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Personalized Medicine in the Resource-poor World

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I AM GIVING A TALK THIS fall on the “Personalized Treatment of Parkinson’s Disease.” In preparation, I reviewed the literature on personalized medicine to be certain that I understood the concept. After all, President Obama talked about the importance of funding research to develop personalized medicine, which presumably will raise the standards of health care in the U.S. This didn’t make a lot of sense to me. As I wrote in a previous column, I view this as an unaffordable expansion of health care to meet the needs of the financially non-needy few. It turns out that I did understand the concept of personalized medicine. There are a number of descriptions of personalized medicine, including a lengthy philosophical inquiry into the meaning of the term, the different definitions that have been suggested, and how, in general, medical descriptions become definitions, and how these definitions become accepted by the medical community. But, in point of fact, the concept of personalized medicine is analogous to the famous quote about the man who was amazed to learn that he’d been talking prose his whole life (from Moliere). Believe it or not, we practice personalized medicine all the time, and have been since doctors started to practice the discipline.

When people and physicians in



wealthy countries think of personalized medicine, they’re thinking of gene testing for identifying the best chemotherapy for their cancer, or enzyme evaluations to choose medications which will not cause side effects, or deciding how often a colonoscopy needs to be repeated; should the

patient have a carotid endarterectomy or not? And the list is endless.

Personalized medicine in the resource-poor world is a bit different. Actually it’s very, very different. It puts our philosophical discussions about the meaning of the term on a different level than the authors had probably ever thought about. I am writing this in Accra, the capital of the West African country, Ghana. I’ve been teaching neurology to house officers at a hospital. I’ve been doing similar short stints at several different teaching hospitals, all in East Africa, until now. Each place is different although all share similar limitations imposed by lack of funds, and the usual problems associated with poverty. Each has a different sort of personalized medicine.

Ghana is a lot wealthier than most of the other countries I’ve been to. Its medical system is different in the starkness in which money figures in. In the East African countries I’ve been in, there was at least a thin layer of medical health insurance. Patients there may have to

pay for their bed but certain basic tests, like a chest X-ray and complete blood count, are included. Most blood and imaging tests have to be paid for out of pocket, and are not performed until paid for. In occasional cases the fees are foregone, but not for most. The medicines stocked in the pharmacy, if actually still in stock, are included in the price of the bed. Drugs not there must be purchased by the family and brought in.

In Ghana, the medical system revealed what the American system will look like in the not-too-distant future. Friends brought a 48-year-old man to the hospital when he was found unresponsive at home. When the admitting team saw him, his friends were gone and not reachable. It was very clear that this man, now comatose, had meningitis. In the U.S. he would have had a lumbar puncture (LP) to analyze the cerebrospinal fluid (CSF), followed immediately by antibiotics, chosen to cover the likely organisms, until the CSF results pointed to the likely culprit, at which time the antibiotic might be changed. If a few minutes could be spared, that is, the patient wasn’t on death’s door, a CT of the brain might be done to exclude the possibility of a mass lesion that might herniate following an LP. This is rarely an issue, and when time is of the essence, should be skipped.

However, in Ghana, no test is ordered until someone agrees to pay for it. So, the next day, the patient still had not had an LP because no one had shown up

to approve payment. Of course, no CT scan was performed either, for the same reason. Somehow, however, antibiotics had been paid for at the onset so he got those. The government, via a grant from an international agency fighting HIV, paid for his HIV test. He died the next day, of course. A few beds over, another patient with suspected meningitis also was unable to foot the bill for an LP. She got treated with antibiotics, too, but her family could only afford half the dose so that's what she got. This is medicine that is as personalized as it gets. And, unfortunately, it's wrong to say that it's coming to a medical center near you because it's already here.

In the U.S., thresholds have become high enough, and getting higher by the year, and many patients are now refusing to have "routine" diagnostic tests performed, such as an MRI. Patients cannot afford a trip to a hospital

emergency department because "routine testing," much of which is irrelevant to health, but important for malpractice risk reduction, might cost over a thousand dollars, not covered by insurance. Ghana's lack of coverage is unbiased. It affects outpatient and inpatient choices. However, in the U.S., inpatient coverage is better, because the costs are so astronomical for everything that the deductible, that is, the threshold at which personal responsibility ends and insurance coverage begins, is reached pretty quickly. So hospital testing is rarely held up by cost.

Genetic testing is very expensive now, and although it should have become cheaper, as it is for laboratory research studies, it has not. A "panel" of gene tests for certain neurological syndromes, ataxias, for example, may cost \$40,000. At this time, none of the disorders, if confirmed, are treatable. The hope for

personalized medicine is that in the near future, some, or all, of these disorders will be treatable, but you can bet that the cost will be in the hundreds of thousands of dollars. At some point, and it is already here for many and coming soon for all, insurance won't cover it and patients and doctors will make the same choices that our Ghanaian counterparts are making now. ❖

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Physicians at high risk for suicide in US; incidence higher in women doctors

Physician Health Programs (PHP) offer confidential treatment

HERBERT RAKATANSKY, MD

ABOUT 18,000 PERSONS yearly in the United States become part of a cohort with a high risk for disability and a mortality rate above that in the unaffected population.

We are talking about medical school graduates. There is evidence that symptoms of burnout are present in well over half

of physicians. Stress and depression are common. And the mortality is high. In male doctors the suicide risk is 1.4 times that of the general population and for female doctors it is an astounding 2.27.

We know that 300–400 physicians commit suicide every year. And there likely are more, since some death certificates may not reflect the actual cause of death. Rhode Island physicians are not immune. In 1989, the chief of pediatrics at Rhode Island Hospital jumped off the roof of the hospital, leaving a suicide note (reported in the *Providence Journal*). Personally I know (in RI) of two psychiatrists who were department chiefs, one psychiatrist in private practice, and one orthopedist who committed suicide. I know of at least three doctors treated in an ER for overdoses and one trainee who attempted suicide.

If this were a mosquito-borne disease it would attract significant attention.

Although effective treatment is available, it generally is not utilized. Expense of treatment and recognition of



the illness are not deterrents. Lack of access to resources is not a problem as doctors generally can “get in” to see treatment professionals promptly.

Impediments to treatment

Impediments to treatment include the perception of a lack of confidentiality. Since much treatment is

delivered through large medical systems that share common electronic records, and the treatment may be provided by professionals in the “system” in which the doctor works (sometimes mandated by insurance contracts), this fear of loss of confidentiality is based on reality.

The training we receive prepares us to care for others but teaches us little about letting others care for us, especially when care is for emotional rather than physical distress. Doctors may avoid treatment for anxiety, depression, etc. even when severe and/or disabling.

A major obstacle to treatment is the fear that if the diagnosis and or treatment are known, particularly to the state licensing board, the ability to practice medicine will be affected.

Recently some disturbing data have been published.¹ A survey of 2109 female physicians (representing 50 states and DC) examined the effect of licensure board involvement on treatment.

Eighty-six percent of state licensure boards ask about mental health on their applications (in 2009). Questions varied from asking about all past diagnoses and treatments to asking about work impairment. Only 8 states do not ask about mental health. The RI board asks: “During any Post Graduate Training, were you ever dismissed, suspended, restricted, put on probation, or otherwise acted against or did you take a leave of absence for medical reasons?”

This question is directed at the work consequences of disease rather than the

If this were a mosquito-borne disease it would attract significant attention.

mere presence of it (a proper question, in my opinion).

One thousand sixty-nine survey participants (51%) had been given a mental health diagnosis since medical school and/or had been treated for one. The frequency increased with age. The participants were recruited from a closed Facebook site restricted to female doctors with children so these numbers may represent a degree of self-selection.

More importantly, however, only 62 (6%) of the 1,069 reported their diagnosis or treatment to the licensure board when asked. Of those who reported, 21 were required to submit medical reports from the treating physician and 10 needed multiple reports. Ten were required to appear personally or be

evaluated by a board appointed physician. Eleven were required to participate in a physician health program (PHP).

Most of the 1,001 doctors with a history of a diagnosis or treatment, who did not report, judged themselves to be safe to practice and/or were afraid of licensure and employment restrictions.

We might conclude that the fear of licensure and employment consequences deters physicians with mental health issues from seeking help. And we would be right. Among the participants, 1,040 felt they had or likely had criteria for a mental health disorder and did not seek treatment. The deterrents included “stigma,” fear of reporting to the licensure board, confidence in their ability “to get through it without help,” ignorance of treatment resources, fear that “colleagues would find out” and lack of time.

Of these doctors, 274 either prescribed for themselves or asked friends to prescribe for them informally (actions that, themselves, are unwise, unprofessional and threaten their licenses).

We should use this data to fashion

effective interventions and treatments to counter this epidemic of disease and death. Access to treatment in a manner that is perceived by physicians to be non-threatening to their professional status must be combined with the protection of patient safety. Such a system must assure that troubled physicians, whose illness impairs their ability to practice, do not care for patients, but must also reassure physicians that recovery from the illness will enable them to return to work. Another lesson, reinforced by this data, is that treatment of mental disease in doctors is best done by physicians outside the doctor’s “home system.” Finally, the state licensure board should be involved only when absolutely necessary.

RI is fortunate to have such a system (though underutilized) in place. The RI PHP (<http://www.rimedicalsociety.org/physician-health-program.html>) has no financial or legal relationship to the RI board of licensure and has no obligation to report to it. Doctors who consult the PHP can obtain confidential treatment from a wide pool of respected

professionals outside their “home system.” Doctors whose work is impaired by their disease are advised to take a medical leave. Only if a doctor refuses and patient safety is at risk, is a report made to the licensure board.

Our profession should encourage the use of our RI resources that provide confidential treatment outside the “home system” and the assurance that, absent an otherwise unsolvable threat to patient safety, the state will not be involved. Without this approach doctors who need help will not seek it and may suffer negative, possibly deadly, consequences. ❖

Reference

1. Gold KJ, Andrew LB, Goldman EB, Schwenk TL. “I would never want to have a mental health diagnosis on my record”: A survey of female physicians on mental health diagnosis, treatment, and reporting. *General Hospital Psychiatry*. 2016; 43:51-57.

Author

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Student Health Council (SHC) at Brown

SOURCE: BROWN WEBSITE

The Student Health Council (SHC) is comprised of a few students selected from each medical school class as well as licensed professionals in the mental health field. The SHC aims to address behavioral health concerns, substance use, and mental or physical illness that may impair students’ well-being during medical school and practice of safe medicine. We facilitate these aims through peer counseling and support, resource connections, wellness advocacy and education. Participation in peer support relationships with the SHC is voluntary and strictly confidential. For additional information, please email studenthealthcouncil@brown.edu

Link to Brown University health services

<https://www.brown.edu/campus-life/health/services/>

More about the background and mission of the SHC can be found in this RIMJ article:

A Student Collaboration to Address Mental Health Wellness in Medical School

<http://www.rimed.org/rimedicaljournal/2015/07/2015-07-26-plme-brooks.pdf>

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Top 15 Tips on Becoming an Effective Medical Simulation Performer/Writer/Director

XIAO C. ZHANG, MD, MS; SCOTT PASICHOW, MD; MELISSA BOWLER; DAVID LINDQUIST, MD, FACEP

As education continues to evolve to correspond with technological advances, medical simulation has been rapidly adapted as a bridging educational platform between classic lecture style teaching and real-life clinical experiences. Through a combination of role-play, simple and sophisticated technologies, and creative case design, medical simulation allows learners to be exposed to rare but challenging clinical and social situations in a targeted, simulated learning environment that are often difficult or dangerous to obtain in real life. A well-crafted simulated environment enables learners to complete a variety of learning objectives, whether it involves mastering bedside procedures or learning how to handle complex or difficult patient encounters such as “end-of-life” discussions or “delivering bad news.” Each simulation learning experience is unique, fully customizable and provides an invaluable insight on the consequences of the learners’ actions without subjecting the learners and the actors to real-life risks such as infected needles, malfunctioning equipment, unpredictable personalities or unintentional patient harm.

An engaging simulation case challenges the participants clinically, creates moments of unavoidable decision-making, and offers a pathway to resolution yet accommodates the range of possible participant responses. While high-fidelity simulation, such as computerized mannequins and hyper-realistic settings



Xiao C. Zhang, MD, center, observes simulated case being discussed by, at right, Dr. Francis M. Sullivan, MD, of the University Emergency Medicine Foundation, at the Lifespan Medical Simulation Center.

may augment a simulation case, the use of human actors/standardized patients as a confederate (a team member during a simulation activity that help provide the professional realism that challenges and teaches the learner) can add significant constructive tension and realism

to a case, and permits exploration of complex patient-provider dynamics. Standardized patients often require hours of training and rehearsal to perfect their new identity, simulate their physical symptoms, and provide realistic, but pre-scripted character responses to

challenging case situations. By providing a consistent and pre-defined account of their case-specific conditions, standardized patients-exams allow higher character-immersion and more reliable performance-based assessment of bedside clinical skills.

The construction of a “great” case also requires the collaboration of the case creator and confederates to clarify the learning objectives and plan for anticipated participant actions. Strong improvisational actors respond well to defined endpoints by giving actors extra room to apply their acting skills toward the learning objective (e.g. “continue to ask questions, appearing anxious and confused until the doctor explains the risks of thrombolytic in lay terms”). At times, however, junior educators and residents may be asked to play a confederate. Although well trained clinically, resident confederates can feel unprepared, vulnerable, and insecure about stepping into this role. These feelings may be amplified when their peers are

the scenario participants.

To understand the requirements of the acting roles, I interviewed DL-the Resident Simulation Curriculum Coordinator, SP-the Chair of the EMRA (Emergency Medicine Residents’ Association) Simulation Division, and MB-a professional actor and expert standardized patient for their “**Top 5 Do’s and Don’ts of a Successful Simulation Actor**” and “**Top 5 Suggestions for a Successful Simulation Case-Writer.**”

As a resident who has written medical simulation cases and acted out my own case scenarios, I have personally encountered numerous unforeseeable obstacles that would have made my learning objectives impossible to be completed without the guidance and support of the simulation faculties and actors who provided these engaging and helpful tips. I hope these 15 tips have sparked an interest in and quelled a few fears about providing a memorable teaching experience for your learners, your peers, and yourself. ❖

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Top 5 “Do’s” for a Successful Simulation Actor	
“Do” Tips	Actor’s Feedback
Be professional	It is important for you to stay in character throughout the entire case to promote believability and encourage your learners to take you seriously. Be professional - Acting is harder than it looks and staying in character while your body is being examined can be very challenging. Take the case seriously and remember that a real patient doesn’t think the details of their symptoms are funny, so avoid giggling
Pull from real-life experiences	While you may never have suffered from appendicitis, myocardial infarction, or inebriation, chances are, you have provided care for patients with these complaints. By drawing from your personal clinical experiences, you are able to reproduce a much more believable character performance throughout the simulation
Be empathetic to your character	In order to convince the learners of your confederate role, it is helpful to appreciate and understand the character that you are portraying by placing yourself in their situation. <i>Example #1:</i> If you are instructed to play a patient with a “crushing chest pain” due to a heart attack, then imagine how you would feel if you had suddenly developed a crushing chest discomfort, with unexplained sweating and uncharacteristic shortness-of-breath after climbing a flight of stairs. Channel that sensation and allow it to fuel your performance
Allow for pauses	Not every awkward silence needs to be filled up with dialogue. Allow the learners to process the barrage of information needed for them to assess the clinical situation; you can take this time to readjust and focus on your role and prepare to guide your learners to the next objective. Sometimes 8-10 seconds of silence is needed for processing, don’t feel the need to fill that time with noise.
Practice...a lot	As obvious as this may sound, practicing your role before the actual simulation case with real-time feedback is incredibly helpful and highly recommended

Top 5 “Don’t” for a Successful Simulation Actor	
“Don’t” Tips	Actor’s Feedback
Hold back	When you are the confederate, do not be afraid to express your emotions when you suddenly find an unexpected connection to your character. These moments will create a much more memorable experience for your learners.
Steal focus	Portray your character based on the case description. Any supplemental gestures or comments outside the script may shift the focus away from the learning objectives and confuse the learners. This isn't your chance to win an Oscar; it's an educational simulation.
Lose sight of the learning objectives	Your primary goal as a simulation actor is to facilitate the teaching process to allow the learners to complete the learning objectives. You can help guide the learners back to the tasks at hand when they lose track of the main goals.
Be self-conscious	The acting-spotlight can both be a blessing and a curse to actors of all level of training. Just stay focused on your role, remember the learning objectives and follow the scripts.
Giggle	This may sound silly, but giggling during your speech can spell instant disaster by shattering the veil of the simulated environment and diminishes your credibility as a believable character.

Top 5 Suggestions for a Successful Simulation Case-Writer (From an actor's perspective)	
Suggestions	Actor's Feedback
Provide a detailed case information	Providing detailed descriptions of the scenario, patient background (both social and medical) and specific emotional responses can be incredibly helpful for the actor as it provides a transparent snapshot into the mind of the case writer on what is expected from the actor and obviates the need for anxiety provoking improvisation.
Keep the case simple	A simple case with clear and concise learning objectives, along with easy-to-follow acting queues allows the actor and learners to focus on the key case elements and leaves little room for unexpected behaviors or complicated and divergent decision pathways
Expected the unexpected	Sometimes learners may not choose the clinical decision pathway that you had envisioned. It is helpful anticipate all potential deviation from the intended pathway and provide your confederates with a scripted response to guide the learners back on track.
Allow for active feedback	Direct feedback after a simulation session is mutually beneficial for both the learners and the actors. You should allow enough time to review the learning goals, gauge the overall reaction to your case, as well as allowing the students and confederates to provide constructive criticisms on both the case design and actor performance to make it even better during future iterations.
Be transparent	Your case, along with the learning objectives and character bios should be discussed with the entire team, including the programmers, actors and introductory. Adding a secret plot twist at the last minute can ruin an entire case.