



H&P

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FIELD REPORTS

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LETTER FROM THE EDITORS

Dear Readers,

Thank you for taking the time to read the latest issue of H&P. This edition of our journal is entitled "Field Reports," to highlight the public and community health endeavors undertaken by medical students. We extend a warm welcome to the medical school's class of 2011, many of whom have joined H&P as writers and editors. We are also excited to introduce Laura Potter, a Stanford undergraduate and experienced graphic designer, as the new leader of our layout department. They have all made vital contributions to this autumn issue, and demonstrate the diverse talents of Stanford Medical School students.

Our featured authors have ventured beyond Stanford's classrooms and clinics in order to understand the lived realities of disease, health and medical practice. Their narratives chronicle the challenges that physicians face in diverse settings, but also illuminate how diverse thinking yields creative solutions to those challenges. Amrapali Maitra (SMS II) narrates her studies of violence against women in Bangladesh, providing insight into the complex nature of a shockingly prevalent phenomenon. Katie Miller (SMS III) recalls her experience studying the health of an isolated population in rural Utah. Katie's poignant reflections highlight the vital need to gain communities' trust in order to study community health.

David Carreon (SMS III) recalls a powerful experience collaborating with a religious community to confront global health problems. His reflections on this oft-overlooked demographic are particularly relevant to challenges facing medical outreach efforts. Harry Flaster (SMS III) concludes the Features section with the moving story of a United States Marine injured in Afghanistan. Harry's article is the first in a two-part series exploring advances in military medicine and the road to recovery for injured soldiers. For the traditional Leaders in Medicine conversation with a Stanford faculty member, Louise Wang (SMS I) interviews Dr. Paul Auerbach, a leader in the field of wilderness medicine. Dr. Auerbach's

experiences provide fascinating insights into medical practice in the field and medicine's synergy with other disciplines.

Medicine also requires us to comprehend the underlying pathophysiology and subsequent treatment of disease. To this end, Natalia Fijalkowski, Shushmita Ahmed, and Michael Kallile (SMS III) revive an H&P tradition: the clinical case report. They present a fascinating case that underlines fundamental principles of pharmacology and the importance of a thorough history and physical examination.

Physicians strive to treat patients as individuals and not just statistics, and understanding this distinction has become a cornerstone of medical education. Matthew Goldstein (SMS VII) recounts the story of an ICU patient who powerfully reminds us of this principle. Aarti Sharma (SMS II) introduces Dr. Richard Kogan, a physician and concert pianist whose career exemplifies the connection between medicine and the humanities, in the service of treating patients as whole human beings.

The medical and psychosocial complexities of sex and gender require us to maintain sensitivity to patients' definitions of their identities. In the narrative "Jared," Jessi Humphreys (SMS II) recalls her encounter with a transgender patient, providing an in-depth recount of the challenges of caring for these individuals. Mihir Gupta (SMS II) interviews Katrina Karkazis, PhD (a medical and cultural anthropologist at the Stanford Center for Biomedical Ethics), who discusses insights from her recent book on caring for patients with congenital disorders of sexual development.

We hope you enjoy this issue of H&P.

Sincerely,
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MAD AS A HATTER

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REPORT

A 15-YEAR-OLD BOY WITH UNKNOWN MEDICAL HISTORY WAS BROUGHT TO THE EMERGENCY DEPARTMENT IN AN ALTERED MENTAL STATE

by two teenage boys who reported that they “tried eating some leaves they bought at school.”



Datura. Illustration of the Datura weed (also known as Jimson Weed). Ingestion of datura is used in various cultures for their poisonous and hallucinogenic effects secondary to their anticholinergic properties.

His friends brought in a sample of the leaf, illustrated below. The patient was unable to provide a medical history and the family could not be contacted at the time of admission.

On initial physical exam, the patient was extremely agitated with incomprehensible and nonsensical speech and batting at hallucinated objects. He was tachypneic, tachycardic, and febrile with dry skin. Pupils were dilated and sluggishly reactive to light; mucous membranes were dry. Neurologically, the patient was alert and oriented only to name, with increased tone and myoclonic jerking of the extremities. The remainder of his examination was unremarkable. The patient was diagnosed with a classical presentation of an anticholinergic toxidrome and poison control was immediately notified. The management of anticholinergic toxicity depends on the severity of presentation. In mild presentations the treatment is supportive care and patient reassurance with continuous monitoring while the toxic effects wear off. For moderate to severe presentations - as with our patient - the treatment of choice is cholinesterase inhibitors such as physostigmine, which increase the amount of acetylcholine present in the synapse, thereby overcoming the anticholinergic blockade.

PATHOGENESIS

Muscarinic receptors (MR), stimulated by acetylcholine, are crucial to autonomic regulation. Anticholinergic effects on parasympathetic and sympathetic responses are summarized in the mnemonic: “blind as a bat, mad as a hatter, hot as a hare, dry as a

bone,” and “the bowel and bladder lose their tone, the heart runs alone.” M1 and M3 receptors regulate pupillary constriction, salivation, bowel motility, and bladder tone. Receptor antagonism therefore manifests in mydriasis, dry mouth, decreased bowel sounds, and urinary retention (*blind as a bat, dry as a bone, bowel/bladder lose their tone*). M3 receptors are also found on sweat glands (*the only sympathetic response controlled by MR*), and result in decreased sweating and hyperthermia when blocked (*hot as a hare, dry as a bone*). M2 receptors slow down the heart, which, when antagonized, results in tachycardia (*heart runs alone*). Finally, receptors M1-5 regulate the CNS, explaining why anticholinergic agents cause CNS disturbances such as confusion, hallucinations, or even seizures (*mad as a hatter*).¹

DISCUSSION

Datura is a genus of perennial plants of the deadly nightshade, or *Solanaceae*, family, used in various cultures for their poisonous and hallucinogenic effects.² In current times, *Datura* has become a fad among young adults who seek the plant to achieve a state of euphoria.³⁻⁵ The plants are found in rural and urban regions throughout North America, Europe and South Asia.⁶ The most common species is *Datura stramonium*, also known by the slang terms ‘jimsonweed’ and ‘stink weed.’ Each plant holds a unique combination of 28 types of belladonna alkaloids (the most abundant of which are atropine and scopolamine), chemicals which block muscarinic receptors, and thereby manifest in a classic anticholinergic response.⁶ The flavor of alkaloids and potency of the plants determine the severity of effects, and therefore pose a challenge to uniformly treating victims of *Datura* ingestion.⁵

Substance abuse and intoxication is a common entity among the adolescent population and necessitates rapid physician identification and treatment while working with very little to no history. Recognition of the classic anticholinergic symptoms of agitation, delirium and hyperthermia with dry mucous membranes is important



for clinicians to internalize in order to promptly stabilize and treat a potentially fatal intoxication. &

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MARIA'S MARRIAGE

MATTHEW J. GOLDSTEIN



Pria Anand

WE HAD JUST FINISHED OUR MORNING ROUNDS IN THE ICU

when I sat down at a computer to finish my notes. One of the patients I was following was very sick with an illness we were struggling to define. A mere two weeks earlier, she had developed a mild cough and a rash on her legs. Over the course of days these symptoms progressed into a mysterious, systemic disease affecting small blood vessels all over her body and damaging multiple organs including the kidneys and lungs. Her previous physicians had done an excellent job of keeping her alive, but with few options left they flew her to Stanford with the hope that we might

be able to stop the course of her rapid disease.

Her name was Maria. She was 26 years old with a loving husband and two young kids. I had met her several nights prior when they rolled her stretcher off the helicopter and into the ICU. Intubated and sedated, she appeared calm—her two long, dark braids resting peacefully over her shoulders. She couldn't speak but struggled to open her eyes. We explained where she was and discussed our plans of how we would treat her -- her squeeze of my hand was the only sign she understood. Her husband arrived in the ICU in the early hours of the morning, looking lost and scared. He had driven over 4

hours in the middle of the night to reach her bedside. He pasted two photos of their young children and a small picture of Jesus Christ at the foot of her bed and listened calmly and intently when we explained the critical nature of her condition. When I left that night, he was stretched across three chairs in the waiting room, asleep.

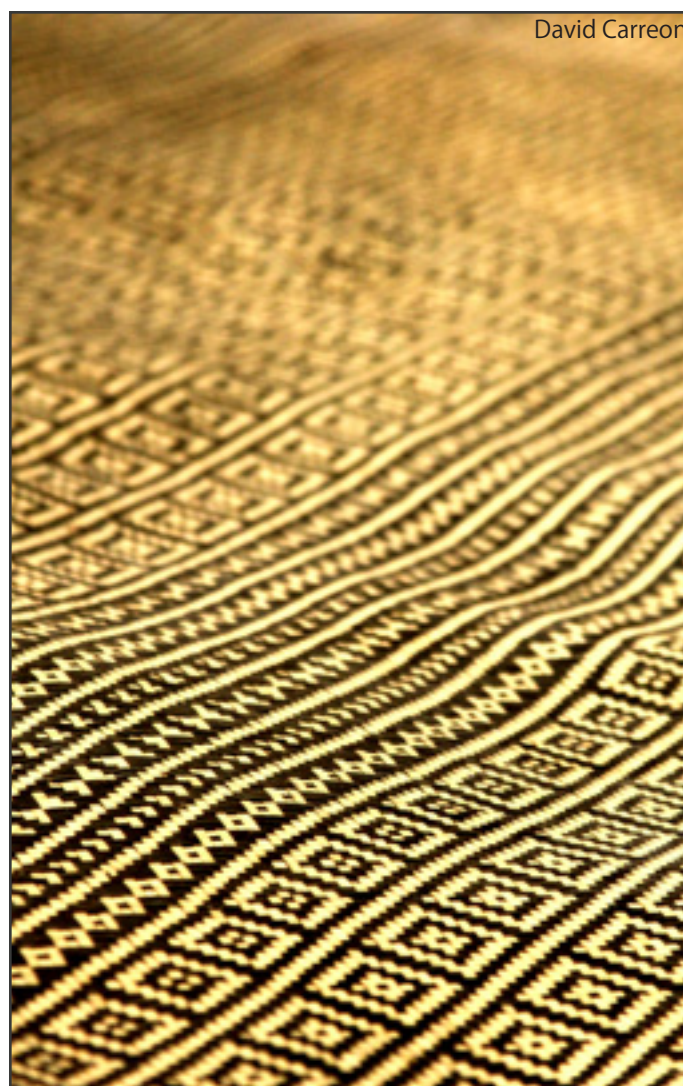
As I finished my notes and phone calls that morning, the resident I was working with came walking quickly down the hall. “Maria is getting married over in the North ICU. The family has asked us to witness the ceremony.” “Married? I thought she was already married,” I said. “They were married in a civil ceremony at the courthouse, but have never been married in the eyes of God. The husband called on Spiritual Care and asked if they could be married by a priest, just in case she doesn’t...well...make it.” Stunned, I sat quietly for a moment. The news of this ICU wedding came crashing in on my perception of the smooth, systematic efficiency of ICU patient care. It took me a minute to set aside my thoughts about sedation requirements and steroid doses and consider the act we were about to witness. I turned off the computer and walked quickly down the hall to Maria’s bedside.

Father Fletcher was already there. A Spanish-speaking nurse was holding the prayer book and standing near the head of the bed. Maria’s husband stood quietly holding her hand. With his hair wet and freshly combed, he wore a prayer shawl around his neck. The nurse had raised the head of the bed and we had decreased Maria’s sedation so that she was alert enough to look up at us and smile when we entered the room. I had walked past that bed over a dozen times and this was the first time I actually saw Maria, the person and not the patient. The ceremony was as beautiful a wedding as I have ever seen. Father Fletcher led with prayers and words. He shared some reflections on the bond of marriage and the meaning of this event at this time. He sprinkled holy water over their hands and just as he was about to speak the pronouncement of husband and wife, Maria raised her hand. She slowly lifted a finger and pointed to me, to the holy water, and back to her and her husband’s interlocking hands. Father Fletcher motioned me over and, with my hand inside his, guided me in blessing them a second time. Husband and wife. A kiss—lips to forehead.

A tear rolled slowly down Maria’s face.

Amazingly, Maria survived. Her course was long and drawn out, but she left the ICU and eventually the hospital altogether. Maria taught me a great deal about managing critical illness in the ICU and undoubtedly our interventions saved her life. But more importantly, she taught me about the value of the human spirit. Our medical team focused on Maria’s disease and the treatment that we hoped was a cure. But for her and her husband, the ability to experience the sacrament of marriage was paramount. When patients come to our hospital they arrive both as patients and as people. Maria and her husband taught me that we must treat both.

A few elements of this story, including the patient’s name and medical details, have been modified for confidentiality purposes. &



David Carreon

JARED

JESSI HUMPHREYS

The Health Stories Project is a national research project that collects narrative experiences of lesbian, gay, bisexual, transgender, and intersex/disorders of sexual development (LGBTI) patients and shares these stories. We recruit participants who have concrete, compelling healthcare experiences that are positive or challenging—often both—and represent a range of sexual orientations, gender identities, races/ethnicities, ages, and locations.

Interviews conducted with participants are constructed into compelling and relatable narratives of LGBTI individuals' experiences in accessing and receiving healthcare.

Through these narratives, we give voice to the often invisible experiences of this underserved population in healthcare. In addition, these narratives can compel healthcare providers to treat their LGBTI patients more sensitively and provide models for doing so.

**Here, we share the health care stories of Jared,
a transgender-identified individual from the North East.**

JARED WAITED IN HIS ER BED, HOLDING HIS SWOLLEN HAND AWAY FROM HIS BODY

and breathing shallowly to avoid moving his broken ribs. He waited for the intake nurse to return so he could finish telling the story of the car accident that brought him in.

Suddenly, the supervisor sashayed in and said, “Well, I got to know, have you had the surgery?”

As a female to male transgender person, Jared hated that question: it could mean so many things. Primarily, it implied that there is some singular surgery that defines a transgender person.

Jared had undergone many surgeries: bladder, heart, and others. He told her he did not understand why she needed to know about any gender reassignment surgery he had undergone. Her response was, “Well, I don’t know what you are,” as if Jared was something different from a person.

“Do you have papers on you?” she added. He had a license, insurance card and social security card that all displayed an “M” for male, his preferred gender. This was

more documentation than the average cis-gendered (one who identifies as the same gender assigned at birth) individual would be asked to carry or produce.

But these were not enough. It was not until Jared returned home and his husband noted the “F” on Jared’s hospital ID bracelet that he realized he had been assigned the female gender against his will. This realization incited Jared to think back on the many healthcare professionals he had come into contact with during the long ER visit: the ultrasound technician, the nurses, the doctors, the hospital aid who used to teach his son at home in their town. Jared appeared male, but with an “F” on his wrist and in his chart he had unknowingly been forced to expose himself as transgender to all involved in his healthcare.

This was not the first time that Jared experienced such frustrations in the medical world. Once, after an umbilical hernia repair, he was approached by a nurse who stated she needed to check his incision but would not let him sit or reposition the sheets to main-

tain his privacy. She lifted his gown in front of a window that faced other patients in an adjacent wing of the hospital. She came up after looking with a smirk on her face.

Offended and upset, Jared felt the nurse was only satisfying her curiosity and gathering fodder for gossip later in the lunchroom. Of the incident, he said, “a lot of medical people still think, ‘well, you brought this on yourself, so I have an excuse to do whatever I want to you, because you’re worth less than normal people.’”

When he sent a complaint to the hospital, the patient quality branch of the hospital responded that they did not have any evidence that the reported event took place and had no ability to follow up without witnesses.

During another hospital visit, Jared was placed in a room with a violent and vocal patient who demanded “this guy” be removed from his room; only once Jared’s heart rate was fast enough to visibly quantify his fear did the nurses approve his move to another room.

Jared has been surprised at times at the lack of knowledge medical professionals display about transgender health. In one clinic, a doctor said to him, “I see you’re taking testosterone. Are you becoming a woman?” Encountering such inadequacies in transgender care has caused Jared to switch physicians multiple times.

Further, Jared has experienced frank discrimination in his dealings with medical professionals. Jared felt obliged to switch from one of his former physicians after the doctor made the comment that he was “against gay people.” Being the husband of a gay man, Jared began to question whether he would be well cared for by a physician who had displayed such open prejudice.

After this experience, he switched to a very supportive physician whom he described as an “earthy,

crunchy, Vermont graduate.” When Jared first came “out” as transgender to her, she said, “Anything that you learn that you think I should know -- give me the articles. Give me the information. Shoot me emails. Send me anything.” She was “willing to learn and listen and take time” with Jared in order to support him in his transition.

Jared has also interacted with nurses in the hospital who have also been particularly sensitive and supportive. Those who gather medical histories in private locations allow Jared to feel safer discussing medical issues. It can be “really difficult to be in the next bed and be telling the nurse that you’ve had a hysterectomy when you’ve got a male roommate.” He appreciates when nurses ask him how he would prefer to urinate instead of assuming a bedpan will be sufficient. Jared has not had genital surgeries that would enable him to use a bedpan.

Although Jared has been “out” as transgender in some medical situations, he has not felt that his workplace is a safe environment in which to reveal his gender

identity. He says, “Unfortunately, there’s a very conservative man at our office who can make my life hell if he knew that I was trans and in the men’s room.” Because he does not wish to lose his job, Jared continues to keep his identity private in the workplace.

Despite his concerns about personal privacy, Jared volunteers to teach

medical students during their OB/GYN rotations about the unique needs of transgender patients in gynecologic practices. He discusses the continuum of sexuality and gender with students and gives advice for working with transgender patients.

He reminds students to ask open-ended questions such as, “What kind of support are you getting?”





Michael Ahdoot

instead of challenging them with questions like, “Why do you think you are trans?” He reminds students to use the name and pronoun that the patient prefers, regardless of what they look like. Jared says, “the worst thing is people who knew me before and insist that they’re still going to use female pronouns and that somehow I’m not a real person.”

When medical students are concerned about making a mistake with a patient’s name or preferred gender pronoun, he says it is always better to ask for a patient’s preferences or apologize, and try again, after a mistake. He tells students to ensure that modesty is maintained with gowns and proper draping during physical exams and encourages them to talk patients through procedures that can be difficult and stressful. Jared also reminds medical students not to ask patients if they have had “the

surgery,” because a person has often had more than one procedure and may not feel any individual procedure is “the surgery” that defined their gender transition.

Because the front desk and other support staff is the first line of healthcare a patient will come into contact with, Jared emphasizes how important it is for physicians to train their entire staff to be respectful to transgender individuals by using preferred names and gender terms. Bathrooms can also be a significant source of stress for transgender individuals and providing single-sex bathrooms helps to relieve that stress.

As he sees more LGBT individuals age and consider entering retirement communities, Jared is especially concerned about the state of elderly care for LGBT individuals. Many are afraid of the potential prejudice they might face and fear being at the mercy of healthcare providers who may be judgmental or have limited understanding of a transgender person’s healthcare needs. Jared says, “When you’re faced with an elderly person whose body is not standard, don’t discriminate, [because] they deserve dignity and respect,” just as any elderly person does.

When Jared finds medical students who are especially enthusiastic and want to learn more about trans health, he tells them to seek him out and ask more questions. He reminds them to avoid asking questions in front of his co-workers, given his concerns about privacy.

Jared’s hope for the future is that there will come a time when transgender individuals will not have to be in fear “when they are on a stretcher somewhere wondering what they are going to face and who is going to say something and what they are going to do.” The hospital can be a terrifying place where you are sick and are at the mercy of others, unable to advocate for yourself. Jared hopes medical students are taught that transgender patients “are people too, and we have bodies that need to be taken care of, no matter how [providers] feel about them...The future would be great if we could just be seen as people.”

VIOLENCE AND THE POWER OF SEEING

AMRAPALI MAITRA



Amrapali Maitra

JULY 5TH, 2011: DHAKA, BANGLADESH

I WRITE THIS POST FROM A CHAIR OVERLOOKING THE QUIET STREETS

of Dhaka's diplomatic zone, Baridhara. For a brief moment the monsoon rains of July hold their breath and the sun peeks through in time for the evening call to prayer. I have spent almost two weeks in this city, and am still unable to predict its fickle moods—when rain will fall tempestuously, or traffic will clog the streets, or the usually pervasive rickshaw drivers will suddenly disappear. On a walking tour of Puran Dhaka, the historic part of the city, we saw that the new Dhaka is built on and out of pieces of the old: homes and businesses lie within ruins of Mughal architecture; a recycling district works wonders molding discarded fragments of metal and plastic into pots, electronics, toys. Here, mango season wraps us as I frantically track down the sugary fruit in grocery stores; on the other hand, after giving pungent jackfruit a try, I have decided that its slimy custard is not for me. Our meals vary from traditional rice, daal, and vegetables in the institute's canteen, to hot samosas on the street, to pizza delivered at our door.

The past week and a half of work at the ICDDR,B (known to locals here as the Cholera Hospital) has shown me how this organized, efficient institute produces such outstanding research including and beyond diarrheal disease. Researchers here are dedicated, hardworking,

and kind; people from all over the world work side by side in labs, hospitals, and rural field sites. My own work lies in the division of Public Health Sciences, where my colleagues study disease and health outcomes in slum and rural communities, issues of women's health and safety, and indicators of child mortality, among many other topics.

The goal of my research is to understand how we can develop an effective screening tool to identify women who suffer from domestic violence. To do so, I need to first understand the clinic site where I will be working, one of the many Marie Stopes reproductive health clinics in Dhaka and a partner for the larger gender violence intervention headed by my mentor here. Therefore, over the past several days I have been developing guides for observation studies and focus groups within the clinic. It is only by assessing the feasibility, readiness, advantages, and disadvantages of screening for violence that we can successfully implement a screening tool.

This process of assessment requires a certain guide or set of principles. Qualitative studies vary in their methodology, and I will be employing one type of study as a launching point for my project: observation. Specifically, members of my research team will be visiting each of the clinic sites and observing patient-provider interactions, clinic logistics, and provider attitudes that yield insight into gender and gender violence. We will make our notes on observation guides that seek to determine key features



of the clinic's approach to identifying and tackling abuses suffered by their patients. This guide was developed by learning from observational studies on clinic gender violence attitudes such as one conducted in districts of Madrid, as well as by identifying key issues in the relevant communities from existing baseline data (such as the informative 2005 WHO Multi-Country Study on Women's Health and Violence Against Women).

This type of work revolves around the power of seeing. A researcher in an observational study does not merely look upon the space in question; she sees the transparent and hidden qualities that define its capabilities. In the case of a clinic study on gender violence, she sees gender attitude among clinic staff, notices (non)-empathetic, (non)-judgmental treatment of patients, and apprehends time and room available for confidential discussion. From this sight she derives observations that can be acted upon — behaviors and services to modify, improve, or maintain. This work is not dissimilar to the general task of seeing in interventions for violence against women. The counselor, the women's shelter volunteer, the lawyer, the nurse, and the survey conductor all play the role of witness to the narrative of a woman who confronts abuse. The invisibility of these abuses within domestic spaces and within social norms is only broken by an act of seeing between a woman and a service provider.

And yet this particular methodology poses challenges. The problem with words is that, perhaps unlike numbers, they are steeped in the local. I participated in a community visit to a slum of Dhaka called *lal maati*, or "red floor." We wove our way around sheets of corrugated tin and post-rain

sludge to enter women's rooms and ask them about their availability for interviews — researchers undertaking a baseline survey, separate from my screening project, were searching for key informants. Two elderly women ushered us into their rented room, warmly seating us on the bed underneath a ceiling fan. As the sweat evaporated from our faces, one of the women stood and launched into a long and passionate story. Shocked, I realized that I couldn't understand what she was saying. I have had no trouble communicating with those around me at the institute, and yet the accent and dialect of Bengali spoken by this woman were informed by her regional origin and educational status. My untrained ear could not make sense of the words that streamed out of her. While I nodded politely, snatching eagerly at words I could recognize and inquiring further, I left feeling as if I didn't understand the very story I had hoped to witness.

If narratives of women's lives are told in the language of the local, how do we make observations about gender in a low-income area of Dhaka applicable to issues of coercion and HIV rates in a large village in Tanzania, or sexual assault in elite college campuses in the United States? Today I attended the annual conference of the South Asian Women's Network, where speakers across the subcontinent proclaimed the importance of sharing knowledge that cuts like rivers across our often-divided, often-hostile borders. The shared joys and shared sorrows of womanhood need translation to be recognized, compared, and consulted across regions. In many ways the power of seeing — through an observational study or in a clinical encounter — is only solidified through an ability to translate this sight into words comprehensible and relevant to the communities we serve. The larger task of my research here is to learn lessons from the environment of urban low-income Dhaka that will be applicable to gender-based violence in communities where I live: on college campuses like Stanford, in the free clinics and hospital systems around me, and in Bay Area organizations that help immigrant, refugee, or unhoused women find safety and freedom from violence. &

INVESTIGATING HEALING TRADITIONS IN RURAL UTAH

KATIE MILLER



“I THINK YOU’D BETTER LEAVE NOW,” HE SAID, HIS FACE DARKENING.

Taking his advice, I quickly exited. So went my unceremonious dismissal from the pharmacy, a jarring welcome to Hildale, Utah. This town, a mere six hours from where I grew up, is not a tourist destination, and those who drive through it when crossing the Utah-Arizona border may never suspect the realities of the people living there. Although I personally entered by choice, I quickly learned that visits here are not to be undertaken lightly.

Beneath a magnificent red butte on the border of Utah and Arizona lies an isolated community known as “Short Creek,” comprised of Hildale, Utah, and Colorado City, Arizona. Driving into that community my first day, I

could feel the air ripple with suspicion, born of decades of mutual distrust between this community and the outside. I have never felt so foreign, no, not in rural Ghana nor the bustling streets of Old Delhi. Our car was unknown, my attire was out of place, and my questions were certainly uninvited.

The roughly 5,000 people who live there are known as the “Creekers,” or those that are from the “Crick,” and have lived in isolation for more than 80 years. These people, the large majority of who are members of the Fundamentalist Church of Jesus Christ of Latter-Day Saints (FLDS), are brought up in a lifestyle of plural marriage, meaning a marriage between one man and multiple women, and are surrounded by their

peers in “the covenant.” While often confused with the modern Mormon (LDS) Church, the two are now so different in their teachings and practices that experts and members of both parties agree that they should be considered completely separate.

This community is largely segregated from mainstream society, and has become even more so in recent years. Community members are distrustful of outsiders and have a history of periodic mutual animosity with local government and church authorities due to their propensity to practice polygamy, illegal in the United States, as well as their intentional removal from mainstream society.¹ Not surprisingly, little research has been done on the community.

Growing up in Salt Lake City, the photos of these people seemed like they came from a distant time and place, not a mere six-hour drive away. Not only do they dress as though they were living in the late nineteenth century, they also live in large family compounds and shun outside influence. Media coverage of their lifestyle is limited to the infrequent scandal or lawsuit, with the community representative being a bearded, middle-aged man, further perpetuating the stereotype.

Deciding to research this population required that I dismiss my preconceived notions and prejudice, and attempt to enter it as an objective, even friendly, observer. Unfortunately, the years of media and government onslaught against the community have left members distrustful, verging on hostile, to outsiders. This is unfortunate, not only because it further perpetuates prejudice and misconceptions about the community, but because it deters them from seeking and gaining improved access to healthcare. The legality of polygamy and the associated stigma has created a community where change is feared, where outside influence is shunned. The emotions my presence, complete with clipboard and digital recorder, incurred are clear evidence of their

fear.

Anecdotally, their medical care can be summed up by a visit to the health clinic, an isolated white building set on a hill, and surrounded by a formidable fence. Those who wish to visit must first gain entry via a security camera at the gate. In spite of this profound isolation, along with their history of rejecting outside influence, community health is much better than many experts expect. My research findings indicate that health in this community is shaped by limited resources, an attitude of health fatalism, and a profound insularity and corresponding isolation from the outside world.

In assessing for community health needs, it is important to parse which circumstances are particular to this community because of their being a rural, isolated community, and which particularities are due to their lifestyle of plural marriage and the associated beliefs. Although the legal status of polygamy is a complex issue, I hypothesize that should this community be able to live without the constant and overarching fear that their families will be separated, many of their health challenges could be alleviated. Further policy and research is ahead! &

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Katie Miller

HOW TO GET CHURCHES INVOLVED IN GLOBAL HEALTH

DAVID CARREON



“...Religious people and secular people alike do fantastic work on humanitarian issues — but they often don’t work together because of mutual suspicions. If we could bridge this ‘God gulf,’ we would make far more progress on the world’s ills. And that would be, well, a godsend..”

- New York Times columnist Nicholas Kristof¹

I WALKED ONTO A STAGE AND LOOKED OUT AT A THOUSAND FACES WATCHING ME.

My heart rate was at a gallop. On stage, I sat across from the pastor of my youth. He started asking questions. About God? Salvation? Faith? No. None of these. Instead, he asked me about measles: *What are the symptoms? How is it prevented? How much does it cost to prevent? How could the church participate?* At the end of the

interview, he gave an impassioned plea for the church to donate to a project I had proposed. When the money was totaled from the weekend, we had raised \$20,000.

The Christian Church is a huge and largely untapped source of funding, people, and passion in global health. Churchgoers around the world donate \$298 billion each year to charity.² If 1% of this were



Aria Jafari

diverted to global health, it would be more than the contributions of the Gates Foundation or Global Fund; with 10%, it would more than double total spending on global health.³

Before this project, I did not believe that the church would fund a direct global health project. I shared the common view that churches and pew-sitters (or even fancy-padded-chair-sitters) weren't going to give much to people outside their community – and if they were, it would have to be inextricably tied to proselytizing. But that weekend, the members of my church funded a project to benefit a group of non-Christian indigenous people. A strong vision given to a big church made funding easy. I had to write no grants. I had to show no preliminary results. I had to go through no committees. I didn't have to bake anything or wash any cars. All I had to do was convince people

that children could be saved if they gave money.

There were many objections. And to create a successful project, I needed to answer the concerns, conscious and subconscious, of the potential donors. The strongest of them was a simple one: “Nothing can be done.” As I talk about global health, I get the sense that we've oversold the problem. It's so bad in the mind of the public that anything that could be tried would be futile. A simple reassurance that things, in fact, could be done and have been done, was enough to persuade my pastor. The contrast between perceptions (“Nothing can be done”) and reality (“The cost to save a life may be less than \$100”) causes a wonderful cognitive dissonance.⁴ After my short interview, I received many miscellaneous questions from the church members. And as I imagine in any large and representative group of people, the concerns ranged widely from “How will you achieve sustainability of your project?”

to “Shouldn’t they have just used birth control?” Most of the concerns were not particularly Christian and could be faced by a secular fundraiser.

The biggest religious problem people had with my plan to give vaccines to children was a concern about a lack of evangelism: “Aren’t you going to be using this project to preach the Gospel?” For many Evangelicals, this is the utmost in the hierarchy of good deeds; to omit it would be, well, heresy. Superficially, my project proposal lacked all public speaking persuading people to be Christians and so violated the evangelical sensibility. Though superficially erring, I believed my project in line with the commands of Christ; and so I answered: “I am preaching the Gospel. Jesus certainly gave sermons, but He also healed; both were a part of His ‘preaching.’” Depending on how much time I had with a person, I would explain that the Biblical commands to help the poor are independent of any obligation to also proselytize.⁵ Nevertheless, for some members of the church, this was probably the toughest pill to swallow. But in the end, they did (at least corporately) swallow it, and paid for a project that would include no “preaching,” beyond treating physical diseases of non-Christian children.



Rowza Rumma

After overcoming the objections, the benefits of working with a church began to appear like wildflowers in a green field: wonderful, varied and unpredictable. One thing that became immediately obvious was the plethora of professional connections available in a large church. The morning I talked about the project, I met a printer

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(who offered to pay for any marketing materials we would ever need), a Filipino manufacturer (who offered to assist us with in-country logistics), and a vaccine salesperson (who offered to help us get our vaccines donated). But the most important connection I made was the missionary from the church. With him, I wasn’t starting out as a foreigner. The missionary spoke the language; in fact, he invented the written language. He knew where to go and whom to talk to. He could help me avoid the cultural taboos. Most importantly, through twenty years of service

and relationship, he had built the trust of several key members of the community, people who were trustworthy, and people who could carry the vision forward. This last piece, reliable and capable in-country partners, is the most important part of any project, and we were able to start with a firm foundation. Never before have I started a global health project with so many human resources.


The relative ease of funding meant that, unlike most charity ventures, we could continue

funding indefinitely without even getting very creative; there was plenty of money already in the church. Also, not having to be creative gave us greater freedom to be creative. Having \$20,000 to work with put us in a very exciting position. That money funded my trip to the Philippines in August and the first few months of our pilot project. The project launched according to plan and it is presently running strong with a Filipino team on the ground and administered by already-salaried church leaders and volunteers. Considering how much time I put in compared with the likely long-term impact, this was the most efficient project I have ever been involved with. I was able to act as a catalyst, activating the dormant resources of the church. Catalysis is a powerful way to recruit new people and monies to the fight against global poverty and disease.

If you have a religious community, get it involved in global health. Talk to your rabbi, reverend, priest, pastor, preacher, imam, or bodhisattva and find out what is available in your religious community and what could be made of it. Even if you are not religious, you can help in getting religious money spent on global health. In fact, the secular person may be in the best position for convicting the religious conscience by asking, "I do global health to show my concern for the poor abroad; what do you do?" On the donor-direct microfinance site Kiva.org, there is a running competition along these lines between the "Atheists, Agnostics, Skeptics, Freethinkers, Secular Humanists and the Non-Religious," and "Kiva Christians" (which the Atheists et

"Catalysis is a powerful way to recruit new people and monies to the fight against global poverty and disease."

al happen to be winning at the time of this writing).⁶ This is uncharted territory. I doubt anyone knows what would happen if an Atheist infectious diseases doctor called up a local pastor and offered his pro bono services as a global health consultant. But there is only one way to find out.

Let us forgive and heal the wounds of old religious (and nonreligious) wars. Let us all join together as a federation, the Christian beside the Atheist and the Buddhist beside the Muslim, marching out against common foes: viruses tearing apart immune systems, parasites feeding on human blood, bacteria drowning babies from the inside. We don't have to agree on the nature of God, or even Good, to agree on the nature of Evil. There are plenty of things for us to debate along the way, plenty of good-natured philosophical wrestling matches we can (and should) have along the way, and even plenty of time to get back to our old battles, if we must, once we are victorious here. But for once, we agree on something very important. Let us be united toward this common end: slaying that monster of old, the Dragon of Disease. Would you join me on that quest? 

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THE NEXT WAR

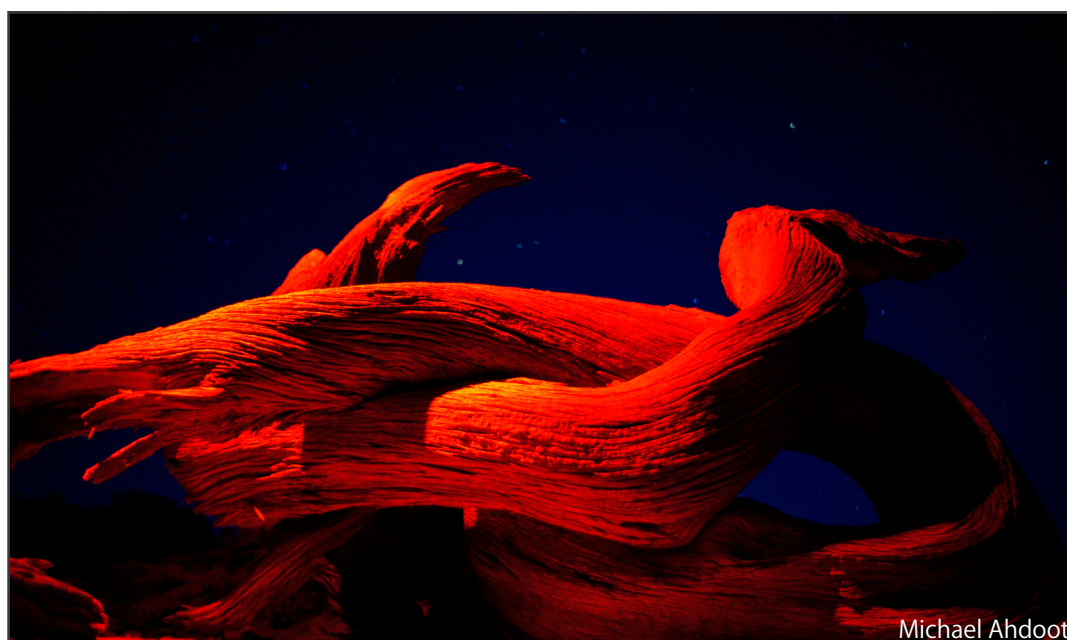
HARRY FLASTER

Part One of a Two-Part Series

ON JUNE 26TH, 2011, 24 YEAR-OLD MARINE CORPORAL “M” STEPPED ON AN IMPROVISED EXPLOSIVE DEVICE (IED) BURIED UNDERNEATH A HOUSE IN SANGIN, a town located in the rural Helmand Province of Afghanistan.¹ The explosion and shrapnel immediately severed both his ankles, ripped through his remaining lower extremities, drove contaminated debris deep into his soft tissue, fractured his pelvis, and lacerated his abdomen and chest. The shock wave lifted him in the air, propelled his head into a wall, caused a frontal skull depression fracture, which partially dislodged his left eye, and resulted in bleeding in his brain.²

He survived.

Corporal M’s survival depended on a unique system of global health care that started with immediate interventions by his fellow Marines on the ground in Afghanistan and continues today at the Veteran Affairs Hospital in Palo Alto. The current U.S. military trauma care system is based on lessons learned in previous wars and the current



Michael Ahdoot

wars in Iraq and Afghanistan. In examining retrospective data from Vietnam, researchers found that most wounded die en route to a surgical field hospital. If a wounded soldier survived transport to a surgical field hospital, their chance of surviving their injury was over 95%.^{3,4} Based on this data, the current emphasis of military trauma care is preparation, stabilization and speed, with definitive surgical repair deferred to tertiary care centers established outside of combat operations. The imperative is to establish mobile surgical teams closer to the fighting to quickly stabilize wounded military soldiers, with subsequent rapid transportation to hospitals better equipped for more advanced care.

Five days, 20 operations, and over 6,000 miles transpired from the time of the IED explosion in Sangin until Corporal M arrived for definitive care at Walter Reed Hospital in Bethesda, Maryland. For some wounded soldiers, this journey is completed in 36 hours or less.³

The IED explosion occurred in a house that Corporal M's unit, 1/5 Charlie Company, occupied overnight to gather local intelligence, a key part of the on-going counterinsurgency strategy. It is protocol for an experienced "sweeper" to scour new locations for IEDs before a unit enters, and that night was no exception. After the house was declared secure, with no IEDs detected and marines positioned on the roof with a 360-degree view of the neighborhood, M followed protocol and removed his bulky body armor in order to sleep. He woke the next morning and proceeded to walk through the house in order to wake up his sleeping comrades. When he stepped on the IED, he had not yet put his armor back on. The explosion occurred underneath

him, in an empty room. It would change Corporal M forever.

Despite Corporal M's catastrophic blast and penetrating injuries, his marines could not help him until their sweeper cleared the room again to avoid additional casualties from other, potentially hidden, IEDs. This took precious time as Corporal M lay bleeding in the small crater created by the explosion. As soon as the room was deemed safe, resuscitation began: marines applied tourniquets to the proximal portion of his lower extremities to control hemorrhage, and placed large bore intravenous lines (IVs). A helicopter transport arrived within minutes of the explosion and rapidly transported Corporal M to a Forward Surgical Team (FST) based in Camp Leatherneck.



Though the sweeper missed the buried IED that Corporal M stepped on, he later emphasized that "everybody did their job...it wasn't anyone's fault what happened."⁵

Forward Surgical Teams are small, consisting of approximately twenty people, typically three general surgeons, one orthopedic surgeon, two nurse anesthetists, and three nurses, with additional medics and support personnel. The team travels in six Humvees, and is equipped to establish a functioning hospital with four ventilator-equipped beds and two operating rooms within an hour. To accomplish this difficult feat, they carry three lightweight, deployable rapid assembly shelter ("drash") tents that can be attached to one another to form a 900 square foot facility. Supplies are carried in five backpacks: ICU, surgical-technician, anesthesia, general surgery, and orthopedic packs. These packs hold all the

equipment needed to operate, including sterile instruments, anesthesia equipment, medicines, drapes, gowns, catheters, and a handheld “istat” unit allowing clinicians to obtain real-time hemograms, electrolytes or blood gases with a drop of blood. FSTs also carry a small ultrasound machine, portable monitors, transport ventilators, and an oxygen concentrator capable of providing up to 50% oxygen, twenty units of packed red blood cells, and six roll-up stretchers. FSTs do not carry angiography and radiography equipment: surgeons detect fracture by feel and apply external fixators. Nor are FSTs equipped for more than six hours of postoperative intensive care. However, they do carry sufficient supplies to evaluate and perform surgery on as many as thirty wounded soldiers.³

At the Camp Leatherneck FST, Corporal M was intubated and a coma induced so that military surgeons could amputate his right extremity below the knee, his left extremity above the knee, stabilize his broken pelvis with screws, and open his abdomen to identify and control hemorrhage and remove shrapnel and other debris. Considered stable enough to withstand another helicopter transport, he was sent that same day to Bagram Air Force Base outside of the capital city of Kabul.

At Bagram, a Combat Support Hospital (CSH) provides the next level of care. CSHs are typically 248-bed hospitals, which, like FSTs, are fully mobile; they arrive in modular units by air, tractor-trailer, or ship, and can be functional in 24-48 hours. CSHs have six operating tables, specialty surgery services, in addition to advanced radiology and laboratory facilities.

Corporal M arrived at the CSH in Bagram in a hypotensive state, and resuscitation continued. Once stabilized, surgeons washed and drained his abdomen, performed a sigmoid colectomy with colostomy, and explored his perineum for further injury. To address his head injuries, his epidural hematoma was evacuated and his right frontal sinus was drained with a catheter.

In 24 hours, M had traveled 400 miles and survived eight operations. His journey, however, was just beginning.

The maximum length of stay in a CSH is intended

to be three days. The policy is to transfer any American who requires more care to a level IV hospital located in Kuwait, Germany, or Spain. The following day, M was transported on a ventilator and with an open abdomen to the Landstuhl Regional Medical Center in Germany, a level IV hospital. At Landstuhl, M’s abdomen was repeatedly washed and drained to remove debris. After several

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of these “washings” the abdominal fascia was closed but the skin was left open. If a wounded American soldier is expected to require more than 30 days of treatment, they are transferred back to the United States, mainly to Walter Reed Hospital in Bethesda, Maryland or Brooke Army Medical Center in San Antonio, Texas. On July 1st, physicians determined Corporal M met criteria and could survive the ten-hour flight to Bethesda.

Corporal M does not remember the explosion or any of the subsequent hospitalizations or travel prior to arriving in the States:

“All I knew is that I had woken up in Bethesda...to my brother looking at me, and I asked my brother what had happened, and you know, my brother was a former Marine, and he was very to the point, and he told me: you lost your legs. I didn’t believe him, all I did was tell him to shut up, I don’t believe you, you’re an asshole, like, why are you telling me this, like why...then the nurse had come in and removed the sheet, and I looked down and my brother wasn’t lying, so...my mouth was just wide open, like, no way – like I was in total shock that it was me.”

After additional surgeries, including repair of his



skull fracture, extensive debridement and finally, complete amputation of his right extremity and part of his pelvis in order to contain a necrotizing soft-tissue infection, he was determined ready for the flight to the Palo Alto Veteran Affairs Hospital, where he would begin rehabilitation.

Remarkably, what is most impressive about Corporal M's story is how common such stories have become in the wars in Iraq and Afghanistan.

Since the beginning of US military operations in Afghanistan, 14,837 U.S. service members have been wounded in hostile action. Those killed in action number 1,828.¹ The number of combat deaths, according to surgeon and author Atul Gawande, is often used as "a measure of the magnitude and dangerousness of war, just as murder rates are seen as a measure of the magnitude and dangerousness of violence in our communities."³ However striking, both are poor measures, because they fail to recognize how important the medical system is in determining whether or not someone dies. For example, US homicide rates have dropped in recent years to levels unseen since the mid-

1960s.⁶ Less appreciated is that during the same time period, aggravated assaults with firearms more than tripled. The difference in mortality, therefore, is not due to a drop in violent crime, as is often misinterpreted, but instead the result of our civilian trauma care system: mortality from gun assaults has fallen from 16% in 1965 to 5% today.^{3,6}

Similarly, there has been a decrease in mortality from war injuries. While more US military personnel have been wounded in the current Wars in Iraq and Afghanistan than in the Revolutionary War, the War of 1812, or the first five years of the Vietnam conflict, a far larger proportion of soldiers are surviving their injuries and the overall number of fatalities is significantly lower. In fact, the wars in Iraq and Afghanistan have had the lowest mortality to wounded ratio of any US War. To put this in perspective, in the Revolutionary war, 42% of all those injured in battle died from their wounds. In the Civil war, 33% died, in World War II, despite the introduction of antibiotics, 30% of all those wounded died. In the wars in Iraq and Afghanistan, to date, less than 10% of all those wounded died from injuries sustained in battle.⁷

Corporal M, who was adopted from an Indian orphanage and brought to America as a child, feels he is "paying back America" through his service. Prior to serving in Afghanistan, he was given the honor of an appointment to the highly selective Marine Presidential Guard. This unit, along with the secret service, is responsible for protecting the President and visiting heads of state. However, in practice, Corp. M's role with the Presidential Guard was often ceremonial and always safe. He served as part of the color guard that escorted President-elect Barak Obama to his inauguration, and was a member of the honor guard for the caskets of fallen soldiers returning from Iraq and Afghanistan. According to his grandfather, JM, "he felt like, 'Look, those guys are Marines and they are all getting hurt, I need to be with them.'"⁸

Surviving a war injury is just the beginning of the story. For Corp. M, one war ended and another be-

gan when he stepped on the IED. The first war involved firefights with an enemy that often blended seamlessly with the civilian population, forced him to decide between the lives of his fellow marines and the lives of civilians, and required, as a team leader, to maintain his composure in front of the marines who relied upon his quick decisions under extreme duress.

The second war began after the IED exploded underneath him. This war is fought in a hospital bed, in a different body, with a metal plate replacing part of his skull, a long scar running down his abdomen, a colostomy bag replacing his normal bowel function, his left leg gone entirely to his hip, and his right amputated above his knee. This war is just beginning.

Despite his injuries, Corp. M remains optimistic. To those who doubt whether life is worth living after suffering injuries like his, he replies:

“It’s definitely worth living, because there are so many other things that are important in life, more important than just having legs. It sucks not having legs, but at the same time, I couldn’t imagine putting my family and my friends through that situation, of having me die that early in my life. It is worth living. It’s worth all of it. I would go back right now in a heart beat if I could, I would go back to Afghanistan on prosthetic legs, and fight still. A lot of people would say that I’m crazy, but it’s just different, it’s just making an impact somewhere that needs help.”⁵

In another month, if all goes well, Corp. M will fly to Camp Pendleton in San Diego, where he began his training in the Marine Corps, to be fitted with prosthetic legs. He hopes to work for the Wounded Warrior Battalion, a branch of the Marine Corps devoted to helping wounded marines recover and transition to civilian life.

As the Wars in Iraq and Afghanistan draw to a close, and soldiers with traumatic injuries return home, the question of how best to care and rehabilitate these “wounded warriors” is increasingly relevant.

Their journey back to health will be covered in the next edition of the H&P. &

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MUSES, MUSIC, AND MEDICINE

AARTI SHARMA



THERE ARE A FEW DOCTORS WHO MARCH TO THE BEAT OF THEIR OWN DRUM, who attempt to strain against the fetters of tradition in order to carve a path for themselves. These mavericks – the writers, athletes, politicians, entrepreneurs – are unique in that their efforts to traverse multiple professional realms have expanded not only their own frames of reference but also those of the patients and people with whom they interact. The Stanford Medical School community had the privilege of meeting one such maverick, Dr. Richard Kogan, who gave the keynote speech at the 10th annual Medicine

and the Muse Symposium on April 12, 2011.

Dr. Kogan maintains a private practice clinic in New York City and serves as an associate professor of psychiatry at Weill Cornell Medical School. He began his formal pre-college education at Juilliard, and after graduating he became interested in medicine, for reasons not necessarily influenced by music. “Honestly,” he says, “everything is related in the mind, but I don’t think there was a salient relationship between my experiences with music and my interest to pursue medicine, and later psychiatry.” He went on to attend Harvard Medical School, where the administration allowed him to continue

giving traveling concerts. Impressively, he continued performing even during his rotations, which is a notoriously stressful time for most medical students. After receiving his MD, his musical and medical lives were led largely as separate entities.

As the years went by, however, these two passions began to merge, whether consciously or unconsciously. His training as a psychiatrist serendipitously led him to explore the mental illnesses of the great composers. He notes that he was “not only [studying] their psychiatric illnesses, per se. Whether Beethoven had a mental pathology is debatable, but whether Schumann had a profoundly strained relationship with his father is undeniable. It is more these kinds of circumstances that led me to a greater understanding of how these composers produced their individual repertoires of music.”

To Dr. Kogan, the overarching “narrative” of a composer’s life - rather than the discrete periods that constituted it – is more fascinating. Considering how each component intercalates within their compositions is both an intellectual as well as visceral exercise in interpretation. Dr. Kogan muses that, “there are so many potent examples of how music reflects a composer’s experiences that it is difficult to truly pinpoint the most representative. For example, there is Tchaikovsky’s *Pathétique* Symphony, which he wrote during the final years of his life, and it is a powerful expression of suicidal despair. Likewise, there are symphonies by Schumann illustrating emotional frustration and rejection.”

Of course, knowledge of the composer integrates into Dr. Kogan’s performances – the emotions, the frustrations, the ambivalence, the drama. Dr. Kogan reflects, “[while] there are people who don’t want to know about the mind of the composer, I feel this is almost a conscious appropriation of the composition. To be an effective musician, I feel that it is definitely necessary to incorporate background knowledge of the composer into the dynamics and expressivity of a particular piece. When I was young, I never practiced

music this way – they told me to memorize a concerto, and I did it. But later I found how much more effective this perspective is.”

Given his dual interests, Dr. Kogan is often asked what would have happened were someone to have “prescribed Prozac to Tchaikovsky” – would the composer still have produced the same heart-rending orchestrations? Through “medicating” these geniuses, is the physician, in effect, stifling a *Nutcracker*, a *Seventh Symphony*, a *Maple Leaf Rag*? Dr. Kogan disagrees. “The drive to create, that brilliance, is not dependent on the depression, psychosis, or polarity of any of these composers. Of course it helped, but even without them the impetus was still there, and would be realized regardless.” His analysis implies a natural segue between intrinsic character and the creative process – the motivation is simply stronger and more directional in particular people.

Dr. Kogan has given lectures across the country analyzing the psyches of Mozart, Chopin, Gershwin, and Bernstein. The topic of Dr. Kogan’s lecture at Stanford’s Medicine and the Muse Symposium last spring was “The Mind and Music of Beethoven.” The lecture illuminated the experiences in Beethoven’s life that may have influenced his music. The lecture detailed the various ‘phases’ of Beethoven’s life and analyzed how they manifested in Beethoven’s compositions. Dr. Kogan began by outlining Beethoven’s early childhood,



which was fraught with neglect, misunderstanding, and the development of an arrogance that became a trademark of his personality. Dr. Kogan also touched on Beethoven's tumultuous love affairs, his unique and dysfunctional relationship with his adopted child, and his attitudes towards his musical mentors.

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To illustrate his arguments, Dr. Kogan delighted the audience by intermittently performing pieces of Beethoven's repertoire on the piano in Li Ka Shing's Berg Hall. First, Dr. Kogan played Sonata Opus 10, No 2, to illustrate Haydn's influence on Beethoven. After explicating that Beethoven possessed some resentment toward Haydn, Dr. Kogan illuminated this point by playing the phrases within the piece that are reflective of Haydn's witty and coquettish Viennese style – one that is starkly parsed from the troubled gestalt of Beethoven's later compositions.

The Appassionata Sonata is a testament to the torrid and ambivalent nature of Beethoven's romances coupled with the consummately frustrating period involving attenuation of his hearing abilities. “The Appassionata contains outbursts of pianistic fury which taxes the modern pianist, reflecting that Beethoven was in the world of his imagination as the pathology progressed. Nobility, heroism, grandeur –

these were all manifest in this iconic middle phase of his life,” said Dr. Kogan, before sitting down to perform the dynamic piece.

The last work – Sonata, opus 110 in A minor – reflected those hallmark last years of Beethoven's life, when his progressive hearing loss forced him to become more contemplative, more introspective, and more expressive. His failing health lent him a nominal vulnerability, and heroism becomes more of an echo in the music he composed during this period. Dr. Kogan's performance of the Sonata movingly illustrated Beethoven's late reflections, as well as his final attempt to “shake his fist at the world” through the medium of music.

In a luncheon with medical students, Dr. Kogan conversed about another extremely important subject: the contemporary relationship between medicine and the humanities. The importance of the humanities in medicine is often overlooked, given the time constraints and increasing specialization of today's physicians. Dr. Kogan emphasized the value of learning to cultivate these aspects of our careers, as they will ultimately translate into a deeper understanding of the patient's holistic medical experience. Dr. Kogan uses the analogy of shamans – members of indigenous communities who performed the roles of healer and musician simultaneously – to illustrate how doctors may begin to incorporate humanities into their careers. This model has been laid by the wayside in favor of the disembodied, albeit prevailing, practice of medicine. “We've lost something as the fields have become more fragmented, and we need to treat the person more holistically – in a more general sense of healing. This is why I feel that bringing humanities back into the medical education is crucial. Especially given the concurrent increase of technology and other factors which encourage the view of a patient as an organ and not a soul or a person.”

Indeed, this is an apt description of the zeitgeist, and one that we, as current and future physicians, must strive to transform. 



FIXING SEX: INTERSEX, MEDICAL AUTHORITY AND LIVED EXPERIENCE

Katrina Karkazis, PhD, MPH, is a medical and cultural anthropologist and a Senior Research Scholar at the Center for Biomedical Ethics at Stanford. Dr. Karkazis' research has illuminated the multidisciplinary challenges of managing intersex conditions, also known as disorders of sexual development (DSD). Her 2008 book, *Fixing Sex: Intersex, Medical Authority and Lived Experience*, is an ethnography of medical practices related to DSD that draws on dozens of interviews with intersex individuals, their families, and physicians. Dr. Karkazis joins H&P to discuss the evolving understanding and management of DSD.

MIHIR GUPTA

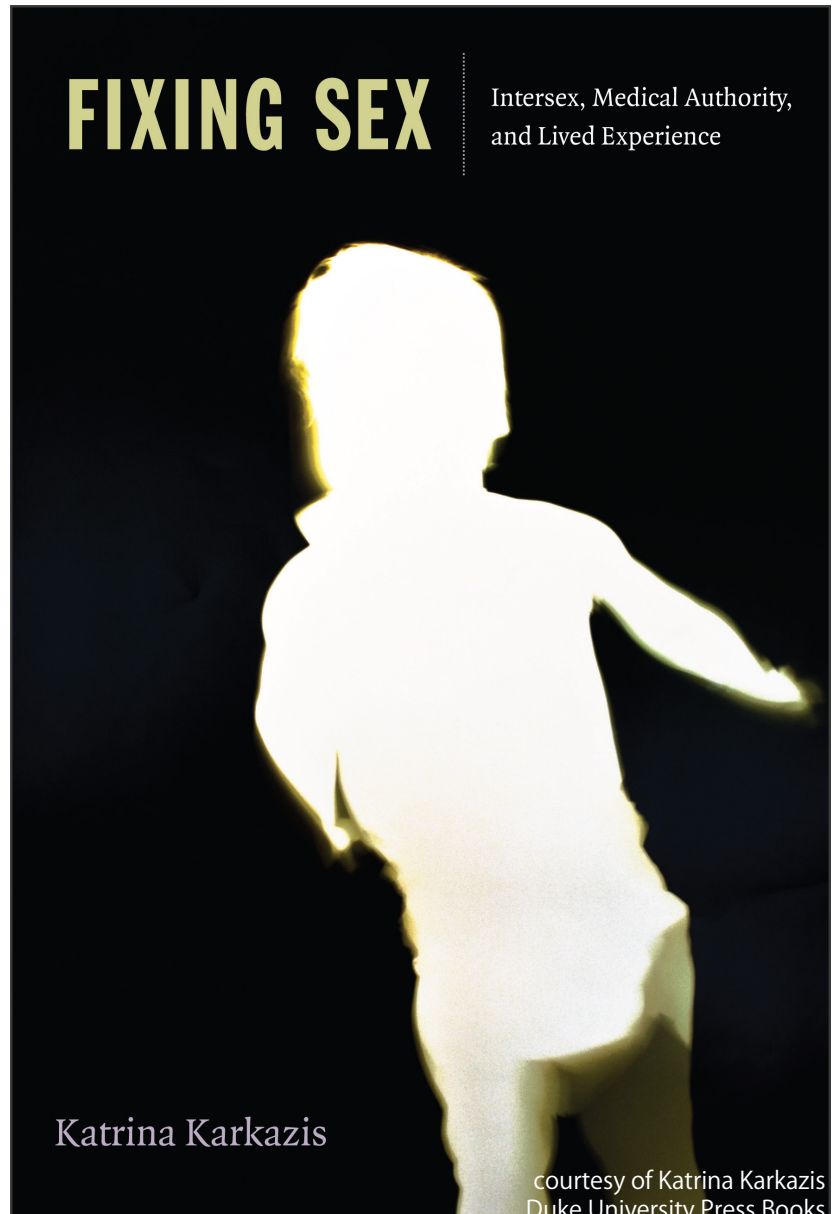
A conversation
with the Author

Mihir Gupta: What are some of the diagnoses included under the DSD umbrella?

Katrina Karkazis: DSD lumps dozens of very disparate diagnoses, and the only unifying feature is that broadly speaking, children with DSD are born with somatic features that are in some way sex-atypical.

Congenital Adrenal Hyperplasia (CAH) accounts for about 60% of DSD. CAH is a family of inherited conditions affecting the adrenal glands. The most common form is 21-hydroxylase deficiency, which can either be called Classical CAH, which is usually detected in the newborn period or in early childhood, or Non-classical CAH (NCAH), which may cause symptoms at anytime from infancy through adulthood. Children with CAH whose karyotype is 46,XY do not fall under the intersex rubric. Babies with a 46,XX karyotype lack an enzyme in the adrenal gland. Without that enzyme, they produce a lot of androgens *in utero*, and the circulating androgens impact developing genitalia and external and internal reproductive features. Girls with CAH have masculinized genitalia. There is a broad range, from an atypically large clitoris to fused labia that resemble scrotal tissue.

Another cluster is androgen-resistant conditions, including complete androgen insensitivity syndrome (CAIS) and partial androgen insensitivity syndrome (PAIS). In CAIS, the child is born completely feminized and there may be no indication that the child has CAIS. It's usually discovered when the testes descend. PAIS leads individuals to have genitalia that we understand to be somewhere between male and female. PAIS is still one of



the most fraught conditions for physicians to deal with because around 66% of people with PAIS change gender later in life from what they were assigned at birth.

There are others, such as 5-alpha reductase deficiency, various forms of hypospadias, epispadias, idiopathic micropallus, Klinefelter's, and Turner's Syndromes.

MG: Are there good estimates of the prevalence of DSD?

KK: DSD are more prevalent than one might think, because the category encompasses several dozen conditions. That said, we

have very poor data regarding frequency, in part because we don't have a national registry or database for keeping track of DSD. How we think about frequency also depends on what we think counts as intersex, which has been incredibly complicated and fraught culturally and medically.

MG: What are some of the main medical issues that physicians encounter in DSD management?

KK: Physicians may want to immediately intervene. Certainly in cases like salt-wasting CAH, we have severe medical problems that need to be dealt with. But the majority of the genital surgeries are what can be construed as cosmetic surgery. I interviewed a family whose child had mixed gonadal dysgenesis and was also born with a heart defect – her genitalia were operated on before her heart defect. That was very telling and also troubling, because there was nothing about her genitalia that was a risk to her health at that point. What we miss in DSD is the whole psychosocial aspect of how to care for parents who have given birth to a child who has a condition that they didn't expect, about which they may have grief, fear, anxiety, and guilt. What we need to do is not “fix the child,” but attend to the parental distress, and not have parents make very important irreversible decisions until they have some time to absorb all of this new and complicated information. The primary thing they need is really quite simple: support, comfort, and knowing they are not alone, which should include offering to put them in touch with other parents.

This subject deals with very taboo topics that people don't talk about a lot. Even physicians, as much as they know about these endocrine conditions, get no training in deeply phenomenological processes like gender identity, gender role, and sexuality. There is already a reticence or a difficulty in talking about sexuality in clinical settings – now imagine making decisions about genital surgeries for a newborn that may involve discussing the infant's future

sexual function or sexual pleasure. And yet for informed consent we must talk about this because genital surgery has the potential to harm these in quite significant ways.

MG: What is the physician's role in long-term DSD care? How do you envision multidisciplinary DSD teams operating?

KK: I don't want every endocrinologist or surgeon to think that they need to be the psychosocial expert in caring for families in this position. They need to know very basic things not to say or do that parents will experience as alienating or dehumanizing towards their child. The physician should focus on what they know best and find someone—whether professional or peer— who can help the family and give them that more sustained open space to talk about all of their feelings and fears. The easiest and best thing we can do is to provide a space for comfort through psychosocial and peer support. That doesn't do harm, and we don't do anything irreversible.

We run into problems when important people are left off of the team or out of the conversation. For example, having an adolescent gynecologist is very important because she sees the sequelae of the surgeries later on. We don't just want the pediatric urologists knowing what happened in the first 2 years after surgery; we want the person who sees these individuals as teenagers and understands what they deal with at that point. We also want a parent or patient on the team to consistently bring in that perspective. I feel very strongly you do not have a team if that perspective is not represented. After all, patient and parent advocacy is responsible for the recent changes in the standard of care. They have the answers for what patient-centered care looks like.

What I really want is an extended conversation between everyone involved. Our current team has several specialists, a patient advocate, a lawyer advocate, ethics, and psychiatry. The ideal DSD clinic would meet

beforehand to figure out any issues around care, the goal of that visit, and what they want the patient or family to understand. They would then meet the patient, and discuss anything else that comes up on the back end. This isn't new to medicine for complex chronic conditions, but it's not applied in DSD very often.

MG: What are the challenges to implementing multidisciplinary DSD care?

KK: You hope to have a primary liaison that the family can feel good coming back to. The family really needs a space to express the emotions that they have. The problem is that most places haven't had that. Psychosocial care often isn't offered. For a while, people even felt that the less the parents and the child knew, the better. Also, there are very few people that have expertise in these particular issues of psychosocial care, parent adjustment, or gender identity.

Another problem is reimbursement. Psychosocial care for parents in the hospital is usually covered. But how do you give ongoing support and care to outpatients? Reimbursement for psychosocial care for parents is probably the biggest hurdle. It's one of the reasons why there are now some amazing peer support groups. We even have a new one in the Bay Area. Parents are turning to each other for support when they aren't getting psychosocial care and even when they are. These are very safe spaces for support and many parents have told me connecting with other parents has helped them more than anything else.

MG: How have perspectives on surgical management of DSD changed recently?

KK: The pattern for 50-odd years was relatively quick gender assignment, and surgery was often done in the first few weeks of life. Now we have a consensus statement that says we do not have good surgical outcome data, and those data we have show that surgeries certainly have complications.

However, surgeons are wont to say that we have better techniques now, and those techniques mean we are likely to have better outcomes. But that allows all the previous poor outcomes to be dismissed. If we look at all of the outcomes studies over the last 40 years, there have been consistent complications irrespective of improved techniques. There is no unequivocal evidence of benefit, but we do have evidence of harm. There's no evidence that the surgery is delivering what we expect, which is normally functioning genitals or genitals that look typical. There is no evidence that surgery relieves parental distress in the long-term—my research shows it persists long after surgery—or that people who have had genital surgery would choose it. It is true some of the patients who did not have surgery have had poor outcomes, but often what we see is that surgery has not necessarily helped those who have had it. The fact that some people had bad outcomes without surgery doesn't justify doing a surgery that also has had bad outcomes.

Gender change for quite a few conditions is much more extensive than what we ever knew before. For example, a child born with PAIS and a small phallus may have that phallus surgically reduced and may undergo vaginoplasty. But if at age 15 that child now wants to live as a male, and the genitals they were born with might have facilitated that more easily - we have done grievous harm if they have already been removed. So gender change is also a concern because children don't declare their gender identity until long after surgery typically has been performed.

MG: What makes it so difficult to achieve consensus around the timing and necessity of surgery?

KK: When I asked physicians how they reacted to arguments about not doing genital surgery some years ago, they responded that without surgery, the child wouldn't have a gender assignment. I thought that

conflation was fascinating because gender assignment is really a social process and a legal process. But we have no cognitive space to figure out that a child can have a gender with atypical genitals. If a young girl with CAH has an enlarged clitoris that looks like a penis, parents start to wonder what that means. Often what they're asking is: will she be lesbian? They're moving from more masculine-looking genitalia to other things including male sexual roles or male-typical sexual attraction. That's in part what no one is helping them with; no one is unpacking it. Fear, discomfort, disgust, or even homophobia can unconsciously and consciously lead to surgery.

I g n o -
rance about the huge variety in human genitalia is also a problem. Physicians and medical students aren't being shown an atlas of the variety of human genitalia, though we have older books from the earlier part of last century detailing extraordinary diversity. This is missing from the conversations. So we have narrow ideas about what so-called normal genitalia look like.

I think it's also been hard to hear from former patients that they have felt harmed by their surgery and to allow that to resonate and even to shape practice. Surgeons were slow to evaluate surgery because they have assumed both the necessity of surgery and the well-being of their patients. But information about outcomes, however carefully researched and presented, is unlikely to solve

these debates. Studies have often utilized small sample sizes and surgeons' assessment of their own work, raising concerns about observer bias. Other factors - like age at first surgery or at evaluation, the surgical method used, criteria for evaluation or success, and ways of assessing sexual sensation - all vary enormously in these studies, making outcomes challenging to assess and generalizations from these findings difficult to formulate. Moreover, their criteria for treatment success generally pay less attention to the psychological well-being of

the patient and all too often employ imprecise or misleading measures of sensation and do not include subjective assessment of something that is deeply subjective.

Finally, there's the semantic construction: not doing surgery is construed as doing nothing. No one is advocating 'doing nothing' - but

what are we advocating doing? And do we know it's helpful?

MG: Do parents' perceptions of the success of surgery change as their children get older?

KK: The presumption is that once you do the surgery, the child has normal-looking genitalia and we never have to think about it anymore. Parents typically think that when the child is very young. One parent referred to it as a "no nevermind" issue after surgery. But there is no feedback from the child; you just do a visual



Tania Reza

look at the genitalia and decide if they look normal. By the way, often enough they do not look normal to either parent or surgeon. But as the child grows, the shape of the genitalia changes so even what might have appeared “normal” earlier in life may not appear that way as the child grows. It’s impossible to do a surgery that will leave no residue of that difference. So the same concerns that are there pre-surgery still exist post-surgery. Surgery can reduce anxiety in the short-term, but in the long-term there are many factors that make people still feel and experience a lot of shame and embarrassment about genital atypicality after surgery, and it may even be exacerbated by the repeated exams, vaginal dilation, further surgeries, and complications from surgery.

MG: What areas of research on DSD need more attention?

KK: One issue that’s very striking is how little attention has been paid to quality of life for the child and parents. Until very recently only about 1% of studies of DSD deal with quality of life. The others deal with outcomes of genital surgery, gender identity, and sexual orientation. Simply looking at those things, whether the gender assignment is right and whether the genital surgery works, doesn’t tell us very much about how to help parents or patients. And all too often we assume that by getting these things “right,” patients had been well served, and that good intentions lead to good outcomes. But patients have told us these issues around gender are not their primary concerns. There is a whole con-

stellation of psychosocial factors that exist around these conditions: feeling deep bodily vulnerability at the hands of medicine, trauma from surgery, a deep sense of alienation from one’s body, frustration and anger and having been lied to about their diagnosis and treatment. However hard it is to hear these, we need to open our ears to hearing the human here. It is the only way we can get to better care.

Some of the aforementioned problems associated with evaluating genital surgery also persist and make it very hard to have definitive outcome studies on which to base decisions.

We have very few studies of parental coping and what has been helpful to them. I would like to know the struggles of children who have had surgery and those who have not – not just a functional outcome, but their own fears, anxieties, and assessments around their own genitalia.

MG: Are there problematic interventions aside from genital surgery?

KK: Gonadal surgery has received less attention than genital surgery. Gonadal surgery takes away reproductive capacity (if the individual was not already sterile). We have laws against involuntary sterilization, but removing the child’s gonads in DSD hasn’t been viewed as involuntary sterilization. I imagine at some point we will have a court case regarding this. The reasons for removing the gonads are not always medically valid. Some are ideas around gender congruence, like ‘girls shouldn’t have testes.’ Some are fears of cancer risk in the testes, which are real in some cases, but in many instances where this is happening, it needn’t happen before the child undergoes a partially natural puberty and can decide about reproduction.

MG: What should medical students keep in mind as

“We need to open our ears to hearing the human here. It is the only way we can get to better care.”



David Carreon

they prepare to care for individuals with DSD?

KK: The shock of atypical genitalia so overwhelms healthcare providers that they forget everything else. Sometimes people will not even congratulate parents on having a baby. For parents, this is their first contact with the child. Years later, parents remember how they were treated, what was said, how they felt. And I am sorry to report that many of the parents I spoke to relayed very painful experiences.

We can do some very basic things. First, we need to do a much better job teaching medical students about sexuality more broadly, and intersex specifically. The recent study published in JAMA by the LGBT MERG group showed that training programs across North America are woefully insufficient training regarding what has been called non-normative sexualities. Moreover, only 60% of schools that responded said they even teach DSD. My guess is that what is taught is probably an antiquated and stigmatizing view of DSD. So that must change. There are other basic things: not,

unless it's medically necessary, separating the baby from the parents right away. Allowing that bonding moment to happen, allowing the parents to appreciate the child. Saying they have a healthy baby (as long as it is true), that we have seen this before, we can handle this. If you normalize it, you give them the best possible chance to accept the condition, to accept the child, to not catastrophize what they think that child's life might look like. Hold it all at once: what might be fearful for them, but also the positives that don't go away just because the child has this condition. Offer to set them up with other parents. Parents say the most important intervention is talking to other parents, because they end up learning that it's going to be OK.

Cradle parents in that moment when they are so filled with fear, guilt, anxiety, and dread, knowing that the likelihood of them coming to a different place is very good and that you are part of how they get there. Set up the support and resources for them to get to that other place, where they feel a mastery over the information and a confidence in their ability to deal with what comes. &

LEADERS IN MEDICINE

DR. PAUL AUERBACH

LOUISE WANG
WITH CASEY MEANS



Mark Tuschman

Dr. Paul Auerbach, MD, MSM, is a Professor of Surgery in the Division of Emergency Medicine at Stanford University and former chief of the Division of Emergency Medicine. He is considered one of the founders of and world authorities on wilderness medicine. Previously, Dr. Auerbach served as Chief of the Division of Emergency Medicine at Vanderbilt University, former editor of Wilderness and Environmental Medicine (formerly Journal of Wilderness Medicine), and founder and past president of the Wilderness Medical Society. He has authored several books and published in journals such as JAMA, the New England Journal of Medicine, and Annals of Emergency Medicine. In addition, Dr. Auerbach has led medical outreach efforts in countries such as Haiti, Nepal, Guatemala, and Niger. He received his Bachelor of Arts and Doctorate of Medicine from Duke University and his Master of Science in Management from Stanford University (Sloan Fellow). He completed his internship and residency at Dartmouth Hitchcock Medical Center and UCLA Medical Center, respectively.

Louise Wang: I'd like to go back to your medical school beginnings. You went to Duke and in 1975 you decided to work on an Indian reservation in Montana.

Paul Auerbach: At Duke, we finished our basic science courses in the first year and completed clinical rotations the second year. After my second year – in 1975 – I was eligible to take clinical electives. I took advantage of a program sponsored by the Indian Health Service in which they offered medical students externships on Indian reservations. This program exposed medical students to potential careers in the Indian Health Service at the same time that it allowed them to assist in providing clinical support in those locations.

LW: What challenges did you face and how did those lead you to developing wilderness medicine?

PA: Montana was my first big look at true wilderness environments: mountains, prairies, and exposure to a variety

of wilderness and environmental medical situations that I'd never seen before. Things like rattlesnake bites, people hit by lightning, drownings, folks who were attacked by wild animals in the national parks, heat illness, etc. I found this all incredibly fascinating. That summer, the seeds were planted to go further in that area. I loved it and it never got away from me.

LW: Duke has a third year program in which you do research. Did you end up doing research in wilderness medicine?

PW: I did research, but not in wilderness medicine. At that point, I was just enamored of having had the experience, but I hadn't processed it professionally or given much thought to what I was going to do with it. That didn't really come until my residency. As a third year medical student I worked in an immunology laboratory developing a blood test for multiple sclerosis and took more basic science courses.

LW: Could you take us through the process of how you formalized the concept of wilderness medicine and how it's evolved over the years?

PA: Wilderness medicine has moved beyond an empirical science. Wilderness medicine is currently recognized as a specialty, which is tremendously gratifying for all of us involved in the field at an earlier stage.

My best friend at the time was a doctor named Edward Geehr. He and I went to medical school together, and in successive years did our internships in internal medicine at Dartmouth and then reunited at UCLA as emergency medicine residents. We both shared a passion for being outdoors and saw the opportunity to create literature in the field. As residents we were approached by an insightful publisher who was willing to take a risk on two house officers and ask us to create an issue of a publication entitled Topics in Emergency Medicine. We chose the topic of environmental emergencies. From that, the concept to do a textbook was spawned. The Wilderness

Medical Society followed soon thereafter. The Journal of Wilderness Medicine followed after that and we realized we had a tiger by the tail. When you're working hard while doing the things you love, that's the best possible situation.

LW: Many Stanford Medical students are interested in wilderness medicine. How can they get more involved?

PA: The Wilderness Medical Society sponsors electives including a very well-run one-month elective in Tennessee each year. That is a great opportunity for any medical student contemplating wilderness medicine as part of their life.

Wilderness medicine strikes a chord because it is a way to combine a recreational passion with a profession. When you're a medical student, your main responsibility is to learn medicine, prepare to become a great doctor, or prepare to become outstanding in whatever direction medicine takes you. With regard to wilderness medicine, it applies to a clinician practicing in a remote area, an expedition team physician, an explorer who wants to be medically facile in that environment, someone interested in global humanitarian relief and wants to be able to practice in an austere setting, or perhaps a basic science researcher studying high altitude, frostbite, or envenomation.

It's key to focus. As you're becoming a doctor, it's okay to pick a particular subset of interests and begin to become an expert in one of those areas. It's supposed to be interesting; it's supposed to be fun. It's supposed to be nourishing for your body, brain, and soul to seek those environments where you can best resonate with whatever makes you fulfilled. If that's the outdoors or a remote challenging setting, then wilderness medicine may be something that's for you.

LW: I was hoping now we could talk about the intersection of business and medicine because you were named a Sloan Fellow. The Fellowship supports mid-

"I want very much to put something back -- that's why I became a doctor and it's even more important at this stage in my career. Humanitarian relief and disaster response are undeniably ways to put something back."

career professionals to obtain a graduate management degree. Did you feel like this was a natural progression for you as a doctor?

PA: The Sloan fellowship was different than wilderness medicine. At the time, I was Chief of Emergency Medicine at Vanderbilt and was contemplating a career progression that would have me be more of an administrator and take responsibility for certain large programs at that institution. The Vice-Chancellor for Health Affairs and I agreed that it would be a good idea for me to get more business and management education, which is not something that you traditionally achieve in medical school. Medicine has a large component that relates to management, leadership, organizational behavior and finances, and I felt that I needed more education for the opportunities offered to me at Vanderbilt.

The Sloan program was terrific. It introduced me to a wonderful new set of professional comrades, many of whom have achieved remarkable business careers — we continue to be resources for each other.

LW: Do you feel that doing emergency medicine made it easier to do business?

PA: Emergency Medicine usually reflects the personalities of the people who enter the profession. The doctors, nurses, and technicians who are successful in emergency medicine tend to like to multitask, have diverse interests, can handle the intensity and adrenaline rush in critical situations and tend to gravitate towards mitigating crisis situations. The Sloan program wasn't necessarily essential for emergency medicine, but some sort of business education is critical for all medical professionals to at least understand the economics of medicine, particularly because our resources are rapidly becoming constrained.

LW: Some people believe that business and medicine don't mix.

PA: Business doesn't necessarily mean making a profit or being hard-hearted. Business can be about efficiency, compassion, and how to integrate environmental preservation with good business management. It can be about how to rationally approach a difficult situation and manage people. When we think about how to build a hospital in an impoverished country, how to set up an EMS system in a land that has never had one before, there are always business issues. It's important to be knowledgeable.

LW: You were part of the Emergency First Response team from Stanford that traveled to Haiti. You've also worked in Nepal and Guatemala. How do you pick where to volunteer and how do you find the time?

PA: This is a logical progression from what I've done in emergency medicine and wilderness medicine. In an emergency department domestically or abroad, you're exposed to people of all socioeconomic classes, and because of the nature of how our world is structured, many people who are poor don't have the same resources as those who are more fortunate. In wilderness medicine, you are taken to austere environments that frequently reside in underdeveloped countries. I



Kevin Nead

very much want to put something back -- that's why I became a doctor and it's even more important at this stage in my career. Humanitarian relief and disaster response are undeniably ways to put something back.

LW: How do you fit everything into your life? You completed the Sloan program. You have won many awards, such as the Diver of the Year award from Rolex and the NOGI award for science. How does everything work in the life of Paul Auerbach?

PA: Sometimes I manage it well, but sometimes I don't. I don't watch much television. I don't spend a lot of time on the computer doing non-productive things. I love being with my family so I try to include them in all of these activities; my children will hopefully do good things in the world. I'm so proud of them. I love my

work. I can't imagine ever retiring. The secret is to find people who are really good and surround yourself with them, then work hard to make them achieve their dreams, to be successful. It's about identifying situations that can be improved or discoveries that can be made and leading people like you and your classmates into those settings and setting them free to accomplish the great things for which they're destined. That's my greatest academic pleasure, and that's why I'm at a place like Stanford.

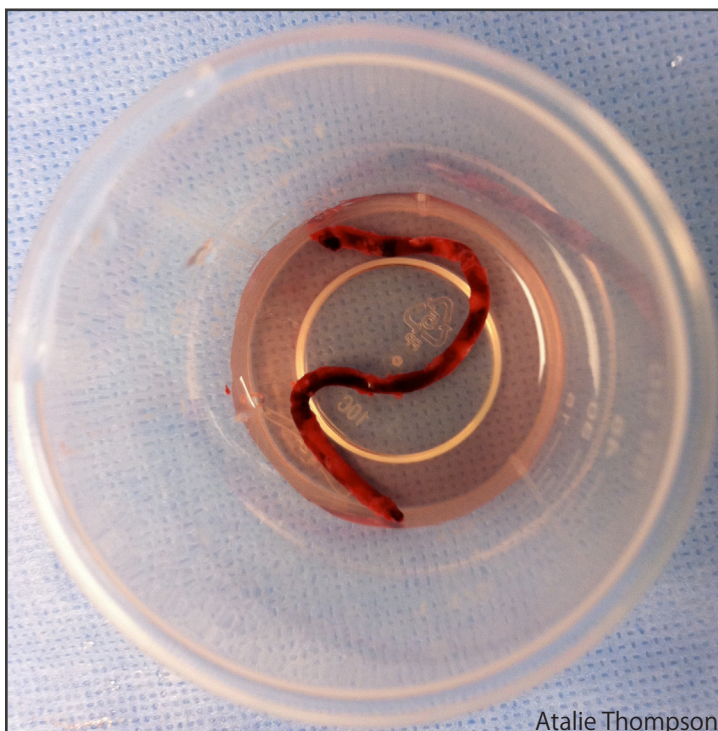
LW: Any words of advice for medical students?

PA: Medicine is the greatest profession in the world. I hope that we always remember to that we're here to help others, and above all, maintain our curiosity and compassion. &



Amy Wasterlain

Above:
Amy Wasterlain in Ephesus, the great ruins in Turkey, standing next to the ancient medical symbol which was the entrance to their hospital.



Atalie Thompson

Below:

Joseph Antonios, first year medical student, shows a high school student how to tie a surgical knot at the Stanford AMA-MSS and SCCMA Transformative Experience in Medicine 2012 Program.



Isabella Lai

Left:

CAPD Catheter Clot. A dialysis patient presented for a CAPD catheter replacement, but upon surgically entering the abdomen, we visualized a large clot within the catheter. This clot proved a challenging fishing adventure for the surgeon, but upon its successful removal we were able to restore the catheter to full function without needing to replace it! -Atalie Thompson



Above: Writing my daily notes on an infant with post-infectious hydrocephalus at the CURE Children's Hospital of Uganda. The patient is awaiting endoscopic third ventriculostomy surgery to allow movement of CSF from the blocked ventricles in the brain. -Aria Jafari



Above: In the winter of 2010 I returned to Colombia after 11 years. During this trip, I visited Guane, a small town in the area of Santander. My grandparents grew up in this town and had half of their 12 children in a small house that still stands today. I asked around to see if anyone remembered my grandparents and wound up in the *ancianato*, a old people's home right in the center of town. The man on the left remembered my grandparents and he told me stories about my grandfather. My grandfather has Alzheimer's, but when I showed him this picture and told him who the man was, he told me his version of the same stories. It was fascinating. -Johana Oviedo



H&P