rapidly, in part accelerated by the proliferation of retail-based convenient care clinics in the last decade. The success of the convenient care clinic industry (retail clinics) has helped to underscore the nurse practitioner's emergence as an independent, front-line provider of first-rate care. Despite these advancements, however, barriers remain before nurse practitioners can be fully incorporated into the U.S. health care delivery system.

Take Care Health Systems, which was an early pioneer in the convenient care industry (and was subsequently acquired by Walgreens), prioritized the role of the nurse practitioner from its inception. My role, as Chief Nurse Practitioner Officer, was the first of its kind, and helped to set the tone internally as a company that our providers were critically important to our future success. That notion was carried throughout the corporate hierarchy, and since the very beginning we have worked hard to imbue in the nurse practitioners who work for Take Care a sense of community, leadership, and a capacity to impact their patients' lives in a positive way on a daily basis.

Retail clinics came into existence due to disruptive innovation, the goal of which was to help address the issue of a growing lack of access to primary care services. Unique features of this health care delivery model included being built from a patient's point of view, nurse practitioners as the primary provider, an "in-the-neighborhood" community setting in a retail store such as Walgreens, and technology leveraged to provide transparency, thereby improving outcomes and ensuring continuity of care.

Today, with over 1400 clinics nationally and over 17 million patients seen, the retail model and the utilization of nurse practitioners have proven their place in the health care delivery system and are becoming more central in discussions with all key stakeholders such as policy makers, insurers, hospital systems, and other health care professionals every day. Retail industry founders united (through the formation of the Convenient Care Association) and set standards for quality and safety as well as goals for collaboration with the health care community. They insisted on rigorous research into cost, quality, and the patient experience. Analytical power houses such as Gallup and RAND Corporation carefully analyzed outcomes.

Results from this research provided empirical evidence that retail clinics were creating a better health care experience for patients. Peer-reviewed publications indicated retail clinics offer a quality of care that is as good as or better than many more traditional settings. Multiple published reports looked at retail clinics' performance relative to the Healthcare Effectiveness Data and Information Set (HEDIS, which is a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service), and each study showed exceptional adherence to evidence-based guidelines and standards of practice.

This concept of innovation and having impact is one that has been central to the advanced practice nurse profession since its founding. Many of the earliest nurse practitioners came from a background of public health and worked directly in the field, bringing health care to those who lacked access to care "by any means necessary." That focus is still felt today and perfectly exhibited in the convenient care industry. Of the approximately 155,000 nurse practitioners practicing in the U.S. today, well over half maintain a primary care focus. Many work in federally qualified health centers, nurse-managed health centers, retail clinics, and other safety-net providers. Others provide care to rural and underserved communities, in schools, and in the military.

Contributor:

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THE ROLE AND IMPACT OF THE NURSE PRACTITIONER AT WALGREENS AND IN THE U.S. DELIVERY SYSTEM *continued*

The true potential scope of impact of the advanced practice nurse role, however, is being impeded by long-standing but outdated barriers to practice. Recently, the National Governors Association recommended that states consider changing the scope of practice restrictions in order to fully utilize NPs to their full potential and improve access to care. While many states recognize nurse practitioners as autonomous primary care clinicians and enable them to provide care to the full scope of their education and licensure, many other states maintain restrictions, which ultimately translate into added costs and barriers to patient care. These burdens range from administrative (e.g., requirements related to a percentage of patient charts a collaborating physician must review), to directly practice-related (e.g., limitations on how a nurse practitioner can prescribe medications to a patient), to reimbursement (e.g., not credentialing nurse practitioners as primary care providers). The difficulties are exacerbated in rural areas, where nurse practitioners may not have easy access to the physician collaborators which many states mandate.

A heightened awareness of access to care issues (due in part to the enactment of the Affordable Care Act and continued steps towards implementation of the law) and the ongoing primary care provider shortage across the U.S., has shined a brighter—and more critical—light on these restrictions. Reports like the Institute of Medicine's *Future of Nursing* have also supported removal of barriers to NP practice and outdated regulations that limit the ability to practice to the full extent of their education and training and result in barriers to care. State to state, individual regulatory change remains slow, longstanding entrenchment of opposition lingers, and support to override some of these assumptions has not yet reached a tipping point. With that in mind, however, we know that change is coming. Or, as the saying goes, "Change is already here, it's just not everywhere."

Many people, nurse practitioners and non-nurses alike, believe advanced practice nurses and related providers, such as physician assistants, are necessarily going to become the front-line primary care providers of the future in the U.S. There aren't currently enough primary care physicians to go around, the population is graying, and costs of care and the prevalence of chronic disease are rising. There is growing recognition that these health care professionals deliver consistently excellent care, and the way we as a public think about and consume health care is fundamentally changing. Primary health care doesn't function like it used to because it can't, and it is time for all of us to respond accordingly to meet the needs of the more than 30 million patients who will become eligible for coverage under the Affordable Care Act.

The theory of disruptive innovation teaches us an established, incumbent industry is susceptible to displacement if it remains unresponsive to changing consumer desires. Traditional medicine is that established industry, currently in the process of being displaced by convenient care clinics, telemedicine, and other novel mechanisms for health care delivery. Even the role of pharmacies is changing: Walgreens is actively positioning pharmacies as points of care for patients and increasing the utilization of pharmacists to more directly support better patient outcomes (See [Take Care Clinics Expand Scope of Health Care Services to Include Chronic Condition Management and Additional Preventive Health Offerings](#)).

I believe the nurse practitioner will remain central to this dialogue and that convenient care clinics such as Take Care will become both a cornerstone for health care services and a resource for consumer education. Founded out of the necessity for a highly skilled health care professional who could and would meet patients at the point of care, wherever that may be, the profession of advanced practice nursing has some experience in molding itself to meet shifting demand. By continuing to work towards the ultimate goal of maximizing patient care access, collaboration and improving health outcomes, the future impact of nurse practitioners in the U.S. health care delivery system and the convenient care industry knows no limits.

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DRUGS FOR RARE DISEASES: PART 1

Ravicti for Urea Cycle Disorders as a Case Study

INTRODUCTION

The development of drugs for rare or ‘orphan’ diseases has received increasing attention from drug manufacturers, payors and the public. Typically, the spotlight has been macroeconomic, with a sometimes harsh or critical view and a focus on price. Here we tell **the ground-level story** of just one drug, glycerol phenylbutyrate (Ravicti™ or HPN-100) developed for the treatment of urea cycle disorders (UCDs), which are estimated to affect ~2000 individuals in the U.S. We tell it as seen through the eyes of the key **protagonists**, including (1) the **patients and families** who live with UCDs and participated in the trials, (2) the **Patient Advocacy Organization (PAO)**, in this case the National Urea Cycle Disorders Foundation (NUCDF) (CL), (3) the **lead academic physician** in the trials, who is also a Howard Hughes Investigator at Baylor College of Medicine and an Investigator in the NIH-funded UCD Consortium (UCDC) (BL), (4) one of Hyperion’s **venture backers (BS)**, and (5) **those at Hyperion responsible for its development (KD, MM, BFS) and commercialization (CN)**.

THE SETTING - UCDs

A urea cycle disorder is a genetic condition caused by a mutation which results in a deficiency of one of the six enzymes in the urea cycle. These enzymes are responsible for removing ammonia from the blood stream. The incidence of UCDs is estimated to be 1 in 8500 births. UCDs are a group of inborn errors of metabolism caused by a deficiency of enzymes of the urea cycle and were first described over 76 years ago by Hans Krebs.*

There are 6 different UCD subtypes, each corresponding to defects in different genes, some of which may have many different mutations. Thus, unlike some inherited disorders such as sickle cell disease which involve one or very few mutations in a single gene, UCDs affect all populations independent of race, ethnicity, and geography.

UCDs can occur in both children and adults. While newborns with severe mutations usually become catastrophically ill within 48 hours of birth, both children and adults can go undiagnosed, either because of a disorder on the milder end of the spectrum or symptoms that are not recognized for what they represent. A diagnosis might only be uncovered when a stressor, such as infection, surgery, extreme diet or exercise, or certain medications, triggers a disturbance in the cycle or causes the production of massive amounts of ammonia. Unlike carbohydrates or fats which can be stored by the body, excess nitrogen ingested as dietary protein cannot be stored and must be detoxified by conversion to urea, which is excreted in urine. As with most metabolic disorders, inherited ‘blockage’ in the urea cycle leads to accumulation of ammonia upstream of the enzymatic block. Elevation of ammonia in the blood and brain (hyperammonemia) is the most important clinical feature of UCDs and can cause severe and irreversible neurological damage. Prevention of hyperammonemia and management of hyperammonemic crises are the primary goals of treatment.

Signs and symptoms may include failure to thrive, chronic episodes of vomiting and drowsiness, an avoidance of meat, hyperactivity, and episodes of disorientation, combativeness, and stroke-like symptoms. If left untreated, UCDs result in brain damage, coma, and death.

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DRUGS FOR RARE DISEASES: PART 1

continued

THE CHARACTERS

Patient and Family Perspective

The UCD community had an enormous stake in the success of HPN-100, as it was called during the clinical trials. While the 1996 approval of sodium phenylbutyrate (Buphenyl®) under the Orphan Drug Act was a huge milestone, adults and families of children with UCDs have struggled ever since with its burdens, which often lead to noncompliance and sometimes life-threatening complications. Its obnoxious smell and taste, akin to butane lighter fluid, are such that UCD children commonly develop behavioral and eating disorders and many require gastrostomy tubes so they can take the drug without having to swallow it. Adults with UCDs sometimes take ≥ 40 tablets per day and often become noncompliant due to its nauseating effects.

The social burden is enormous. Several-times daily administration may require trips to the school nurse or work breaks until the nausea or vomiting pass. Equally difficult are the risks from the high sodium content, to which some UCD patients are particularly sensitive. Some young adults have struggled to the point where they decided that a life tethered to sodium phenylbutyrate was not worth living. The potential for a nearly tasteless, less burdensome treatment would be life-changing and potentially life-saving.

PAO Perspective

Patient advocacy organizations (PAOs) such as NUCDF representing rare genetic disorders drive research focused on the unique needs of their communities. In order to attract and influence development of new treatments, NUCDF has forged close relationships with UCD researchers and clinicians that enable it to foster and help orchestrate and coordinate cooperative research networks. NUCDF must understand the nuanced convergence of agendas and develop a set of principles that unifies, organizes, and guides development.

NUCDF is focused on assuring that the process is patient-centric. Successful collaborations require a culture of transparency and trust that enables the partners to make fully informed decisions and facilitates a collective approach to overcoming barriers, problem-solving, communicating results, and driving the development process. Despite the success of the UCD patient and medical community on many fronts, its prior experience with drug companies left it mistrustful.

Hyperion's leadership understood these principles and the critical difference between the 'who' vs. the 'what.' They did not repeat the internally-entrenched, 'siloed' approach of prior companies, but rather understood the need to partner with the most important stakeholder in the drug's success – the UCD community.

PAOs often serve as the 'moral authority' to help ensure that patients' lives and well-being, not dollars, are the bottom line. NUCDF partnered with Hyperion at all stages, from protocol design through enrollment and interpretation of results. NUCDF:

- provided guidance with respect to the 'enrollability' of the protocols, i.e., a design such that patients and families could actually participate and comply
- recommended the most experienced and diligent clinicians to serve as Investigators to help ensure optimal patient care and collection of the high quality trial data
- provided insight on non-medical barriers to enrollment. UCD patients are widely dispersed, and the burden of travel with chronically ill children can severely impact participation. NUCDF helped identify solutions to minimize the burden of trial participation.

DRUGS FOR RARE DISEASES: PART 1

continued

Once the protocols were finalized and ready for enrollment, NUCDF used its reach and influence to help mobilize the community. The transparency of the communication with the company addressed NUCDF's concerns that full attention was paid to the safety, concerns, and needs of participating UCD families.

The impact of NUCDF was particularly visible at a critical juncture in the development program, when the FDA signaled the need for data from UCD children under age 6. NUCDF worked with the investigators and the company to develop the protocol. It then mobilized families with young children ages 2 months - 5 years such that the trial was fully enrolled in just two months – an astonishing feat – with a waiting list! Throughout, NUCDF was included in advisory and investigator meetings, was provided real time access to non-blinded trial data, and consulted regarding the development of the new drug application (NDA).

Stay tuned for Part 2 in the next issue of the Wharton Healthcare Quarterly.

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HEALTH CARE DISPARITY SERIES

Understanding the Hispanic/Latino Culture to Improve Health Outcome

“Al buen entendedor, pocas palabras bastan.” Translation: “Talk less. Listen more.”

Overview

Understanding a person’s culture plays a vital role in the delivery of effective and quality patient care. Cultural influences are powerful determinants of health-related behavior. A lack of sensitivity to health beliefs and practices of different cultures can limit one’s ability to provide quality healthcare. This article will focus specifically on understanding the Hispanic/Latino culture and its customs and beliefs that impact the patient-provider relationship.

History

The term “Latino” was introduced in the late 1980’s as a reference to persons living in the United States whose ancestors were from Latin American countries in the Western Hemisphere. The term “Hispanic” did not gain widespread use until the 1970’s and 1980’s. Prior to this time, Hispanics tended to position themselves around their own national identities as Mexicans, Cubans, Puerto Ricans, etc. The term Hispanic became a reference to all Spanish-speaking ethnic subgroups into a more unified voice around a variety of social, civil, and political causes.¹ The Hispanic/Latino population in the U.S. is very diverse in terms of national origin, immigration and migration patterns, historical and racial backgrounds, languages, dialects, and cultural values.

Hispanics generally have lower mortality rates but higher morbidity rates compared with the overall U.S. population. Therefore, chronic disease management (e.g., diabetes) is an area with which all health care providers should be concerned when working with this population.²

Demographics

The U.S. Census Bureau collects race and Hispanic origin information following the guidance of the U.S. Office of Management and Budget’s (OMB) 1997 *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*. These federal standards mandate that race and Hispanic origin (ethnicity) are separate and distinct concepts, and when collecting these data via self-identification, two distinct questions must be used. The OMB defines an individual of Hispanic or Latino origin in the 2010 census as a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin. A person who identifies his/her origin as Hispanic, Latino, or Spanish may be of any race.

The 2010 Census data clearly illustrates the nation’s changing racial and ethnic diversity. It reports a 9.7% increase in population from the 2000 Census.² More than half of the growth in the total population of the United States between 2000 and 2010 was due to the increase in the Hispanic population, which increased by 15.2 million between 2000 and 2010 and accounted for over half of the 27.3 million increase in the total population of the United States.³

The growth within the Hispanic population varies by subcultures. The Mexican origin population increased by 54% (accounting for three-quarters of the total increase), Cuban by 44%, Puerto Rican by 36%, and Hispanics who reported other origins by 22%.⁴ Among Hispanic subgroups, Mexicans ranked as the largest, at 63%. Following Mexicans were Central and South Americans (13.5%), Puerto Ricans (9.2%), and Cubans (3.5%). Additionally, 33.9% of Hispanics were under the age of 18, in comparison to 20.1% of non-Hispanic Whites. Among Hispanics, Mexicans have the largest proportion (37%) of people under age 18.

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HEALTH CARE DISPARITY SERIES

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The 2010 Census also indicated 41% of Hispanics lived in the West and 36% in the South. The Northeast and Midwest accounted for 14% and 9%, respectively. Over half of the Hispanic population in the United States resided in just three states: California, Texas, and Florida. In addition, 75% (37.6 million Hispanics) lived in the eight states with Hispanic populations of one million or more – California, Texas, Florida, New York, Illinois, Arizona, New Jersey, and Colorado. In New Mexico, 46.3% (953,403 individuals) of the population is Hispanic.⁴

According to the 2011 U.S. Census Bureau⁵ population estimates, there were roughly 52 million Hispanics living in the United States.

Language

Language fluency varies among Hispanic subgroups who reside within the mainland United States. Census 2009 and 2010 data show that 76% of Hispanics speak a language other than English at home: 92% of Salvadorans, 82% of Cubans, 76% of Mexicans, and 66% of Puerto Ricans. Thirty five percent of Hispanics state they are not fluent in English. Within that group, 54% of Central Americans, 42% of Cubans, and 37% of Mexicans are not yet fluent in English.⁵

Education

According to the 2010 U.S. Census Bureau report, 62% of Hispanics, in comparison to 91% of non-Hispanic Whites, have a high school diploma. Thirteen percent of Hispanics, in comparison to 31% of non-Hispanic whites, have a bachelor's degree or higher.

Socioeconomic Status

This same report indicates 26.6% of Hispanics, in comparison to 14.9% of non-Hispanic Whites, work within service occupations. 19% of Hispanics, in comparison to 40% of Whites, work in managerial or professional occupations. Among full-time year-round workers in 2010, the average Hispanic/Latino family median income was \$40,165 in comparison to \$54,168 for non-Hispanic White families. 24.8% of Hispanics, in comparison to 10.6% of non-Hispanic Whites, were living at the poverty level.⁵

Insurance Status

It is significant to note Hispanics have the highest uninsured rates of any racial or ethnic group within the United States. In 2009, the Census Bureau reported private insurance coverage among Hispanic subgroups varied as follows: 51.6% of Puerto Ricans, 51.6% of Cubans, 39.6% of Mexicans, and 46.4% of other Hispanic and Latino groups. Public health coverage varied among Hispanic subgroups: 39.8% of Puerto Ricans, 31.6 % of Cubans, 30.3% of Mexicans, and 26.8% of other Hispanic or Latino groups. Those without health insurance coverage also varied among Hispanic subgroups: 42.4% of Central Americans, 23% of Cubans, 33.6% of Mexicans, and 14.9% of Puerto Ricans. In 2010, 30.7% of the Hispanic population was not covered by health insurance, as compared to 11.7% of the non-Hispanic White population.⁶

Some Common Cultural Characteristics for Latinos/Hispanics

There are a number of cultural distinctions which govern many social interactions within the Hispanic community. While a majority of Hispanics are bilingual, for many Hispanics language remains the most frequently encountered barrier to accessing healthcare. It is important to remember that one may speak a language but may not use it in a manner that reflects understanding of culture.

Health beliefs and customs influence the way many Hispanics seek healthcare services, their perceptions about illness and disease, general health, healing and wellness, and their experiences with healthcare providers. They also impact adherence to prescribed therapy, including medications. Some of these cultural characteristics include personal relationships (*personalismo*), who within the family structure are the primary healthcare decision-makers (*la familia*), trust (*confianza*), respect (*respeto*), and a holistic approach (mind, body, spirit) to care.

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When we speak of family (*la familia*) in the Hispanic culture, this includes not only immediate parents and siblings but aunts, uncles, cousins, grandparents, and godparents. *La familia* is central to the care of the patient. You will often see a family member accompanying the patient to a visit to the medical clinic or physician's office. There is an emphasis on interdependence over independence and cooperation amongst family members in both the care and decision-making process for the patient. This is important in the patient-provider relationship, as it may be a family member instead of the patient asking or responding to the healthcare provider's questions. This person may be a son or daughter, the spouse, or the elder of the family. It is also important for the healthcare provider to identify this person early on while establishing a relationship, especially if this family member is positioned to make recommendations and decisions for or with the patient. Who is the family member the family and the patient listen to? Who cares for the patient? This person needs to be included and also educated in the disease management process.

Personalismo

Hispanics, like most patients, wish to have a personal relationship with their provider, which is why so many Latinos rely on clinics and community-based organizations for their primary care. In addition, many clinics have in-house clinical lab and diagnostic imaging services on-site; some may also have a pharmacy within the clinic. This is important to the patient and/or family, as it results in coordinated services in one location. In addition, many Hispanics may be uninsured or work in positions that do not compensate for time off from work; therefore coordinated care results in less time away from their job.

There is a common saying among Hispanics, "If you are further than a handshake away, you are too far." Touch, such as laying hand on shoulder or a firm handshake, generally positively influences the patient-provider interaction. The expectation is that the provider will take an active interest in his/her patients' health and life circumstances. Do not be surprised if a healthcare provider leaves an organization and establishes a practice in another location, and the Hispanic patient follows the clinician to the new setting. This emphasizes the importance of a relationship with a provider, not necessarily an organization.

Respect (*respeto*)

Hispanics generally value the information, direction, and services given by their healthcare provider. One important skill to remember when using an interpreter is that the healthcare provider should look directly at the patient even though someone else is interpreting the information. Respect also dictates deferential behavior towards the patient based on age, sex, authority, or economic status. Greeting someone formally with *Señor* or *Señora* demonstrates respect and is especially important if the provider is younger than the patient. Healthcare providers, by virtue of their education and training, are seen as authority figures and are highly respected by Latinos. If the provider speaks some Spanish (even just greeting the patient with a few phrases), and helps with questions the patient or family may have, this significantly and positively increases trust (*confianza*.)

Similar to many within Eastern cultures, many Hispanics view health from a more synergistic viewpoint, a harmony of mind, body, and spirit. In many Hispanic communities there is still an extensive practice of traditional (non-Western) medicine by *curanderos(as)*, *yerberos*, *espiritistas*, and *sobradoras* (massage therapy). In some communities these traditional practices or remedies are found in Hispanic pharmacies, where the pharmacist is familiar with both traditional treatments (herbal teas) and western prescription medicines.

Healthcare providers should have a basic fundamental working knowledge of concepts of race, culture, ethnicity, family structure, gender roles, religion, death and end of life, communication styles, and principles of disease management as they relate to the Hispanic population. Effective communication skills, relationship building, Spanish language proficiency or effective use of interpreters, ability to differentiate varying views of illness and healing, and an ability to recognize culture-related problems are all necessary skills for working with the Hispanic community.

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WHARTON AROUND THE GLOBE

Transformational Change of Health Systems Is Inevitable on a Global Level

Health was a cornerstone issue at the World Economic Forum's 2013 Annual Meeting at Davos. Within this context and over the past year, the Forum, in collaboration with McKinsey & Company, engaged over 200 health system leaders, policymakers, and experts in an ambitious global effort to provide a long-term and holistic analysis of sustainable health systems. The central questions: What should our health systems look like in 2040? What strategies should we pursue today to realize that future?

The Forum engaged with leaders from five leading health systems across the globe: the Netherlands, Germany, China, Spain and England. In each country, the Forum hosted working sessions focusing on two core elements: vision and strategy.

- A vision is an aspirational statement that describes the health system in 2040.
- With that vision in mind, participants suggested a number of strategies to achieve those aspirational futures.

The country visions resulting from these workshops are depicted in [Figure 1](#).

For decades, healthcare spending has increased faster than economic growth, by an average of 2% in OECD (Organization for Economic Cooperation and Development) countries. This has yielded great dividends in terms of longer and healthier lifespans and higher economic productivity. Achievements and advances in health and healthcare are a major success story of the past century. However, this success has come at a cost, with healthcare expenditures outstripping GDP growth for decades across the OECD. As a consequence, in today's economic climate, many governments are targeting healthcare expenditures for cost-cutting as part of broader austerity programs.

A discussion on long-term sustainability, therefore, is timely, to ensure short-term priorities do not damage long-term value. Health system leaders need to think for the future, expand the group of responsible stakeholders, and break from the status quo to deliver high-quality, full-access, affordable, sustainable health services. Transformational change is not merely necessary; it is inevitable. As non-communicable diseases (NCDs) rise globally and as many populations age, financial sustainability will occur only if societies work together to make three things happen.

First of all, we must not only allow, but also embrace data and information to enable significant advances in health. The medicine of tomorrow needs to be better tailored to the needs of individuals, thereby increasing its effectiveness and reducing unintended negative consequences. Improved data and information are even today beginning to change the way health systems operate and make decisions, a transformation that can be accelerated by faster and more productive adoption and integration of these data.

Secondly, healthcare systems need to introduce new delivery models. Medical science has made tremendous strides in understanding the basis of disease and means of treatment, but the ways in which healthcare is currently delivered have not progressed for decades. Health systems must adapt to face the challenge of a 21st century disease mix, breaking legacy delivery molds and spurring innovation to produce better services, better outcomes, and better overall value.

Lastly, entire societies must build healthy living environments. Only if nations reshape demand for health services, thereby reducing disease burden by helping people remain healthy and empowering them to manage their health, will health systems become sustainable. Health systems can encourage people

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WHARTON AROUND THE GLOBE

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to develop healthier habits, incentivize healthier consumption, and create an environment and infrastructure that promote population health.

Health is a cornerstone issue, because it is a critical economic issue. As societies wrestle with achieving financial sustainability of health systems, the three themes of embracing data and information, innovating healthcare delivery, and building healthy cities and countries stand out as common strategies across the world. Their success is neither assured nor guaranteed, but they definitely represent our best chance. The only way to capitalize on this chance is to focus on taking action – collaboratively across the whole of society.