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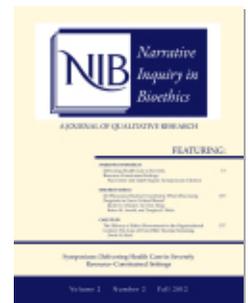
Poverty, Surgery, and Systems

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Narrative Inquiry in Bioethics, Volume 2, Number 2, Fall 2012, pp. 95-98
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2012.0032>



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Introduction

Developing Health Care in Severely Resource–Constrained Settings

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This symposium of *Narrative Inquiry in Bioethics* catalogues the experiences of health care providers working in resource-poor settings, with stories written by those on the frontlines of global health. Two commentaries by esteemed scholars Renee Fox and Byron and Mary–Jo Good accompany the narratives, helping situate the lived experiences of global health practitioners within the frameworks of sociology and medical anthropology respectively.

The burgeoning interest in global health among students, health science trainees, clinical practitioners, social entrepreneurs, philanthropists, and government officials is often linked with substantial *moral* claims. People working in global health often start with the rhetorical premise that *each and every human being, regardless of economic, social, or political circumstances that lie beyond his or her control, deserves equal access to quality health care services*. This is a bold position at risk of trivialization, in part because the sentiment is so commonplace among global health equity activists.

Despite this relatively recent global outpouring of solidarity and concern, billions of poor people still lack access to basic health services. All too often, interventions that perpetuate existing trade practices and market economics are promoted, usually to the detriment of the poor. As our good friend and colleague Arthur Kleinman warns:

The irrelevance of ethics can be seen when considering universal ethical formulations of justice and equity that do not begin with the local moral conditions of poor people, those experiencing the systematic injustice of higher disease rates and fewer health-care resources because of their positioning at the bottom of local social structures of power. (1999, p.72)

If we are serious about reducing health disparities globally, we must be prepared to mobilize resources in Africa just as we would in the United States or in Europe. If we fetishize cost-effective (read: low-cost) interventions for the poor, we must ask whether we use the same metrics in other situations. In other words, we must always strive to address the fundamental structural and social causes of health inequity.

We believe that global health must avoid the “iron cage of rationality,” to use sociologist Max Weber’s words. One unanticipated consequence of the growth of global health as a field is that the “audit culture”—which encourages accountability and effectiveness—can at times reinforce power differentials between donors (whether government agencies or multilateral foundations) and their intended beneficiaries. Agendas are often set not by community members but by global health leaders who rarely demonstrate sustained commitments to a local community.

As the guest editors of this issue, we hope to recapture the *soul* of global health work through the art of storytelling. Narratives, even when presented as raw and unrefined as many within this issue, remind us of the immense challenges—both programmatic and moral—involved in this work. The profound scarcity of resources available to health providers in poor countries forces ethical questions on doctors, nurses, pharmacists, social workers, and other health care workers, who make difficult choices every day about what to do with the few resources they have. These are the ethical dilemmas of mortal dramas at their most dire. Global health work demands of its practitioners an alternate mode of audit than academic methodologies can provide. Narratives return us to the basic human commitments that led many of us to this work, and they remind us to use words like equality and justice meaningfully.

The narratives that follow offer unmitigated perspectives on the working lives of global health practitioners. They highlight the translation of the moral and programmatic challenges of health care delivery into real choices: for example, between a visiting surgeon's desire to treat a patient and his capacity (or really incapacity) to provide follow-up care. They acknowledge the necessity of interdisciplinary cooperation in resource-constrained settings, as well as the difficulties in collaborating across cultures and continents. Most importantly, they make the claim that a newborn in distress in a tent in Port-au-Prince merits the same resources and attention as one in Boston, and that his or her death merits the same indignation. They demonstrate the radical solidarity inherent in the belief that health care is a human right.

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Personal Narratives

Delivering Health Care in Severely Resource-Constrained Settings

Lisa V. Adams, Helga Naburi, Goodluck Lyatuu, Paul Palumbo, and C. Fordham von Reyn; Maneesh Batra; Jeffrey L Deal; Richard Keidan; Maricruz Merino, Jonathan Iralu and Sonya Shin; Paul Pierre; Vincenzo Pezzino; Robert Riviello; Sadath Sayeed; Ryan Schwarz, Duncan Smith-Rohrberg Maru, Dan Schwarz, Bibhav Acharya, Bijay Acharya, Ruma Rajbhandari, Jason Andrews, Gregory Karelis, Ranju Sharma, and Mark Arnoldy; Sridevi Seetharam, Bindu Balasubramaniam, G. S. Kumar, and M. R. Seetharam; Prasanta Tripathy

Closing the Gaps in Pediatric HIV/AIDS Care, One Step at a Time

Lisa V. Adams, Helga Naburi, Goodluck Lyatuu, Paul Palumbo, C. Fordham von Reyn

Fatuma's* doctors were completely perplexed. It was 2003 and she had returned to the DARDAR clinic in her hometown of Dar es Salaam, Tanzania three times that week with vague complaints of various pains and aches. Her doctors were considering whether these symptoms were due to the initiation of her recent treatment with antiretroviral medications for her HIV infection or related to the last administration of the investigational tuberculosis (TB) vaccine that the DARDAR Health Study was evaluating. Fatuma's doctor, Dr. Lillian Mtei, consulted with Dartmouth's chief of Infectious Disease, Dr. Ford von Reyn, who happened to be in Dar that week on a site visit. Neither physician could determine the basis for her symptoms. Dr. Mtei returned to the exam room once more and this time emerged with the answer: Fatuma had just learned that her three year old daughter was HIV-infected, likely contracted from Fatuma during or shortly after she gave birth to her daughter.

*Name changed to preserve confidentiality.

Fatuma believed that her HIV diagnosis was a death sentence for her daughter since antiretroviral therapy was not widely available for children.

Dr. von Reyn, Dartmouth's lead clinical researcher in Africa and a father, knew too well the harsh reality of inequities in a resource-limited country. He turned to Dr. Mtei and said decidedly, "we need to do something about this."

Thus the DARDAR Pediatric Program was born.

Pediatric HIV: A Neglected Disease

The need for HIV treatment among children in Tanzania, as in most of sub-Saharan Africa, is compelling. At the end of 2009, approximately 160,000 children aged zero to fourteen in Tanzania were living with HIV (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2011). Even with successful roll out of prevention of mother to child transmission programs in Tanzania, there were nearly 29,000 perinatal infections in 2009. As of December 2010, only 18% of these were enrolled in HIV treatment programs (UNAIDS, 2011; World Health Organization [WHO], 2011). Without antiretroviral therapy (ART), one-half of HIV-infected children will die before their second birthday. Since clinical research to determine efficacy and safety of new medical treatments is conducted almost exclusively in adults, provision of new medical treatments to

children always lags behind advances for adults. Furthermore, children are often underrepresented in programs for antiretroviral drugs for the following reasons: 1) they are not prioritized for care; 2) facilities lack infant diagnostic capabilities; 3) there is limited pediatric HIV training and consequently, a shortage of pediatric providers; and 4) pediatric antiretroviral formulations are frequently unavailable. The unacceptable delays in pediatric HIV drug development and treatment access led the international organization Drugs for Neglected Diseases initiative to publish an editorial in which they referred to pediatric HIV as a “neglected disease” (Lallemant, Chang, Cohen, & Pecoul, 2011).

The Tip of the Iceberg: More than Just Medicines

With a grant from the New York-based Foundation for the Treatment of Children with AIDS, the DARDAR Pediatric Program, a joint collaboration between Geisel School of Medicine at Dartmouth and Muhimbili University of Health and Allied Sciences, began seeing patients in May 2006. It was the first dedicated pediatric HIV Care and Treatment Center in Tanzania and operates in accordance with Tanzania’s National AIDS Control Programme’s guidance. Testing for both children and infants (the latter of which requires a more sophisticated assay) is available.

The day the clinic opened we celebrated this collaborative effort that would provide HIV-infected children in Dar es Salaam access to antiretroviral treatment. One of our first patients was a six-year-old boy whose mother, like Fatuma, was a participant in our TB vaccine trial. She had been advised to bring her son to us for HIV screening. Her son looked healthy so she was surprised and understandably distraught when his test results indicated that not only was he HIV-infected, but his CD4 percentage was very low. His mother was reluctant to have him started on antiretrovirals given his general appearance and young age—and that he was her only child. We worked closely with the family to help them understand the importance of initiating therapy as soon as possible and within

a few weeks the parents agreed. Fortunately, his treatment was started in time. Today, at 12 years of age, he remains adherent to his medication regimen, is doing well in school and has never had any major health problems. His mother and father, who has remained HIV negative, are considering adding another child to their family and working with the Prevention-of-Mother-to-Child Transmission program to do so safely.

However, for every story with such a happy ending we also saw our share of children for whom our services were accessed too late. Every death of a child is painful and it was particularly tragic when we learned that it was fear or misinformation that kept parents and caregivers from seeking care for their child earlier. Most of the deaths among our clinic patients occur when the child presents very late in the course of their disease. With advanced HIV, even our best medicines can fail.

Furthermore, we quickly learned that HIV medical care was simply the tip of the iceberg in terms of the needs that our pediatric patients experience. While dispensing quality-assured medicines and supporting adherence is a primary goal of effective HIV care—and clearly saves lives—the impact of the child’s HIV infection extends well beyond the need for life-long therapy with antiretrovirals.

Our patients presented with serious concomitant medical conditions, including severe malnutrition, tuberculosis and malaria. We expected and were prepared for these complications and had established protocols for comprehensive screening and management for these very ill children. Even in the absence of clinical malnutrition, food insecurity in the home makes adherence to medications a challenge, especially when children should or prefer to take their medicines on a full stomach. Our patients also arrived with complex psychosocial situations. These issues are more challenging to address in a setting with a limited number of mental health specialists with training in pediatrics and even fewer social workers to provide the extensive case management these children often require. We witnessed how these children carry adult-sized emotional burdens by having to cope with their medical needs, a less than ideal home situation, and

quite often the loss of one or both of their parents. In a setting where access to medical care for HIV has been a struggle and an important focus, most children have not had the opportunity to discuss the challenges they face at home, let alone to grieve for their lost parents whose deaths may be shrouded in shame—something that children need not be told but can sense by the behaviors of those around them and what is explicitly *not* said.

At our program, we offer a nurse-led youth empowerment and psychosocial support group on the weekends. Originally scheduled for one hour in the morning, the children were eager to extend the time they had together for both the educational and play activities. The group now meets for an entire morning. Also, it is open to children regardless of HIV status, which allows our patients to bring their friends and relatives and avoids singling out those who are infected. Despite this group's success in providing a supportive and safe space for children, we constantly struggle with a desire to provide more comprehensive programming to address their extensive needs, and to triage more serious mental health issues.

One of the most complicated situations we have faced in our work has been the process of disclosure—when and how to tell a child that they are HIV-infected. What is the right age to start the discussion? Is this a culturally bound question such that the U.S. experience and input is irrelevant? Parents are often terrified at the thought of discussing HIV infection with their child, dreading the questions about the source of their infection, and having to tell them it was passed unknowingly from them. Non-parent caregivers of children with HIV also worry about tarnishing the memory of the deceased parent, and fear any resultant anger from the child could harm the child's health and their (often fragile) household. Frequently, neither data nor anecdotes about the benefits of disclosure can fully reassure a parent that the time is right to address this issue. This has been a particularly sensitive matter and the American side of the cooperation has been careful not to impose their values. The Tanzanian health care workers have been our guides on this issue, setting the pace on when and

how fast to approach this subject on a case-by-case basis. One situation that had both Tanzanian and American partners challenged was learning that a senior physician in the community advised against telling his 13-year-old granddaughter about her HIV status, feeling that 13 is too young to shoulder such news. The problem of family members who are medical professionals being unable to provide unbiased care is one that cuts across cultures and resource levels. With several years of experience, we can now gently and confidently inform parents and caregivers that knowing one's HIV status can actually increase medication adherence and improve their child's health and well-being.

Confronting stigma and fear is an every day occurrence for HIV-infected children and their families. Many times these issues impact the provision of care. We were well aware that most parents and caregivers of our pediatric patients would not feel comfortable confiding their HIV status to any relatives or friends, including their spouses. These concerns are not unfounded: the reports of women whose husbands forced them to leave the house, thereby leaving them without any source of income or supports, are real and frightening. Early on, we saw mothers go to great lengths to ensure that their child's status was not shared with others in an effort to reduce the risk of discrimination, teasing and ostracism by their child's friends and family members. In some situations, children whose HIV status became known were expelled from school, the thinking being that death was imminent and they should not take the spot of a healthy student. With the treatment that is available today, children with HIV can have life expectancies and quality of life similar to children without HIV. Yet fear and shame continue to prevail. When one of our nurses made a home visit to see a child that had missed several appointments, the mother panicked when the car pulled up outside their home and she saw many of her neighbors out front looking on with natural curiosity about who the visitor was. The mother thought fast on her feet and loudly and prominently greeted the nurse as her distant cousin who had finally come to visit. Ironically, we thought we were providing a patient-centered service (a

home visit), when in fact we may have been putting the mother at risk and unintentionally revealing her and her child's status.

Slow but Steady Improvements

Due to numerous efforts to scale-up pediatric HIV services, care and treatment for HIV-infected children is now available at a number of sites in Dar es Salaam, elsewhere in Tanzania and in numerous other resource-constrained countries. Fatuma found treatment for her daughter through the private sector before our clinic could open but today she would have a choice of facilities from which to receive free care and treatment. As with adults, effective combination ART has made HIV a manageable chronic illness for many children and investments in their future have followed. We continue to emphasize the importance of education for our patients as part of their clinical management and healthy lifestyle education. Prevention-of-mother-to-child transmission programs continue to be scaled up in HIV-endemic settings with wider reach each year. Combined with adoption and implementation of new ART recommendations for pregnant women, these programs will help drastically reduce the number of children who are born with HIV infection each year. However, until that number reaches zero, programs to address the unique needs of children living with HIV will be necessary.

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The Triplets

Maneesh Batra

I am a neonatologist and for the majority of my clinical time I care for babies and their families at a large University-based referral neonatal intensive care unit (NICU) in the United States. In 2003, I first visited this rural Ugandan hospital shortly after the opening of a special care baby nursery there, and have been involved with development of that program ever since.

Uganda is a beautiful, land-locked country in East Africa with a sordid political history. It is a developing country that is poor, mostly rural with a high fertility rate and a life expectancy of 42 years. The government spends \$5 per capita per year on healthcare. The district with the hospital has a population of 500,000, the majority of which is rural. Access to health services is poor, even by Ugandan standards, and child mortality is in the higher band in the country.

Most people in the region live in extended family clans. A common home is made of earth, with a grass roof, and a jerry can out front for collecting water from the well. It is an exquisitely lush landscape with fecund soil. At the hospital, there is limited electricity, lab support, medications, blood supplies, and health care workers. For the 200 bed hospital (that accommodates upwards of 400 inpatients when necessary, no one is turned away) there are four to seven Ugandan doctors, who do everything from C-sections, to colostomies, to HIV care to resuscitate babies in the NICU. For a ward of 20–80 patients there are one to two nurses, and maybe a nursing aide. Families do the majority of the care in the hospital, even in the NICU. Mum's express breast milk, perform tube feeds, wash the linens, notify staff when an IV infiltrates, and keep babies warm.

Day One

Another beautiful morning, with fresh instant coffee in hand, birds chirping and kids playing outside. It is good to be back. Over the last eight years, I've

made some close friends here and it's good to be among them again. Every time I visit and return home, I leave a piece of me here, and bring back something new with me. This morning that feeling is overwhelming me, an incredible inspiration swells. I am not tired and I want to be busy. It is no wonder that this is where I was inspired to pursue caring for babies as my career. Over these years, it has been amazing to see the staff care for the community's babies and mums here. As an outsider, an opinioned one at that, I feel burdened at the thought of these babies dying somewhat needlessly. Is it really no-one's fault? How should one act in the face of scarcity, knowing there is a better standard to be had if only circumstances were different?

I walked into the NICU to find triplets had arrived! Born at about 33 weeks they were two months early. Since they weighed around 1.5kg (about 3 lbs) each, they were at very high risk of dying—however, it was absolutely incredible to see the way they were tucked in by the skilled team. Within an hour of delivery—they were in incubators with IVs, having their hypoglycemia corrected, and two out of three were on oxygen (all of them had their O₂ saturations checked). The three babies were tucked in so calmly, with the finest skill and expertise neonatal care anywhere has to offer. In stark contrast to the first admissions I witnessed years ago, the nurses now knew exactly what to do and how to do it. As a result, they had saved many lives and restored hope among the mums of the region that there was somewhere to go to get help. This success resulted in a healthy swagger among the staff because they could intervene successfully.

These were spontaneous triplets to this young mum, who already had three other children. She looked tired when she walked into the NICU one hour (yes one hour) after delivering the trio, but if I hadn't known prior, there was no way to know that she had just delivered three babies.

Mum was shy, as many of the mum's are, with all the staff but certainly with me—a somewhat loud “muzungu” (white person) who tends to make too much eye-contact for their comfort. But this mum opened up a bit faster—she seemed happy, truly happy and proud of her two boys and one girl.

From the outset, Baby C, one of the boys, didn't look as strong as his siblings. In most hospitals in Uganda the trio would likely have been in the same bed or isolette together, but this is such a fortuitous NICU. Indeed a side-effect of the increasing resources and knowledge here was to separate siblings into separate isolettes, much as we do in the States. Back home, I struggle against this practice—feeling that twins should be together. The thought did cross my mind briefly, that if Baby C wasn't going to make it, would he ever feel his siblings close by? Though he was struggling, he was by no means tiring—so the thought entered and left my mind.

Day Three

Baby C continues to struggle. He is having desaturation episodes (low O₂ levels) that require some resuscitation. It is really great that he is on continuous oximetry monitoring, for if he had not been, he likely would have arrested before anyone noticed that he was becoming blue. I guess oximetry is a double-edged sword: before it was available, staff relied on clinical exam, while now they rely on the number on the monitor much more (even when it is inaccurate). Furthermore, now that there is oximetry, these little babes are resuscitated from deep desaturation episodes, whereas previously they would have passed. Who knows what is happening to their organs, and their brain with these recurrent resuscitations?

The mum is around all the time. She is sleeping outside under the tree with all the mums, and they seem to be developing their own unofficial mentoring program. The veterans among them chaperoning the rookies through the throws of washing breasts, expressing breast milk, eating and drinking, holding back tears, maintaining hope, and learning to live away from family and support with your baby in a plastic box. Maternal nutrition is such a huge issue here. The mums seem to be used to sacrificing their health for their children, and are in the habit of foregoing eating so that their children can have some food. The burden on the families is huge. The financial piece alone is massive—many

of the families have no money to speak of as they live in a subsistence culture, and some have sold land or other belongings to pay for babies in the hospital. The mum of the trio has left behind her three other children and her husband (who works) in a home without other adults. Her husband will come next weekend to make a payment, but until then she is alone with her babies in boxes. She is happy—she sees that Baby A and Baby B are pink and getting better. She trusts that everything will be okay for Baby C (even though I am becoming more doubtful). If we had had CPAP (continuous positive airway pressure—a treatment that keeps airways open), this would have been an easy save. If mom had received antenatal steroids, perhaps we wouldn't have even needed the CPAP. Without both, surfactant therapy could probably reverse the process. Without these valuable yet expensive prevention and treatment modalities, I am witness to the natural history of respiratory distress syndrome in exquisite and gruesome detail with this little guy. He is beginning to lose his lung volumes, and because we can't nourish him and he is working so hard to breathe, he is becoming weak, he's turning greyish, and his bones are showing through his skin. I have seen babies like this turn around here, but I am afraid this little guy won't.

I asked the nurse in charge if she thinks that mum knows that Baby C is sick. She tells me that she has told her such, and that mum is praying. The mum has been holding the baby daily until this morning when it seemed that the baby was too weak. I look over at her, and she is holding the baby's hand through the hole in the plexiglas.

Day Four

The babies don't have names yet. When I inquire about a short-list of names, mum beams a radiant yet coy smile. She is waiting to get them home before disclosing their names. Baby C hasn't been able to turn a corner—he looks ashen, emaciated, and uncomfortable. It is very sad. I wish we could provide ventilation for him. I asked the mum if the father was coming soon—she said that he wasn't supposed to come until the weekend. Without

telling her why, the nurse in charge mentioned to mum that dad should come sooner. I think mum knows what is happening, plain and simple, yet she is maintaining hope for all three of her babies.

The staff here are becoming skilled, very skilled at managing the little ones with the resources that they have here—so much so, that it seems now they are facing many of the same dilemmas that we face in the U.S. with respect to “viability” and “morality” in pursuing aggressive care. What about prolonging suffering here, in the name of trying to save more babies—this baby? What will the families think if we offer non-resuscitation?

Day Five

Baby C is struggling to live. In contrast with the past, when I would notice the staff here begin CPR in these situations, I think they all knew what was happening, and they fetched the mum from under the tree. We spoke with her, explaining that Baby C's lungs are too immature to sustain life. Two of the most skilled nurses were with me and I asked if the mum would like to hold the baby, and she said yes. She held the baby for a while, and during that time the saturations came up, briefly—but within a few hours the baby passed. I cried as I watched this little ones hands and feet and eyes and mouth as he died. If mom had received antenatal care, and had received antenatal steroids when she presented, could this have been prevented? If CPAP or surfactant had been available here, would this seemingly preventable death have been averted?

Fortunately the father was able to arrive before the Baby C passed and was able to see the baby, although according to the staff, he was less brave and did not want to hold him. The nurse in charge sort of urged him to hold the child. The whole while he was holding the struggling baby, he didn't look at him. He only looked at the nurse, asking about arrangements and such for after the baby's passing. It struck me that this papa is doing the best he can, and is simply trying to help his family survive. Who is caring for their other kids now?

In this community transporting remains after passing is a huge challenge and expense. The

matatu (minibus) drivers won't allow passengers with a dead body, nor will a boda (motorbike) driver. While the father was worried about how to handle the hospital fees, and also getting their dead baby back home, mom was weeping silently. I believe that the loss of a child in Uganda is no different than in the United States with respect to the impact on families. The way we all show pain and fear is just different. As I looked back at the two surviving twins now co-bedding in the same isolette, glowing under the blue phototherapy lights, I wonder how the two remaining babies will do and what they will hear later about their brother who didn't survive.



The Day I Touched Jesus

Jeffery L. Deal

She deserved better. They all do. I met her early on a morning that promised to be hot and wet, as Sudan tended to be at that time of year. Hot all the time. Hot and wet in the summers. I touched her for the briefest of moments, felt her leg move against my hand and caught a fleeting glimpse of a foot that was barely the size of my fingertip. I was there because a missionary asked me to come, told me stories of conditions in Sudan and convinced me that I could save lives. He was right.

Her twin brother was born eight hours earlier, sometime around midnight. The birth attendants managed the delivery as well as anyone could in the same situation. The last time I had attempted to manage such a problem delivery was almost twenty years earlier when I had been a Navy Lieutenant fresh out of my surgical internship on temporary assignment to a Marine Corps battle group in the Philippines. On that deployment, a corpsman brought me to a grass hut where a woman who looked barely more than a child herself labored against a breach delivery. I spent the day examining

her while her family brought me things to eat that I do not believe should be eaten. After six hours of no progress, I radioed for a helicopter to take her to Clark Air Force base where they had operating rooms and obstetricians. In South Sudan, we had no such resources.

My oldest daughter, a premed student at the time who had worked with me in Sudan on other occasions, sat in the corner with her classmates and watched as I put my hand inside the mother. She was of the Dinka ethnic group and was a large, robust woman who sweated profusely and occasionally caught her breath, but otherwise seemed unmoved by her contractions. Fluids gushed over my gloved hand and the students gasped. I felt the baby's leg retract slightly as if she resented my intrusion.

I could not get past the baby's hip—she was wedged tightly in the uterus. I had some medicines that were used to hasten delivery and, not really knowing if it was the right thing to do, I gave the mother some through her IV. Still I could not dislodge the child. I told the students and birth attendants that we would give her one hour while I rounded on the other patients in our remote and poorly equipped clinic. If she did not deliver by that time we would take her to a facility run by a Catholic relief agency several hours drive from us—a drive that due to war, weather, or mechanical problems we could not always complete.

I saw the rest of the patients in a hurry while browsing through all of the medical texts and the few books we kept at the clinic. This child's only hope of surviving was for her mother to have a cesarean section, and as quickly as possible. After determining that none of our other patients were in imminent danger, we loaded the mother, the first-born twin, and the grandmother into our vehicle for the long ride. One of the medical students, who at the time of this writing was completing her residency in obstetrics and gynecology, asked me if I shouldn't pray for the woman while we drove. I felt guilty for not praying out loud without being prompted, so I reached back and placed my hand on the mother's abdomen and prayed while I drove. I felt a slight movement. It could have been the rough road or the mother shifting, but I believe to this

day that I felt the child move. I would not feel her again. I drove as fast as the rough, bomb-cratered dirt road allowed.

Mother and unborn child were doing well when we finally arrived three hours later. I knew the facility and many of the workers so I drove past the guard and directly to the obstetrics ward. Two nurses rushed out to meet us with a gurney and whisked the patient into a delivery room, a dusty place of peeling paint and old, powerless lights. They told us the surgeon was nearby and that they would take care of her.

The rest of us left to find something to eat and to purchase supplies. We were gone for a couple of hours. When we returned, we found the head nurse.

"The baby has died," she told me with a professional mask of seriousness. "We felt the baby's leg and thought we could make the delivery. The child died while we were working."

We asked to see the mother and were taken to the ward next door. The mother we had worked with so hard sat upright in the bed with a sheet over her lower body. Amazingly, she still did not look tired. Her Dinka name, my wife reminds me, was Adut which means "comfort." It is a name given to the next child born after the firstborn dies. Adut cradled the twin brother in one arm and stroked his cheek. The mother nursed the child and gazed at him with the look that only a mother can have—one of love, adoration, and hope. My daughter stood beside me while we spoke briefly to the nurse and to the mother. Adut did not seem troubled that we did not save her other baby and was content with the life she held to her breast. I had feared she would hold our failure, my failure, against us. When my daughter and her friends had left, I asked the nurse a question to which she responded, "It was a girl."

I kept my face turned from the others as I got into the truck. The ride back was mostly silent and seemed to take forever. Darkness had fallen over the flat land by the time we made it back to our tent camp. We all drank our filtered water, spoke encouraging words to one another, and went to rest for the coming day.

In the week before my failed attempt to deliver Adut's child, a mother had come to us with a child

in distress. She had given birth to three other children besides the newborn—two dead of unknown diseases. The older surviving child hung back and hid in his grandmother's skirt every time I walked in to see his mother. He was thin, like all of the Dinka in those days. His legs looked barely substantial enough to hold the naked body that grasped the slim woman's legs as he peeked at me. When I stopped to speak to them, I always reached tentatively to see if he would trust me and each time I was rewarded by a scream.

I went in to see his newborn brother, ignoring as best I could the stern look that the grandmother always cast toward me. I was not sure what she wanted of me. I did not want to admit it, but I resented her lack of friendliness and gratitude. The Dinka I treated never said thank you, despite the fact that I was living in a tent and toiling in the brutal heat when I had a perfectly comfortable house in the U.S. In the years I worked with them, I heard the term for "thank you" used rarely and most commonly directed to *Niahlic*, God, and almost never to me. While I felt loved by my Dinka friends and colleagues, I hid the embarrassing need to be thanked as a marker of the selfish and egocentric attitude it was.

As I entered the small, squalid hut the missionary-preacher called a clinic, other mothers with sick children raised their eyes and stared. I dreaded going to the darkened back room because I knew that today, the mother and child behind the warped wooden door would have no need to thank me because I could do nothing for them. In fact, I had done nothing over the past forty-eight hours since she had come to me. She had delivered the child squatting in the middle of a dirt trail several miles from where our birth attendants worked. She cut the umbilical cord with the only knife she had with her. Almost assuredly, this knife carried the spore that made the toxin we know as tetanus. In the best of places with the best equipment and personnel, the child's prognosis was bad. Here, it was hopeless.

Within hours after her arrival, her newborn son began to have painful and sustained muscle contractions. He cried weakly at first, and then he became just too weak and tired to make any noises

except for the slightest grunting sound with every breath. I had no antitoxin for him, no way to feed him, no medicines to ease his passing. Touch him and he went into a spasm of contractions. Even slight sounds or light triggered his spasms, so we did what physicians all across Africa do with such children. We put him and his mother in a quiet, dark room and waited for him to die—prayed for him to die quickly, feeling ashamed of the prayer and the fact that I deserved the grandmother's scorn. The next day, my prayers were answered.

South Sudan is filled with moments like this where the world contracts around suffering and death and nothing else seems to matter except the patient before you or the drought-tortured, empty gardens. When I emerged from this world into the one where television rules mass thinking and money flows by the billions to iPods and cosmetic surgery, I spoke with a stridence that surprised me as I tried to connect the world of Sudan with sources of Western money. Mostly through one of my private patients whom I later learned was quite wealthy and a dedicated philanthropist, I had enough success collecting money to build a new medical facility to replace the one where I watched the newborn die his horrible death. This one had solar collectors, generators, a kitchen, and cleaning staff. On the day we opened, I sent word via my satellite phone to my wife that seeing Dinka patients on clean sheets and being fed was the best moment of my professional life. As good as that moment was, however, we never seemed to have enough funds for the escalating flow of patients and the unexpected epidemics. When I returned to raise additional funds, I remained appalled by the indifference many of my friends and colleagues showed when confronted with such desperate need.

I learned to despise American churches during that time, a time when my world encompassed a dying newborn in Sudan, as well as the air conditioned padded seats of our affluent suburban church. It took a couple of years after leaving Sudan for me to regain a sense of balance in the way I understood the great calling that Jesus made for his church to minister to the sick and needy. It took even more time for me to be able to speak to others

about Sudan without being overwhelmed with anger, despair, and guilt. Anger and despair that conditions in the area continue to be so abysmal. Guilt because I am no longer there with them. My daughters, however, have stepped into the gap. One is a nurse presently working in Haiti, while the other is a physician who, after working in Honduras, is likely to spend at least part of her time in a similar area. Both have worked with me in Sudan, and both, in response to their faith, have dedicated their lives to the aid of the most needy—a fact that makes the ghosts of my own absence from the field easier to manage.

I have worked through epidemics of cholera, malaria, and meningitis where we lost scores of people each week. In the few short years since, most of those hard days have receded to a distant yet still troubling memory. Some memories have remained sharp reminders of our work there and almost daily I relive my encounter with Adut and her labor to bring the twins into the world. Something about the one, tiny being I encountered that day haunts me in ways that I cannot easily explain. How low can a person be when she can die having never been held? Never been stroked or fed by someone who loved her? How low must a person be to die without a name in a place that will keep no record that you ever lived and where your own mother does not mourn your passing? It is hard for me to imagine anyone of lower standing than the girl whom I touched ever so briefly that hot morning in Sudan.

Jesus spoke passionately of His desire for us to care for the poor and downtrodden in His stead, never more poignant than when He said, "Truly I say to you, to the extent that you did it to one of these brothers of Mine, even the least of them, you did it to Me."

The partially born girl I touched that day had to be the least of the least. In retrospect, I could have administered enough local anesthetic to have surgically removed the child through a few incisions, but it had been years since I had done or even assisted in such an operation. We had no lights, no cautery, limited instruments, and no sterile rooms. Even had we gotten the child out, we had no way to manage Adut's bleeding and would have had to pack the

wound open and rush her to the same hospital. It would have been like performing a cesarean section in your garage without electricity. Perhaps I should have tried. Perhaps I could have made the decision to drive her to the hospital earlier and she would have lived. Perhaps, perhaps, perhaps—but I am not sure of any of that. Of one thing only I am certain.

She deserved better. They all do.



Building a Foundation

Richard Keidan

A guiding principle of Judaism is “*tzedakah*,” which translates as charity but actually means righteousness, reflecting that *tzedakah* is an obligation, not a choice. This concept of social justice was taught to me at home, at school and at synagogue. I gave to charities and did occasional charitable work. As my parents had taught me, I taught my own children the spirit of giving, but it did come from a place of obligation, not passion. I have since come to learn that there is a world of difference between just fulfilling our obligations to each other and letting them guide the kind of person we become.

It is ironic how the process of becoming a doctor—a person society expects to be selfless—requires total self-absorption. Think about it. I was trained to compete with my classmates in order to be accepted to the best university, medical school, residency, and then fellowship. I spent more than one hundred hours each week in the hospital during surgical residency. If I had free time, I wanted to do what I wanted to do. I was so focused on the end result that I had little time to think of others, let alone to ponder the inequities of the world.

Several events led to the awakening of my conscience. One was an opportunity to go to Ethiopia and perform a couple weeks’ worth of cancer surgery through Mother Teresa’s Clinic. Quite frankly, I went because it seemed like an exciting adventure.

However, I was completely overwhelmed by the experience. The conditions were abominable. The stories of each of my patients were heart-wrenching. I encountered a 14-year-old boy, the same age as my son, who had a tumor 15 cm in thickness wrapped around his neck. In order to hide the tumor he wore a scarf, but this still did not prevent him from being shunned. He traveled by himself for several days on a bus to reach the clinic. He had no one to advocate on his behalf, was unable to speak the local language, had never been outside his village (let alone in a motor vehicle), and he fearlessly underwent major surgery all by himself.

The inequalities in health care compared to my suburban hospital were unfathomable. I cried every night in my hotel room. There seemed to be no solution to this situation. Soon after I returned home, Ethiopia became a distant memory. The experience cut me to the bone, but for whatever reason, I did not rally. I did not see myself as part of the solution. It took an entirely different international experience to open my eyes.

There is a saying, “One goes to the Himalayas to see the mountains, but returns for the culture.” In 1982, on a sabbatical from my surgical training, I went to Nepal to see the Himalayas, but fell in love with the people. Living in the most basic shelters, eating the most basic diets, with no access to clean water or toilets and little access to health care or education, the people seemed happy. I was invited into their homes and lives, slept on their straw mats, ate their rice and drank their tea. Their spirit and sense of contentment drew me back over the years 15 times. Nepal became a sanctuary for me, a place that gave me time to reflect upon what is truly important, a place that provided energy and inspiration for me. Its public health and education needs were apparent to me, but again, I felt sympathy for my Nepali friends; I did not see that I could—and must—help.

It took a chance meeting to change that. Two years ago, I was on an exploratory trek on the Great Himalayan Trail in the Kanchenjunga region of Nepal. Namgyal was our sirdar (head sherpa guide), short in stature, but a giant of a man. Lacking a formal education, but very bright and

motivated, he rose through the ranks from porter all the way to lead sherpa of Everest Expeditions. He had reached the summit of Everest ten times by the age of thirty. He led the all-Nepali Extreme Everest Expedition last year which cleaned up 4,000 pounds of garbage and dead bodies from the death zone (over 8,000 meters, or 26,000 feet). He regularly leads Himalayan rescue operations. Yet he works his notoriety not for self gain, but to help the children in his remote home district of Khotang.

At the end of our trek, he asked me if a future trip to Nepal could include a trip to his village area to perform a few weeks of medical care. He offered to pay for my expenses, including my air ticket! I was humbled by his offer, but also embarrassed, given the vast gulf between our financial situations. Furthermore, I was ashamed that it was he, not I, who initiated this process.

Namgyal did what no one else had: he woke me up. I finally realized that I had a moral and ethical imperative to address social injustice. After a bit of research and consultation with my friend and advisor, Buddha Basnyat MD, it was soon clear to me that bringing a duffle of medicine and a stethoscope to Namgyal's villages would not create any meaningful change in the status quo. Before I made any decisions on what I should do, it was clear I needed to make an exploratory trek to Khotang.

A few months later, I returned to Nepal and to Namgyal's home area of Khotang. I saw the same conditions I had seen for the last 27 years, but through different eyes. Nepal was no longer a place for my amusement, thirst for adventure or sanctuary, but rather a place for a different kind of inspiration. I now went to Nepal to see if I could make a difference, to give instead of taking.

It was readily apparent why the life expectancy in urban Nepal is over 70 years, while only about 50 years in rural areas such as Khotang. Access to both health care and education is severely limited. Adding to those already restrictive conditions, waste management and toilets are non-existent, leaving no doubt as to why all water taps I tested during this trip revealed fecal coliforms.

The one district hospital in Khotang housed the only three or four doctors in a district of 250,000

people. These recent medical school graduates, lacking post-graduate training including those even in basic surgical and gynecological procedures. They had no vested interest in being there; they were merely serving their obligations for service to the government.

Attempting to meet the needs of those 90% of residents who lived more than a day's walk from the district hospital were about 60 health posts and sub-health posts manned by mid-level health care workers, all with eight to twelve years of basic education, and a further six to eighteen months of technical school. Worker absenteeism was rampant, equipment and means of sterilization were lacking, and vaccinations and medicines frequently unavailable. Furthermore, most villagers sought medical advice from the traditional Nepali faith healers, not the health post system.

The education system echoed the shortcomings of the health care system. Schools were far away, making attendance of children with responsibilities at home and in the fields virtually impossible. One elementary school providing education for 90 children had two small rooms with dirt floors and wooden benches. Students had to make a four-hour round trip by foot in order to attend grade six. Given the children's other responsibilities, this distance was prohibitive. It came to my attention that if they had the money to buy the adjacent land, the government had agreed to build a new school with a larger capacity to hold grades one through eight. I took my first step and made the commitment; I would give them money for the land. I will never know why I had not acted in the past, but I was relieved that I could finally embrace my obligations.

At the time of writing, I am just into the tenth month of development for the Miles Levin Nepal Foundation for Health and Education, which can be contacted at: miles2nepal.org. Miles was an amazing teenager who succumbed to a rare malignancy. He was gracious, articulate, and wise beyond his years. Miles was a distant cousin of mine who I knew only briefly during his lifetime. I came to really know him through his writings. He wrote about his experiences and feelings while dealing with cancer treatment and his ultimate demise

on CarePages, a website that allows families and friends to communicate while going through a health crisis. He wasn't scared of dying or of cancer, just of dying before he had an impact in this world. Miles' legacy was a perfect fit for the philosophy of this foundation.

The response has been overwhelming. A network of talented and caring people appeared out of nowhere. Everyone at the Miles Levin Foundation is a volunteer. More money than I could have imagined has been raised in the first year; most of those funds have come from people who have never heard of Nepal. The message is simple: people really do care. If you can convince them of your passion and commitment and give them something tangible to think about, they are on board. People do have a conscience, they do recognize social injustice, and they will rally when called upon. Passion is contagious.

All projects are initiated by the local people. They tell us what they need. Our toilet project was initiated when villagers learned that all the water taps were shown to have fecal coliforms. We asked them to write a proposal and contract for the project, and show how they will be vested in the project: they will provide some money, local supplies, and transport for remote supplies. All projects will be managed and maintained by local non-governmental organizations. Outsiders (that is to say, westerners) will not carry out or manage any of these projects.

Traditionally, much of foreign aid in health care in Nepal, as in other developing countries, is directed "outside the system."—to nonprofit organizations working independently from the local government and health care infrastructure. It is the Foundation's belief that if we are to create sustainable changes, we are much better off working within the system—with the government and a medical school. It is more difficult in the short run, but more likely to be meaningful in the long run. We will support the training of Nepali medical students and Nepali mid-level health care workers all from Khotang, who will have a vested interest in taking care of their own community.

In my new life, I have made a commitment to embrace my ethical and moral obligations. It is no

longer out of a sense of duty, but out of passion. I have never known such fulfillment, and such happiness, as I have this past year or so. I cringe when people refer to the sacrifices I have made to do this work. This is a common misconception. I have sacrificed nothing, and in truth, I receive much more than I give. I am the luckiest person in the world to have been given the opportunities of which I have now taken advantage. I love what I do. It has recently come to my attention that the highest degree of *tzedakah* seeks to eliminate social injustices rather than simply alleviate symptoms. Who knew?



Global Health Careers: Serving the Navajo Community

Maricruz Merino, Jonathan Iralu, Sonya Shin

Gallup Indian Medical Center (GIMC) sits on a hilltop in Gallup, New Mexico, a town of 20,000 in the four corners region of the Southwestern United States. From its third story windows one can see the red cliffs of the nearby Navajo Nation, a 27,000 square mile reservation that reaches into Arizona, northern New Mexico, and the southern edges of Utah. It is a vast, rural landscape that houses more than 350,000 Navajos. For many on the reservation, healthcare is provided by Indian Health Service hospitals such as GIMC.

"Are you going to stay?" is a common question for new doctors at GIMC. The Navajo know that their geographic location, while beautiful and attractive to many young providers, will also be the reason they leave. It is hard for doctors to be away from their own homelands. Aging parents get sick,

**The following narrative is the opinion of three physicians working for the Indian Health Service in Gallup, New Mexico. It does not reflect the views of the Indian Health Service or the Federal Government.*

educational opportunities arise, and children who need to be near extended family are born. But to the Navajo, the story of an individual provider is not so important or memorable. All they know is that providers come and go.

“Are you here to experiment on us?” is yet another question. Years of exploitation and efforts to destroy traditional ways and language have made many Navajo wary of healthcare providers, no matter how genuine their intentions. Many are so fearful of the hospital—they regard it as “the place to go die.”

Yet despite this initial suspicion, the Navajo are welcoming people at heart, and tend to develop relationships of trust with their providers. Parents will begin to talk about their grief over a son that has committed suicide or a daughter who died from alcoholic cirrhosis. The elderly will tell you how they care for their five orphaned grandchildren while they can barely take care of their own diabetes. A carpenter tells you he has not worked in a year and feels worthless. An HIV-positive woman will tell you she has been sleeping in a dry river bed because she has no place to go. It quickly becomes apparent that as a physician you will be treating patients with enormous social challenges in addition to complex medical conditions.

The origins of the Federal Government’s involvement in the healthcare of American Indians and Alaskan Natives (AI/ANs) in the 19th century arose out of both legal obligation and concern for self-preservation. Health services were promised to AI/ANs in exchange for land, settlements, and agreements. In addition, infectious diseases endemic on reservations as a consequence of crowding and abject poverty, including smallpox and tuberculosis, were seen as a major public health concern. The responsibility of Native American health was first granted to the War Department, then to the Bureau of Indian Affairs, and finally to the Public Health Service in 1955 under the heading of the IHS, or Indian Health Service (U.S. Commission on Civil Rights, 2004; National Library of Medicine, 1994).

Since then, the IHS has had many successes. Vaccination rates have gone up, and rates of pneumonia and tuberculosis have gone down significantly.

Maternal and infant mortality have declined, and life expectancy has increased (Indian Health Services, 1999). Nonetheless, these improvements remain overshadowed by glaring health disparities among AI/ANs across a broad spectrum of diseases, both communicable and non-communicable, acute and chronic. Native Americans experience higher rates of obesity, diabetes, and cardiovascular disease than the general United States population. They are also more likely to die from alcohol-related causes and in accidents. Life expectancy remains more than five years less than that of the general U.S. population (U.S. Commission on Civil Rights, 2004; U.S. Department of Health and Human Services, 2000).

Underlying these health indicators is the continued impoverished status of most AI/ANs. In Navajo, almost half of the population lives below the poverty line. According to the Navajo Nation, the current unemployment rate is 42% (Navajo Nation Department of Economic Development, 2011). Many Navajo on the reservation do not have running water or electricity. They heat with wood, which they chop and haul themselves—regardless of age or gender. Some live in traditional eight-sided structures called Hogans with dirt floors and perhaps one blanket per person. Many others live in trailers, and they are lucky if the windows are all still in place. Despite sub-zero temperatures in the winter, amputated limbs or debilitating arthritis, a fair number of patients still rely on outhouses. They often live far from the hospital and do not have access to reliable phone service or transportation. Some choose to live in this more traditional manner, but many do not.

Given these complex structural barriers, it is actually surprising that the situation is not worse. How can a diabetic eat well if they do not have refrigeration for fresh foods and can only make one monthly trip to the market? How can an elder contact their physician about increasing leg swelling when they do not have a phone? How can an alcoholic stop drinking if they have to rely on hitchhiking to get to Alcoholics Anonymous? How can a teen stop thinking about suicide when everyone else they know has thought about it? Personal responsibility and motivation, although important, are often

eclipsed by factors that present insurmountable barriers far beyond the individual's control.

Those that wish to address Indian Health have to acknowledge the historical violence and neglect that have led to the present day conditions. They must acknowledge that there is a cycle of poor health, disability, and poverty. For an intervention to be successful, it must chip away at these fundamental structural barriers to health care and healthy living, and do this within a context that is grounded within the specific cultural reality of each Nation.

Fortunately, there are many examples of large-scale and local efforts to do just that. Given the importance of actively reaching out to the community to overcome the cultural, geographic and logistical barriers of clinic-based care, community-based initiatives provide a compelling model for linking clients to medical services. Since 1924 Navajo Area IHS has included public health nurses (PHNs) and in 1968 it incorporated roles for community health representatives (CHRs) as part of their public health model. PHNs and CHRs are paid outreach workers that provide home-based care, education, emotional support, and advocacy. When optimally linked to the clinic-based team, they can be the eyes, ears and arms of the provider, helping patients follow their providers' treatment plans, including adherence to medications, appointments, and healthy lifestyles. While some outreach workers are dedicated to disease-specific control (for instance, sexually transmitted infections, or tuberculosis), others provide a broad range of support to their assigned communities. CHRs are especially effective in "brokering" these barriers to care, in that they are respected members of the communities they serve, speak their native language, and are familiar with traditional customs. In small communities where family, clan and personal relations are key elements to gaining trust and respect, CHRs can be instrumental in helping the most marginalized patients engage in their health. Often, the act of listening to an elder—patiently sitting with someone who has little opportunity to be heard in a rushed clinic visit—allows opportunities for true communication.

An early example of multi-disciplinary care utilizing community outreach workers was instituted

in the 1960s under the visionary leadership of Navajo tribal councilwoman Annie Wauneka. Long before directly observed therapy (DOT) was issued as an international recommendation by the World Health Organization, DOT was implemented on Navajo to combat the rising incidence of tuberculosis. Today, a team comprised of physicians, nurses, and CHRs known as Navajo Nation Tuberculosis Technicians work together across the network of service units in the region to coordinate management of TB cases, including home-based DOT for all doses.

This multidisciplinary team model has also worked well in caring for individuals with HIV/AIDS on the reservation. In 1987, the first case of HIV was diagnosed on Navajo; by 2006, the Gallup Indian Medical Center was caring for 100 AI/AN individuals living with HIV (Iralu et al 2010). This population was largely socially, legally, and economically disenfranchised. Most individuals were unemployed, had a history of incarceration, and half of them had a diagnosis of alcohol abuse. Many individuals seen in HIV clinic had migratory lifestyles, moving back and forth from larger cities to the reservation due to interrelated factors such as employment, substance use, medical illness and family support. Not surprisingly, achieving good clinical outcomes in these patients required active efforts to retain individuals in care and provide comprehensive psychosocial support.

In response, we developed the HIV Program at GIMC. Collaborators include a multidisciplinary clinic team (physician, nurse, nutritionist, pharmacist, psychologist, and native healer) as well as community-based case managers. Monthly team meetings allow efficient case discussion and development of holistic treatment plans. For example, treatment for a patient with poor adherence may be changed based on input from outreach workers who see the reality of the patient's day-to-day life during home visits. A pharmacist may be able to confirm missed refills, while case managers aide in coordinating substance abuse treatment and a traditional healer provides an important ceremony to bring closure to a recent trauma. This team-based approach ensures that there is comprehensive

care and consistent communication to the patients among different team members. If a patient should migrate from service unit to service unit, there is an internet-based secure system for communicating with regional service units and ensuring that patients receive longitudinal follow-up from our network of providers.

Given the disproportionate burden of diabetes, dyslipidemia and hypertension, we also developed a recent initiative to enhance CHR outreach to individuals with poorly controlled chronic diseases. The COPE Project (Community Outreach and Patient Empowerment) was initiated in 2010 as a formal collaboration between Brigham and Women's Hospital (BWH) in Boston, the Navajo Area IHS, and the Navajo Nation CHR Program. Based on an initial needs assessment, we reported areas which CHRs and providers identified as challenges to providing care to "high-risk" individuals with chronic health problems. A team from BWH has been stationed on-site in Navajo for the past two years to build relationships and work with IHS educators to deliver high-quality training to CHRs and develop patient educational materials that are sensitive to the needs of the Navajo population in terms of cultural considerations, health literacy, and standardization with IHS best practices. Additional training for CHRs on motivational interviewing, strategies to elicit behavior change, and self-care and wellness as caregivers themselves has enhanced the skill set of CHRs. Preliminary outcomes and local endorsement has led to formal plans to scale-up the COPE project throughout Navajo in coming years.

With increasing awareness and sensitivity toward issues of global health, disparities within the United States are often overlooked. It is our job, as physicians who believe in health equity for Native Americans, to advocate for this long-neglected minority group. We must support ongoing local efforts to build communities in addition to treating our patients in the office. We must also raise broader awareness about the hardships facing our patients and lobby for change. We must partner with academic institutions and educate our physicians-in-training about the work that we do, and

inspire others to help us pursue life-long careers in this field. The task is daunting; it is also a privilege with infinite rewards.

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Moral Responsibility in a Context of Scarcity: the Journey of a Haitian Physician

Paul Pierre

Almost all Haitian physicians have been involved in some sort of "social movement" at one point in their professional life. In a country characterized by a natural inclination to question authority, fighting the status quo of the ineffective, corrupt and disorganized

Haitian health system often appears to be the right thing to do.

In 2002, I played an active role in a large protest movement for better working conditions at the largest health facility in Port-au-Prince: the General Hospital (GH). Port-au-Prince is the capital and economic center of Haiti. It is home to close to a third of Haiti's ten million people. At that time, the situation at the GH facility was dire. All of the 400 beds at the GH were dirty. The staff was underpaid and unhappy. Drug and medical supply stock-outs were routine. Medical equipment was rarely maintained and only one of the six operating theatres in the surgery block was working. Unsupervised physicians in training (like me) were the main health care providers. Attending physicians were busy running their own private clinics, and most of them would come to the hospital solely to "recruit" the less poor patients for their clinics. As physicians-in-training, we had the responsibility of caring for the poor, but we had no means. We grew frustrated and angry witnessing our powerless patients losing legs, arms and their lives for lack of care. On many occasions, I had the parents of my patients buy the gloves that I would use to examine their sick relatives. I've seen patients fighting for the inheritance of medications left by others who had just passed away. There was no way for this hospital to fulfill its mission, and no way for its staff to deliver anything other than mediocre care. We could not accept that situation at such an early stage in our medical development, and so we refused to continue to work. We went on a strike, which completely paralyzed the delivery of care at the hospital for nearly two months. After intense negotiation, the strike ended with a signed agreement with the Minister of Health that addressed, more or less, the reasons of our movement. However, the implementation of the agreement was permanently delayed by other competing "state emergencies" including a general insurrection.

At the time of our movement, I thought we were making history. After witnessing 11 "social movements" that similarly paralyzed the GH in the following decade for reasons identical to ours, I am now convinced that we were not. We were

temporary actors performing in the cynical play of scarcity on permanent display in Port-au-Prince. The social movement that we started ended up hurting the very same people that we were trying to help.

Extending access to health care to poor people seemed to me at that time to be too complicated and too expensive for an unorganized state like Haiti. I realized that local protests could, at best, influence the allocation of local resources. But so-called local resources are so limited in "resource-limited" countries. Haiti spends only \$40 U.S. dollars per capita for health care. This is not enough for good care. The options we were provided were not real ones—since all of them would end in more suffering. The case of providing health care to poor people needed to be approached differently.

I was born in Port-au-Prince at the same general hospital in which I would later work. I am the third of four children, and the first male child in my family. My father made me understand very clearly that my first responsibility was for my siblings. My sisters made me understand equally clearly that I had no authority over any of them. I ended up with a lot of responsibility but with very little authority. The few of us who completed school, entered university, studied abroad and "emerged" were considered, to some extent, responsible for the others—the ones who couldn't go to school, university, or abroad, the ones who had "sunk." They had to sink in order for us to emerge. All the luck, intelligence and education of Haiti was invested in so few of us. We are community assets and are expected to deliver. In reality, we neither have the authority nor the means to deliver.

I felt that imbalance between my responsibilities and my authority particularly bluntly during my sixth year of medical school. I was in rural Haiti performing a required one-year medical residency program called the "social service." In this program, freshly graduated physicians choose a health facility from a pool of understaffed public hospitals and health centers in rural Haiti. There, we usually worked unsupervised as primary care providers for one year. The best ranking among us would choose first and often would try to stay as

close to Port-au-Prince as possible. I ended up in Hinche, a dead-end town, located six hours from Port-au-Prince in the dry season and an unpredictable amount of time during the rainy season. I should have been closer to Port-au-Prince given my grades, which while not among the highest were certainly good enough to spare me this kind of place. However, I was away the day when we had to choose, and was left to pick among what was left by everyone else.

Hinche was my first rural experience as a physician. I was working in a 100 bed district hospital in a state of ruin. There was no electricity in the city but the hospital had a generator and a German aid organization donated fuel for daily operations. The hospital also had a limited backup power system to be used, in theory, for emergencies. In practice, the backup system was only used to power the hospital director's office. One night, I became so frustrated trying to do surgical procedures on a bleeding patient under the dancing light of a candle that I decided to break the door of the room where the power system was kept. I am 6'4" tall and wear tough boots. When I hit the door, it collapsed, along with the wall around it. I got scared, but returned to my patient to finish the job, reinvigorated by the precious technology. I started to feel bad only when I realized that the clerk who was keeping the key for the room where I broke in, stayed there all night. He was terrified that all the equipment kept there would be stolen and he would lose his job. I barely fought when the director of the hospital and the administrator decided to hold my monthly paycheck for the repairs. I might have been involved in the right war, but I was definitely fighting the wrong battle.

I was provided with the option of working peacefully at a clean health facility in the small town located 35 km south of Hinche in September 2003. Operated by Partners In Health (PIH) through its local partner organization, Zanmi Lasante, the Bon Sauveur Clinic offered comprehensive and dignified primary care services to vulnerable people living in the underserved community of Cange. There, I began to more fully understand the fundamental mechanism of the cycle of poverty and

disease in which poor people are trapped. Poor people living in an underserved place like Cange were likely to remain poor because they have little chance to access education, health, security, food and jobs. Only the State had the legitimacy to address sustainably and equitably all these issues. Therefore, all comprehensive health intervention in resource-limited countries should have as its core strategy to be supportive of the public sector. Since, I've been working to help poor communities realize their socio and economic rights by providing direct primary care and supporting advocacy efforts that promote the sharing on the basis of needs, of resources, and technologies that humanity have harvested during these past centuries.

I was not in Haiti in January 2010, when a powerful earthquake struck Port-au-Prince, killing 316,000 and injuring as many more. At the time of the earthquake, I was working as a primary care physician and community organizer in rural Africa. I arrived in Port-au-Prince on January 25th, driving from Santo Domingo in a large SUV loaded with energy bars. Within days, I became part of the small team in charge of organizing health care services in Port-au-Prince for PIH and Zanmi Lasante. We decided to focus our efforts on trying to deliver health care services at four internally displaced persons (IDP) camps located in "reputed dangerous" parts of the city. It is well known that social marginalization, extreme poverty, and violence are part of the same mix. We were interested in helping to break the causality fundamentally entrenched in this association. The conditions at these IDP camps were heartbreaking. The "reputed dangerous" people that we found were extremely poor and greatly needed care. They lacked everything but civility and gratitude. We quickly established systems that allowed us to hire more than 500 staff members, including more than 40 physician and 14 nurses, in a matter of weeks. We began to offer comprehensive primary health care services that included psychosocial accompaniment, basic laboratory services, and drugs. We partnered with other NGOs to supply drinkable water, sanitation, shelter, and food. The U.S. military provided tents to shelter the clinics, and docked a ship in the bay were

we could refer our patient for surgery. Everything was running at full capacity by February 15th. In 2010, these four clinics ended up serving more than 200,000 adults and close to 55,000 children under the age of five and were the principal providers of care for many thousands of “reputed dangerous” people living in Port-au-Prince until their closing in November 2011. My colleagues and I are particularly proud of what we helped accomplish. I am grateful that we had the means to deliver care to these people. I am honored to be part of the global health movement that is trying to make the world better by working relentlessly to overcome social injustice through human solidarity.



Delivering Health Care in Saharawi Refugee Camps Near Tindouf (Algeria)

Vincenzo Pezzino

Introduction

In the years 1991–2002 I visited the Saharawi refugee camps near the town of Tindouf in south western Algerian desert ten times. The objective of these visits was to provide medical assistance in various areas of health care and organize more effective health care services. Each time I spent 8–12 days in this territory, either alone or as part of a team of medical doctors and nurses. These medical missions, were organized by “Al Awda,” an association of solidarity for Saharawi people, located in Catania, Italy. A comprehensive range of services were provided during each of these trips.

Context

About 170,000 Saharawi people have been living in this region since 1976, when they escaped from Moroccan occupation of Western Sahara (formerly Spanish Sahara), a large territory (266,000 sq. Kms.) located on the Atlantic Ocean coast, south of Morocco. Since then, Saharawi people have been camped in Algerian territory, under prohibitive

environmental conditions—especially for children and elderly people, in a desert area where summer temperatures easily reach 131°F. After the exile, they have worked to slowly re-organize their life with the aid of the Algerian Government and international solidarity, including UNHCR (the Office of the United Nations High Commissioner for Refugees), ECHO (the European Union’s European Community Humanitarian Office), and NGO (Non-Government Organizations) projects.

In addition to this dramatic exodus, a real war followed between Polisario Front army (the political representative of Saharawi people) and Moroccan army. This lasted until 1991, when a cease-fire armistice was signed, in view of a subsequent referendum for auto determination (never celebrated).

Consequences of these complex events were terrible: victims of the war, victims of the exodus, displacement of Saharawi society and families (the majority of Saharawis still live in their homeland under a rigid occupation by Moroccan army and suffer violation of fundamental human rights), precarious life in refugee camps (mostly tents and sand-made huts), poverty, food deprivation, unsafe drinking water from wells, lack of essential services, and so on.

An education system and a health care system (including vaccinations) were gradually organized with some success. However, health care services remain far below the standards of western countries. Essential drugs, diagnostic tools and instruments, and specialists are largely needed.

Solidarity for the Saharawis’ terrible life conditions prompted me and other colleagues to offer our medical expertise to help providing better health care. I have always been concerned by the disparity in access to medical care existing around the world, and so I felt committed to help alleviate this problem. My efforts could be only a drop of water in the ocean, but the ocean is made of drops. My contact with the Saharawi population, their welcome, and my life in these refugee camps—all this experience markedly increased my commitment to providing any kind of support I was able to give in favor of these admirable people.

To my eyes the Saharawi people appeared as a proud and dignified population, who were firmly

seeking for a peaceful and legal solution of their struggle. Their objective is to be recognized by the international community as an independent population, with the right of self-determination and to return to their homeland, where they would like to build up a new country inspired by democracy and freedom. The Saharawis' dramatic vicissitude has won this population numerous international acknowledgements, as well as the admiration of all those who have become acquainted with their cause.

In spite of very difficult environmental conditions, the Saharawi people have been able to survive and to organize life in the refugee camps in a way that arouses amazement in any visitor. In addition to social, educational and health organizations, they have started experimental cultivations (vegetables) and breeding (goats and chicken).

Delivering Health Care

The activity of our medical team was usually carried out as follows: date, objective and components of the medical expedition, which were planned preliminarily with the Saharawi representative in Italy. Then we flew from Rome to Alger, where we spent a night. On the following day we embarked on a domestic flight from Alger to Tindouf, where some Saharawi people were waiting for us and drove us to the refugee camps (about 35 km away). Upon arrival we were lodged in special quarters for guests and then we met the local health personnel and authorities to make a plan of our activity. The following day we started our work.

The territory inhabited by Saharawi people includes four large "wilayas" or villages and some other settlements with various aims (official institutions, military, education, hospital). Each one of these sites can be reached by a 30–60 minute drive, except one wilaya, Dahla, which requires a four-hour drive. It is easy to understand that transportation is one of the major problems in the daily life of Saharawi people. Every day our team was transported, usually by a Toyota Landcruiser, to one of the four wilayas where the population lives (when we went to Dahla, we slept there). An outpatient clinic was prepared for me in the local hospital or in a health care post. People were informed of my

presence and the types of consultation I could offer as an endocrinologist—diabetes, thyroid diseases, and infertility. As a matter of fact, these areas cover the vast majority of endocrine disorders all over the world. People that needed to be examined came and sat down on the floor, either inside or outside the building, waiting their turn for consultation. I usually worked all day, in two sessions, morning and afternoon, separated by lunch time. This break often took one to two hours, because a lunch was generally offered in someone's tent and this implied that we could not hurry, in order to appropriately honor their hospitality. I usually examined 30–50 people a day. I was constantly assisted by someone from the Saharawi health organization, who translated from Hassanya (the Arabic dialect spoken by Saharawi population) to Spanish for me, and the other way around from Spanish to Hassanya for the patient. On one side, the translation took some time, but on the other side, it was impossible to go into very complex problems. As diagnostic tools I used capillary blood glucose for diabetic people (and pretty soon my assistant helped me a lot in this measurement), and thyroid ultrasound was performed by a colleague on the team with a portable instrument carried with us from Italy, for people with thyroid diseases. All consultations were recorded on sheets of papers, in Spanish. Instructions and therapy were immediately given, using either drugs that we had brought with us, or drugs already present in the local dispensary. My other colleagues worked more or less in the same way, each one of them in their respective specialty. Surgery was possible in a fairly well-equipped hospital. Gastroscopy was also performed with an instrument carried from Italy.

The story of one of these Saharawi assistants is very peculiar. Mr. Rahmani Sidi Mustafa, aged 40 and father of four children, constantly and enthusiastically assisted me in my work until 1996. Then, supported by solidarity funds from Cuban Government, he went to Cuba, where he stayed for six years and got his M.D. degree, when he was almost 50. I saw him again in 2002, in the Saharawi refugee camps, where he had returned and was now working as a medical doctor. It was a moving and joyous meeting. I congratulated him for his strong determination to achieve this result.

Some general observations can be made on this professional experience. As expected, diabetes mellitus is relatively frequent even in conditions of limited access to food. Apparently it never goes below 1–2% of the entire population. I was struck by the occasional lack of insulin store, which represents a life-threatening condition for all people with type 1 diabetes who have an absolute need of insulin therapy. I heard that when such situation occurred, patients desperately go and search for insulin in the nearby Algerian town of Tindouf.

I also found a goiter endemic in the Saharawi refugee camps. Having observed an elevated number of people with large goiters (mainly women), one of the expeditions was mainly dedicated to survey the population for the presence of goiter by thyroid palpation. On this occasion I surveyed thousands people, children and adults, and found a goiter prevalence of 28% in schoolchildren and 21% in female adults (the results of thyroid palpation were evaluated according to WHO criteria). However, less than two percent had stage 2 goiter and all the others had stage 1. Interestingly, this goiter endemic was not due to iodine deficiency, as might be expected since this is the most common cause. On the contrary, measurement of urine iodide excretion in random samples from 72 people from different wilayas revealed that iodide excretion was moderately high. Therefore, the cause of goiter endemic in Saharawi refugee camps is presently unknown.

Unfortunately, for the infertile couples very often there is not much that can be done, especially in a place like these camps. Since I went there several times, I noticed that many couples came back every year for consultation, even if expectations were not optimistic. They kept hoping that I might bring some good news for them, for instance some new therapy. I was impressed by their hope in the future. The same happened for secondary infertility, that is couples with “only” one to two children, who would have liked to have more and failed to obtain other conceptions. So, I learned that in developing countries infertility may represent a social problem even greater than in western societies. Failure in generating children has a dramatic social impact. Children (more than two) are considered a very important feature of “normality” in Saharawi

society. They probably represent the continuation of family life, the family future and a warranty of support for parents and grandparents. I realized that the usual demographic issues that tend to discourage families from having many children in a condition of poverty may not apply to developing countries. Contraception principles would not be easily accepted there. I also feel that western countries should not give lessons on this topic, because we cannot just impose our view of the problem to people with a different cultural and traditional background.

Not Only Work

Every now and then during these short visits we took some time to discuss and report to local authorities, to meet social organizations (like Saharawi women, Saharawi youth and so on), to visit particular sites or with friends already met in previous visits. This gave me the opportunity to become more deeply acquainted with Saharawi society. In spite of the obvious poverty, the visitor is welcomed and surrounded by a friendly and warm atmosphere of hospitality. I experienced a pleasant immersion into Saharawi habits, which include rich traditions of music, dance, and feasting. Saharawi people are open-minded, moderate Muslims. Their tents are safe places, where the visitor is welcomed like family and everything is done to assure a comfortable stay. Thus, one discovers the great dignity of these men and women, their intense longing to return to their homeland, their expectations for the future, their friendly feelings, the freshness of the young Saharawi women dressed in their traditional customs, and the noisy intrusion of children—fascinated by the presence of foreign people and readily scolded by their parents. In the tent, among pleasant chatter, they offer you Saharawi tea, a true ritual, which is a fundamental aspect of your visit. If you do not drink their tea, in three rounds, it would be as if you have not visited that tent. Tea will taste bitter as life on the first round, sweet as love on the second one, soft as death on the third one.

Saharawi people like to drink tea several times in a day. One time tea was served in a very particular circumstance. While we were traveling towards the

remote wilaya of Dahla, our vehicle must have hit something and suddenly a front wheel came off. After a few seconds of panic, the driver successfully and luckily stopped without any harm for passengers. This happened in the middle of the desert, about 40 km from our destination. Some minutes later, while we were waiting for some aid, the driver calmly drew out all the equipment to prepare tea from a drawer of the car, including a gas–stove, water, tea–pot, cups, spoon, sugar and tea, and started preparing Saharawis’ preferred drink, under our amazed eyes. After few minutes he was placidly offering hot tea to all passengers.

Conclusion

The experience of delivering health care in the Saharawi refugee camps has deeply impressed my understanding of the health care needs of populations living in resource–constrained settings. I am now more conscious of the tremendous worldwide disparities in human rights, adequate access to acceptable health services, and expectations for the future are a global and ethical concern. I learned important lessons from Saharawi people, and I feel that I received from them much more than I gave them.



Poverty, Surgery, and Systems

Robert Riviello

Meet Jean de Dieu*

I first met Jean de Dieu during ward rounds at Butaro District Hospital in northern Rwanda. He was alone in an isolation room off the male ward—not because he had a transmissible disease, but because he smelled.

*Name changed to preserve confidentiality

He had been admitted to the hospital several months earlier with advanced rectal cancer that caused him to be perpetually soiled with feces. His story is painfully similar to others I have heard before in Rwanda and Angola. Over the past two years he presented to multiple providers, mostly at sector–level health centers, with complaints of rectal discomfort and bleeding. He was never given a rectal examination, he had never been referred to a specialist, and had been variably diagnosed with and treated for hemorrhoids or intestinal worms. His condition only worsened, and he eventually came to Butaro Hospital. Here he was found to have a large, fragile, bloody mass protruding through his anus. On rectal examination, one could not feel the top of mass, suggesting it was rather extensive. He was unable to sit because of the pain. The tumor had infiltrated and destroyed his anal sphincters (the muscular valves that allow us to control our bowel movements), leading to his continual incontinence of stool. He had devised makeshift diapers from scrounged plastic (hard to find in Rwanda) and cloth strips. He was emaciated, his gaunt face and sunken temples reminiscent of photos of concentration camp prisoners. In the weeks prior to my arrival the tumor had been biopsied, the specimen reviewed by pathologists in Boston, and found to be adenocarcinoma (cancer of the glandular tissue) of the rectum.

First Reactions

I am immediately uncomfortable. Is there any chance I can offer Jean de Dieu the best care possible?

Even in the best of circumstances, attempts at complete surgical removal of a locally advanced tumor in a nutritionally compromised individual is challenging at best. In a comparatively weak surgical delivery system, operative extirpation of aggressive disease is less likely to be curative, more likely to have devastating complications, and there are fewer options and tools to address complications should they occur. It makes me wonder if the surgical risk versus benefit ratio is in his favor.

Further complicating decision–making is my own status at this hospital—I am only going to be around for a week now and then back for a couple weeks in a few months. Two decades ago,

as I graduated high school, I envisioned my life's work as a long-term missionary surgeon, providing continual surgical care at a hospital like Butaro. Now, making rounds with Rwandan colleagues, I am acutely aware of the change in career path. I am an academic surgeon, working at Brigham and Women's Hospital (BWH) in Boston, spending approximately three months per year in Rwanda—supporting the growing surgical programs in the Rwandan Ministry of Health and at Partners In Health (PIH) supported district hospitals. As I interact with Jean de Dieu, I recognize that I cannot offer him the robust commitment to individual patient care, which my surgical mentors imparted as a hallmark of our professionalism, since I will be on a trans-Atlantic flight to Boston next week.

As a surgeon, most people see the greatest utility in my skill set tied to the ability to take sick and injured patients into the operating theater with the goal of fixing their surgical problems. And frankly, as a surgeon, providing direct clinical care by operating on patients who need surgery is my highest yield activity in terms of positive feedback. The return on investment is usually visible and immediate; at the end of the day, you know you made a difference for someone. As a result I find internal dissonance in my current style of hybrid, academic engagement—I spend most of my energy in programmatic and administrative efforts with at best delayed gratification, and comparatively little time delivering the surgical care and training that provides immediate satisfaction. Of course, you need an operating theater and a surgical system that works to provide that care and training—so, I cling tenaciously to the belief that this hybrid life is building for a better future. One where destitute injured and sick patients can receive timely, appropriate care by well-trained and adequately-resourced surgical providers in their own communities. But honestly, most days I still long to pack my things, my family, and our efforts and move to Africa for a life of direct service.

Next Phase of His Story

Shaking myself out of this reverie, it is clear that we need to make some decisions about how to best

help Jean de Dieu now. I raise concerns about his nutritional status, citing his evident tumor-wasting syndrome. Dr. Thotho, my colleague, a Rwandan-Congolese general practitioner with advanced surgical skills and experience, elicits a better history and points out that our patient's cachexia is actually a result of his intentional under-eating to decrease the constant soiling from his incontinence. I am reminded here that honest local partnership is critical for a myriad reasons—one of which is providing this kind of contextual expertise and linguistic and cultural competence.

A few days later, John de Dieu undergoes an exploratory laparotomy; thankfully we find no evidence of metastatic disease—it has not spread anywhere else. His rectal tumor *is* quite large; I can feel it at the pelvic peritoneal reflection—the deepest part of the abdomen, perhaps 10 centimeters from the anus—confirming the findings of the poor quality CT images we had previously obtained. We then perform a diverting colostomy to provide him relief from the incontinence and the related excoriation and pain. This procedure detours the stool away from his anus, and his cancer, by bringing an end of his colon out through his abdominal wall, to be collected in a plastic bag—allowing him to regain control of his personal hygiene again. “A dirty shirt is better than dirty pants” is an aphorism often cited by my former mentor. Post-operatively, he begins nutritional supplementation—essentially adding as much peanut butter as possible to his diet. Over the next few months he gains 20 kgs. Already he looks healthier and happier.

Next, we need to think about a multi-disciplinary approach to his locally advanced cancer. Gratefully, a remarkable collaborative multi-institutional team from BWH, the Dana Farber Cancer Institute, and PIH guides this discussion. Neo-adjuvant (that is, pre-operative) combined chemotherapy and radiation therapy has been demonstrated to shrink tumor size, and increase the likelihood that his next operation—removing his rectum and the tumor—will cure his cancer. Chemotherapy we can provide for him within Rwanda. Radiation therapy is another story—that can only be delivered in neighboring Uganda and is quite expensive. The

Right-to-Health-Care funds that usually provide for these services are already depleted for the year. I muse that John de Dieu's case highlights an ever-present tension—we seek, from a rights-based approach, to provide the best health care possible for each of our patients, and yet the all-too-visible resource-constraints often force a utilitarian reality on our ideals. Jean agrees to be transferred to Rwinkwavu, another PIH-supported district hospital to undergo FOLFOX (a combined chemotherapy regimen) for three months. Why three months? Because that is the window of time until a surgeon, me, will be available again to operate on him to remove his tumor. Again, I am forced to wonder if we are doing the best by him. Wouldn't it be better if his cancer resection operation were timed around an optimal chemotherapy regimen? But I know the (very few) other surgeons in the country, and I know that they are swamped. Ultimately, Jean de Dieu's treatment course has to pivot around the scarcer resources—in this case, a trained surgeon.

Three months later, he undergoes an abdominal-perineal resection of the rectum. A big operation, usually done with two surgeons—one working from above in the abdomen, the other working from below in the perineum—to remove the entire rectum and the surrounding tissue. This time it's done with one surgeon and takes all day. The operation is difficult. The left ureter is inadvertently divided, and so has to be re-implanted into the bladder. His tumor, though substantially shrunk by the chemotherapy is still rather large and locally advanced. At the worst spot, it is densely fixed to the prostate. Given the limited lighting, equipment, and reconstructive options, I decide that the safest course of action is to shave the tumor off the gland delicately—rather than a radical resection, which would require a complex reconstruction of his bladder and urinary system, which we lack the capability to perform or to care for. Ninety-eight percent of his tumor is removed, but the last two percent still remains in his body, stuck to his prostate. We discuss further with the multi-institutional cancer team—he will require further chemo, but it is unclear if this will offer any survival benefit.

Is Jean de Dieu Better Off?

I think so. But I continue to wonder.

Am I his primary doctor, as my surgical training has inculcated in me that I ought to be? No. There are many actors in his story that have contributed, and continue to contribute, to his care. The district-based teams composed of Rwandan general practitioners, American internal medicine specialists, and Rwandan oncology specialized nurses have done most of the heavy lifting of his day-to-day care. They have had guidance from the multi-institutional cancer team based in Boston. On the surgical side, a BWH Global Health Equity resident in general surgery worked along with surgically-oriented Rwandan general practitioners, operating theater staff, and PIH procurement teams to strengthen the surgical delivery system. A senior Harvard medical student working on a quality improvement project at Butaro Hospital has acted as the coordinator for the surgical team, as there is currently no in-country national coordinator. A BWH anesthesiologist is now working full-time in Butaro, constantly training Rwandan anesthesia providers, and strengthening the critical care capacity. Working in concert, this team has been Jean de Dieu's primary doctor. And these individuals are also actors in the stories of countless others. In as much as they work together to improve health, they've created a *system* of health delivery to benefit the many.

There are clearly joys in doing this work. There is joy in seeing Jean de Dieu receive and benefit from high-quality multi-disciplinary cancer care. There is joy in seeing him be able to sit erect, now that the tumor is removed. There is joy in seeing a surgical delivery system grow and transform. A year ago, Butaro Hospital was essentially able to only offer emergency caesarian sections—a critical service, but hardly a full complement of surgical care. Now, with a more robust system and team, it is providing more complex orthopedic, plastic, and general surgery services, as in Jean de Dieu's case.

And there are also frustrations. We didn't get it all right for Jean de Dieu. He had surgical complications. We didn't get all the cancer out. In our oncologic lingo, his ongoing chemotherapy is

“palliative only” (it won’t cure him). However he is grateful for the ability to sit up comfortably. He recognizes he may eventually die of cancer progression or recurrence, but he is still grateful. I’ve learned something here.

I still long to be the full-time surgeon based at the rural district hospital, and I continue to have angst about the hybrid life. But Jean de Dieu’s story has reinforced for me that delivering quality surgical care for destitute, sick, and injured patients will require developing and strengthening collaborative, interdisciplinary systems of care. The system strengthening that happened around his care continues to improve health for countless others. And so, for now, I live in the hope that I can best serve Jean de Dieu and others like him from this academic, hybrid post—helping to deliver care, training, and build and strengthen systems of care.

A few months ago the Chair of the Department of Surgery and the President of Brigham and Women’s Hospital visited Butaro Hospital. While performing a thoracic surgery operation for empyema (pus in the chest), my chairman looked up at our president and commented, “This is hard work. It’s not that any one thing is going wrong, it’s just that all of it is harder than it is in Boston.” It really is harder—our patients are poorer (a lot poorer), their diseases are more advanced, our diagnostics are more limited, the human resources are thinner and less well-trained, the systems to care for patients are weaker, our therapeutics are more limited, and there are a lot fewer funds with which to tackle these problems. From a rights-based approach, our patients here in Rwanda deserve excellent care as much as do our patients in Boston. This is, of course, true wherever there is poverty, injustice, and disparity. When the work is hard, I am reminded that seeking justice and loving mercy are guiding principles for all of us in this work of solidarity. And when the dissonance of the hybrid life hits too high a pitch, I reflect that, “who knows but if perhaps we are in this position for just such a time as this?”



How was Haiti?

Sadath Sayeed

“She smelled of milk and urine. Chacko marveled at how someone so small and undefined, so vague in her resemblances, could so completely command the attention, the love, the *sanity* of a grown man.”

—Arundhati Roy from *The God of Small Things*

Father and Son

Twenty minutes before I was to be taxied to the airport in Port-au-Prince, the baby boy handed to me did not breathe continuously. He didn’t breathe at all. Born a few hours earlier at home—probably in one of the hundreds of make-shift tent cities. I did ask if the baby cried after he came out of mom. Yes. He didn’t suckle well and stopped crying. Dad decided to get help. Climbed onto a moped with his baby wrapped in a blanket. Must have tucked him under one arm and rode between piles of rubble to the closest health care facility.

People at this other place tried to help his baby boy breathe. They pushed air into his mouth like you are doing. After a few minutes, they said that they couldn’t help anymore.

“Go to the University hospital.”

From a shirt sleeve pocket, he pulled a crumpled white piece of paper with some writing scribbled on it. I gathered it documented this last visit. They took the time to hand him a note before they sent him on his way.

What did Dad think? Thanks for the note. Okay, now what? Swaddle my baby. Tuck him under one arm. Hop on my moped.

Strained Resources

L’Université d’État d’Haïti has been the main teaching hospital for all of the country for decades. Many, if not most, formally trained Haitian health care providers have spent some time in Port-au-Prince at this institution. As important as it is, it has suffered from neglect over many, many years. The earthquake made matters exponentially worse.

Dad must have been directed to the pediatric service when he arrived. There, a few Haitian pediatric residents and nurses were doing what they did every morning. Tending to an overcrowded patient population of babies, children, and parents. The pediatrics building was left uninhabitable. All inpatient and outpatient care took place on a street where the tents had been erected.

In the ICU, tent twenty beds filled a space probably meant for ten military style cots. Metal cribs and full adult hospital beds were jammed next to one another to fill every possible nook. Parents slept on the adult beds with their sick children or underneath the cribs. Siblings too. Outside, hundreds of parents would line up starting at six a.m. and stand in line for hours so that they could get their children seen in a couple of smaller tents that were used to run the outpatient clinics. Moms would fan their kids under the shade of trees on the side of the road. Feed them some milk or juice while they waited. Smile at us passers-by. They seemed to possess a bottomless well of patience.

Power cords with extension wires littered the street-hospital floor under the canopy.

When it rained, we were only modestly concerned about electrocution. A single 1950's style metal desk with two worn out chairs greeted visitors to the entry way and was usually occupied by some of the medical staff. A single, large metal fan that had collected enough dust and soot in its circular cage to look bearded hummed a breeze toward the desk.

A bottomless well of patience *and* resiliency. In the popular media, this last word has been thrown around a lot to describe the character of the Haitian people. It is insufficient. Their adversity is truly absurd. Sense cannot be made of the scene in the pediatrics tents months after the earthquake struck, nor elsewhere on that campus, let alone outside its walls.

The local medical staff hadn't been paid a dime in many months even prior to the earthquake. They suffered unimaginable losses during the earthquake. They still came to work.

"We love our children. They love us too."

What so many of us think of as charity, they think of as duty. What so many of us think of as

missions, they think of as jobs. What is spectacle for a few minutes is reality for decades. I get to go home. They are home.

Can you Help, Please?

The house staff didn't have the means to treat the little baby boy brought to the ICU tent that morning. They sent dad back past the nursing school down the street to the E.R. It was serendipity that we hadn't yet left for the airport when an American nurse came running out to our housing structure.

"Can you help? Please!"

That's how I became attached.

"Someone feel for a pulse—the femorals or umbilicus."

"I don't feel anything. I am starting compressions."

We push on the heart when we believe that it is not pumping enough oxygenated blood to the vital organs. Which organs are vital? All of them, but we tend to rank vitality as follows: brain and heart first and second. My cardiology friends tend to reverse the order. Either way—can't live long without the latter and can't live well without the former.

My pulse checker was not a pediatrician. He was an adult E.R. doc—part of the on-going volunteer effort by one of the humanitarian aid outfits. They had staffed the University's E.R. continuously 24 hours a day since the earthquake. Two week shifts for most volunteers. Hard work—lots of stories to tell back home.

"Please stop compressions. Someone listen to his heart, tell me can you hear a beat?"

"Yes, yes, it's beating, but not very fast, doesn't seem like more than 60 a minute."

Sixty beats a minute is a magic number in newborn resuscitation. Give epinephrine after 30 seconds of chest compressions if the heart rate stays below 60. Give another round 30 seconds later if the rate stays below 60.

"I am starting compressions again."

"It looks like the baby is moving air. He's got good chest rise."

"But he isn't taking any breathes on his own. His muscle tone sucks. He's totally flaccid."

"We need a line."

"I'll take over the airway."

"Get me a 24 gauge angiocath and a flush, please."

The baby looked like he was in shock, so the blood perfusion to his distal veins was not exactly robust. This is one of the problems with secondary apnea, it eventually leads to circulatory collapse.

One thing about attending at an academic hospital in the US—I have plenty of resources. I am so well off, I rarely have to write orders anymore. What's the drug dose? Someone is always there to look it up for me. Sometimes, I feel superfluous to the action. Am I really needed today in the unit? If not, I'd much rather go for a swim with my daughters.

I struggled to hit a hand vein on my first two attempts.

"Someone listen to the heart rate."

I was hoping for a needle stick induced adrenaline response.

"It's still slow."

"Draw up epi for the ET tube and for an IV, and someone run and see if you can get Sally from our house. Here give me those—let me listen."

Two sticks wasn't a lot. I wasn't giving up now, but knew I wasn't the most skilled set of hands in close proximity. Sally was just one of those veteran nurses that I have come to treasure over the course of my career. A few are built in just such a way. Unflappable when you need them the most. Unfazed when the shit hits the fan. Need an IV, I've got it. Exudes confidence in a crisis when you are paying extra special attention to the tone of voices around you. Neonatal medicine, like all of medicine, is a team sport. There are no heroic doctors without heroic nurses. And there are no heroes without someone or something to care about.

"His color looks better."

"His heart rate is definitely over 60. Stop compressions for now. Let me listen again."

"He's got nice chest rise."

"His heart rate is over a hundred."

"But he is still not taking any breaths on his own."

Even though no code alarms were ringing this sunny morning in Haiti, Sally seemed to appear out of thin air in 30 seconds.

"Can you get an IV?"

"I'm on it."

"Okay, guys, let's evaluate the situation. We've got this baby, whose heart rate is now over a hundred, he still isn't taking any breaths on his own, but he looks better in terms of his perfusion."

"He's been down for a long time."

"I could intubate him—we could transport him to another facility that has the means to care for him."

"Not sure anyone will take him."

"How long do you think he wasn't breathing for? He has to have had serious brain injury, don't you think?"

"Dad says he delivered at three this morning. It's what, eight o'clock now?"

"We have no idea how long he's been deprived of adequate oxygen—whether and how much he's been breathing on the ride over."

"Well his heart rate has responded to our efforts,"

"Is he taking any breaths on his own?"

Our airway man stopped breathing for the baby. I listened to his heart. It was over a hundred beats a minute. If we kept breathing for him, it wasn't likely to slow down anytime soon.

"He's not breathing on his own—oh wait, maybe there was a gasp."

We watched for several seconds. It certainly wasn't continuous like I had hoped

"I could intubate him and we could breathe for him. What do people think?"

"I'm in. Hand me the flush."

"Grab a bag of D10 and check his sugar."

Man is Sally good. Boy, do I feel incompetent.

How to Choose—Life or Death?

"I don't know. What are the chances he is going to get well?"

"I know. I know. It's just that I could—it's hard to know—I know."

What I knew better than everyone around the gurney, but had a hard time acknowledging unlike everyone around the gurney, was the prognosis for this little boy. It was piss poor. He almost certainly had sustained major permanent damage because of a lack of blood supply to his developing brain. Even

under the best of conditions, we worry about kids who come in like this back in San Francisco and Boston. If they have had profound oxygen deprivation for a long period of time, should they survive, they often survive lacking even the most rudimentary abilities like being able to suck, swallow, breathe consistently, let alone walk, talk, and think.

“His blood glucose is 156.”

“Nice stress response. His adrenal axis seems to be working.”

Several high quality studies from the earlier part of this past decade demonstrated the efficacy of the cooling neonates after an asphyxiating event. As is the perpetual wonder of modern medicine, now many babies with this kind of injury and who can reach a hospital within a few hours after birth are being cooled to a core temperature of about 33.5 degrees Celsius for a couple of days. If we were back in Boston, I would have seriously entertained chilling this latest patient of mine.

Cooling. It must have been over 100 degrees in Port-au-Prince that morning.

MRIs. It costs patients one hundred US dollars to get a cat scan in Port-au-Prince. Out-of-pocket. There’s that damn equity gap again.

“What do people think? Should I intubate him?”

“What do you think the outcome will be?”

Reflexes are not just physical. Here’s a classic reflex in clinical medicine when no one wants to make a decision. Ask the question in a slightly altered way back to the questioner. I was the expert in this situation. In more ways than one.

Emotional Baggage

I wept uncontrollably at the airport when my colleagues finally found me. I avoided them throughout the baggage screening, ticketing, passport control. I ran from the anticipated consolation. Hid with my face toward the bar on the balcony of the pristine air-conditioned American Airlines terminal. I didn’t want to appear vulnerable.

“So much for me and my detached enlightenment.”

“It’s okay buddy. You made the right decision.”

“Now you guys can officially say I am human—just don’t tell anyone back home.”

“It’s okay.”

People will ask me, “How was Haiti?” and I’ll say something like, “It was okay—challenging—hard at times.” Knowing that the question itself is nonsensical despite being asked with the best of intentions.

How was Haiti? Do you have a few hours to listen to my real answer? Or would you just prefer the not-so-polite one liner? Here, let me summarize my last few minutes in the hospital with my last patient for you: Good luck dad getting back to your tent safely on your moped with your dead son wrapped in a blanket tucked under one arm. Good luck telling your wife her newly born son is dead. Good luck finding a place to bury your baby tonight.



On Partnership

Ryan Schwarz, Duncan Smith-Rohrberg Maru, Dan Schwarz, Bibhav Acharya, Bijay Acharya, Ruma Rajbhandari, Jason Andrews, Gregory Karelak, Ranju Sharma, and Mark Arnoldy

Recently, Bayalpata Hospital, in the rural district of Achham, Nepal almost collapsed under the weight of its own staff’s discontent. The hospital had been largely abandoned until 2009 when our organization, Nyaya Health, renovated and opened it in partnership with the Nepali government. Since then, the hospital has seen great progress and has experienced widespread community support. Nonetheless, earlier this year, a broad-based staff revolt occurred, led primarily by our senior clinical staff members, raising concerns that Nyaya’s management policies were ineffective, and wages and benefits were too low. The unrest included everything from a strike, limiting services to our patients, to aggression against non-strikers and slander and racist comments in public media against the Nyaya Health Board of Directors. Ultimately, the conflict was resolved, though not without the departure of our three most senior clinicians. The incident deeply damaged staff morale

and impeded basic services to our patients, and from our perspective as a leadership and management team, it was deeply troubling and spiritually challenging. We have learned much in the wake of the strike, but here we focus more narrowly on the concept of partnerships in our work by examining the recent strike and the two key issues that lead to it: wages and benefits, and management policies at Bayalpata Hospital.

In grappling with the recent staff crisis, some of our leadership team expressed concerns that we would never be able to develop a true partnership in Achham if our senior-level employees led strikes against the organization. The leaders of the strike were our most well-educated and high-ranking staff. They were also individuals who had come to work for us specifically citing the moral imperative of our work, and their pride in helping to serve the poorest of the poor. One leadership team member asked, “What is ‘partnership’ then? We came into this work with the premise that we would work together, with our partnership built around the right to health—but who are our partners if they lead strikes damaging the very services our collective mission aims to offer?”

Another leadership team member commented, “The first time I visited Achham I was invited for tea at Meena’s* house (one of Nyaya’s midwives). We arrived at her house and Meena greeted us warmly. She showed us in to a small room: there was no furniture, but there was an immaculately swept mat which we joined her on. We drank tea, seated on her rug, and listened to her tell us how she had come to live in the house, how she had come to work for Nyaya, and her pride in now being able to provide both for her own children, as well as, the children of her relatives. As the only employed family member, she now had the challenge of providing for all of them. When we question our partnership, I’m taken back to Meena’s warm, but extremely poor, home. She has worked for Nyaya for almost four years. She has helped our organization provide free care to over 75,000 people. Is this not a type of ‘partnership’?”

*Name changed for privacy reasons

Allow us to offer some background on the issue of wages—Meena has been with our team since 2008, and has been paid about \$2,500 per year—a generous wage compared to other employers in the region. Meena was one of the striking staff members. Among other concerns about the way the hospital was being run, she and other staff asked indignantly why we couldn’t provide them with higher wages, better benefits, and more resources, both for her and the hospital. Notably, Meena’s salary (and the rest of our staff’s) was well above her equivalent in other, more urban hospitals (to compensate for the extremely remote area in which we work), and in a district where most families are farmers, our staff’s salaries occupy the highest income bracket in the region. Nonetheless, as is common throughout the world in both rich and poor areas, our staff regularly asks for raises. We have consistently provided our staff with annual raises to incentivize long-term employment, as well as additional benefits for longer-term employees, though it is nonetheless exceedingly difficult to maintain skilled professionals in an extremely remote and impoverished area. However, in keeping with our commitment to support the public sector, and as signatories to the NGO Code of Conduct (for more information on the NGO code of conduct, please visit <http://ngocodeofconduct.org/>), we aim to ensure our salaries are in keeping with a long-term and sustainable approach to the public health system. To the extent possible we aim to avoid the detrimentally high salaries provided by some other NGOs that often have the unfortunate and unintended consequence of recruiting staff away from the public sector.

As our leadership team grappled with the strike, a key lesson we learned was that we may have entered the discussion with a falsely elevated sense of what “partnership” implies. Nyaya’s leadership team is comprised of Nepalis and Americans. We have trained and worked at some of the finest institutions in the world. We are privileged enough to travel around the globe when we choose, and our day-to-day lives are primarily in well-developed cities with access to great luxury. For us, our “partnership” consists of giving our time to support

Nyaya's work, but many of us will also come and go, intermittently or permanently, from this work when our jobs and lives take us in different directions. Conversely, Meena's life has been lived primarily in the destitute and rural west of Nepal. She has never received the opportunity to travel leisurely throughout her own country, much less to a different country 8,000 miles away to do "global health work." By the time she was in her mid-20s, she was responsible for her own *and* someone else's family. To Meena, her partnership to Nyaya has been showing up to work, every week for the last four years, and ensuring that our organization has successfully seen over 75,000 patients.

The ideal of partnership is often glorified in images of "struggling equally, for the cause, together." In reality, however, it is a much more complicated concept. A true partnership necessitates that each partner bring to the table what they are able, making each contribution quite different than the next, and indeed, sometimes "unequal" in magnitude or scope. But the point is that it is not about keeping score—it is about working together for a common purpose. As we have volunteered our time building the organization and fundraising, Meena's service to our "partnership" has been her employment. If another job with a better salary arises, she will take it—and we will continue to struggle through the complicated issues of internal and external brain drain—but that does not cheapen her role in our partnership over the last four years. In the same way, any of us as leadership team members moving on to a new job would not call into question our commitment to Nyaya's mission.

Back to our discussions, another team member countered, "Okay, we all understand that poverty and structural violence are inextricably linked to this work and do deeply impact how our staff are able to live their lives and work as Nyaya employees. But that doesn't explain or excuse some of the unprofessional, hurtful, and deconstructive things that were said and done during the strike." And another leadership team member reminded us, "I agree with that too. But let's also not forget how many mistakes we made that led to this strike in the first place."

As always in Achham, poverty played a significant role, and it's easy to understand a continued push for higher salaries and better benefits when our staff live in a setting of abject poverty, supporting not only their own families, but the families of their relatives and friends as well. We have seen this before, and we know we will see it again. We choose to work in Achham for these very reasons, and these same factors will continue to lead to staff displeasure with any salary we offer. But this strike was different than staff conflicts in the past. Never before had Nyaya's employees publicly defamed the organization, nor had such internal strife arisen amongst our staff, pitting one side of the conflict against the other.

As the strike progressed, we came to understand it more clearly, and learned that while it was in part about wages and benefits, there were other grievances as well. Staff told us that our leadership team had done a poor job of supporting them with effective management structures. Our policies, guidelines, documentation, and reporting structures were deeply flawed. There were redundancies and gaps that resulted in ineffective work place policies and made our staff's day-to-day jobs significantly more challenging. While money was certainly a key cause of the strike, we were surprised to learn how our own mistakes as a management team had also led to continued and progressive staff discontent, ultimately culminating in the strike. We have made significant changes to our policies in an attempt to avoid such conflicts in the future; we share a summary of some of these in Table 1.

The leadership team member who started the discussion continued, "Yes, I do understand that we made a lot of mistakes here as well. But neither our mistakes nor the impoverished conditions that we work in excuse the way certain employees acted; so, what next?"

Ultimately, the answer to that question resulted in three of our most senior staff leaving—one's contract was allowed to expire and two resigned. Their actions had crossed the line from constructive dissent to frank unprofessionalism and destructive behavior. They were successful in highlighting our inadequacies as a management team, but they also

Table 1**Description of Mistakes, Mis-steps, and Systems Changes During the Bayalpata Hospital Staff Crisis**

Core Mistake	Practical Mis-step	Systems Changes
<p>We did not appreciate the power of pride and shame, particularly given that we call upon very inexperienced leaders and clinicians to work in an extremely challenging environment.</p>	<p>We suggested we would not provide a letter of recommendation to our Medical Director; we provided a strongly-worded letter of condemnation for various destructive acts perpetrated by the physicians; we used the Nyaya Health Interantional (NHI) leadership as a condemnatory structure without previously having established it as a supportive one.</p>	<p>We have established new roles within our NHI leadership that will communicate regularly and provide greater support to our clinical staff and leaders.</p>
<p>We allowed salary negotiations to serve as a wedge between the core hospital leadership: the Medical Director and Country Director.</p>	<p>We left salary negotiations for both senior clinical leadership and other staff members in the hands of the Country Director alone.</p>	<p>We will revise our policies such that Nyaya Health Nepal (NHN) negotiates the salary directly of the Country Director and the senior clinical leadership, and we will de-authorize the Country Director in any role in salary negotiations with senior clinical leadership. As had been previously, the hospital management committee, including the Country Director and Medical Director, will have hire, fire, and salary power of mid-level staff but not over the firing/hiring over senior leadership. This will hopefully prevent power struggles as we saw previously. We will provide block salary budgets to the Country Director and Medical Director to negotiate with staff.</p>
<p>We had a weak Nepali leadership, and a Country Director hamstrung by being an expatriate and without effective Nepali support mechanisms.</p>	<p>We had been unsuccessful at recruiting a more experienced hospital administrator and clinicians. This necessitated a more forceful/involved Country Director, the only non- Nepali on site, to help get things accomplished. However, while we had over one month prior agreed to hiring a translator/assistant for him, we had failed to do so.</p>	<p>We will prioritize, and be willing to pay more for, more experienced, older, more mature Nepali leaders who have been extremely difficult and costly to recruit. For those positions requiring an on-site expatriate leader, we will have an effective Nepali assistant or translator.</p>
<p>Our leadership has been continuously changing, with most physicians, Medical Directors, and Country Directors staying on for less than one year.</p>	<p>Due to the challenging circumstances and remote area of Achham, we have not been able to recruit, establish contractual mechanisms, or provide supportive environments, to make long-term commitments feasible for leaders.</p>	<p>We will revise our recruitment strategies to look for longer term leaders; we will develop mid-level leadership positions to cultivate leaders; and we will look harder for local Achham-side leaders.</p>

<p>Bayalpata Hospital staff in general had unclear structures for staff grievances and management</p>	<p>Owing to our multiple transitions of leadership, many of our hospital operations, oversight, and management documents were unclear or outright contradictory.</p>	<p>We have revised all these documents, following reflection and input from the various staff and community meetings.</p>
<p>NHI had itself unclear roles for its leaders during the crisis.</p>	<p>Because NHI leadership lacked clear roles, many of us took part in providing advice and support as ways to help out, but that ultimately was not done in an efficient or effective way. As such, while many people spent much time on the crisis, we still were unable to get core tasks accomplished.</p>	<p>We have started to carve out more clear roles, with clear chains of command and specifications of who is in charge of what type of crisis, among our NHI leadership.</p>
<p>There was a lack of a sense of partnership between NHI and Bayalpata Hospital staff throughout this crisis.</p>	<p>We had not prioritized regular, consistent mechanisms for the staff to understand who NHI is and what NHI does.</p>	<p>We will start regular conference calls between an NHI leader and local Bayalpata staff, with photos and stories about NHI members, and with more readily available documentation about NHI.</p>
<p>Staff were overworked and overwhelmed by the work load.</p>	<p>We failed in identifying and recruiting additional mid-level and ancillary staff.</p>	<p>We will endeavor to hire several new staff to better manage the workload.</p>
<p>During the transition, we did not have rapid ways for recruiting new doctors.</p>	<p>While we knew even before the crisis that we needed an extra doctor and had agreed to recruiting one, various priorities had made it such that we did not get our application process started for over two months since we had agreed we would start recruiting.</p>	<p>We were able, through our contacts, to get a doctor out within a week after our previous doctors left. We are aiming to recruit more senior doctors for longer periods and to have more doctors on staff at all times.</p>
<p>Our procurement mechanism did not have appropriate safeguards for ensuring quality.</p>	<p>We did not provide sufficient oversight and support to our new young, inexperienced hospital administrators. We were unable to recruit and pay for a more experienced team. We failed to involve NHI leadership, who have experience in procurement, to assist in reviewing potential vendors and offers.</p>	<p>We will engage NHI in better oversight over procurement. We will work to better capacitate and support a more effective hospital administrative team, with the organizational willingness to pay a higher salary.</p>
<p>When the procurement problems happened, we failed to address them sufficiently in the eyes of staff.</p>	<p>While we discussed the problems internally and with the Hospital Administrator, we did not communicate this effectively to the staff.</p>	<p>We are conducting an independent investigation, led by external community members, into the affair.</p>
<p>We underestimated the importance of having on-site presence from senior members of Nyaya Health Nepal leadership to help guide NHI's local staff.</p>	<p>We could not create an effective local non-profit organization, owing to various challenges with the culture of non-profit industry in Nepal and the lack of a solid base of core leaders living in Nepal willing to be volunteers without economic gain.</p>	<p>The President of NHI, for the first time, travelled to Achham from Kathmandu to help mediate the community and staff meetings. We are working with him to engage NHI more effectively in Achham, and to evolve into a more legitimate non-profit organization, rather than a legal mechanism.</p>

brought about unnecessary and unhelpful strife that damaged our ability to serve our patients—the primary mission and one that we all share, despite our disagreements. As we reflected further, where we had initially questioned our staff’s fulfillment of our partnership, we found that we had also failed to deliver on our own end. We also came to realize that while some staff had acted in inappropriate ways, many of our staff had not. The majority of our staff—including Meena—had joined the strike seeking better salaries and because they were understandably frustrated with the inefficiencies and ineffectiveness of their hospital’s management.

Work in the global health field is both morally compelled and deeply challenging. While the partnerships involved are often discussed superficially and glorified as seamless, in practice they are rarely such, and at times can be extremely difficult to navigate. It is critical to understand the context each partner comes from, and that privilege, contrasted by the structural violence of poverty, impacts heavily on how partnerships evolve and interact. Further, partnerships are dynamic, and sometimes hard choices must be made to ensure that the mission of that partnership is upheld. For our role as a management team, we had failed our staff and are working presently to amend our policies to enable them to better fulfill their own part of the partnership (Table 1)—employment and the day-to-day health care that Nyaya provides our patients. In parallel, this incident also highlighted that ultimately, Nyaya’s mission is to serve our patients, and a professional and respectful partnership must be maintained to ensure that our mission is successful. Unfortunately, implementing that mission sometimes requires making difficult and painful decisions.

We know that there will be many more challenges ahead; if there were not, we would not have chosen to work in Achham. While the unfortunate recent events have not helped our patients in the short-term, they have taught us much about this work and helped us to better understand how, as an organization, we can continue to work towards our mission. While our initial reaction was to see only our staff’s errors, we’ve learned to be more critical

in understanding our own. All crises are opportunities, and no matter how painful such conflicts are, we are confident that as a team we are stronger and better, and such experiences will indeed serve our patients in the future.



Pains And Gains Of Rural Health Practice: Lessons Books Never Taught

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How The Journey Began

In the early 1980s, as fresh graduates from Mysore Medical College in southern India, we were brimming with a zeal to “cure the sick” and “change the world.” We had an ideal of evidence-based, rational, ethical and equitable health care and set out to serve rural and under-served communities which included displaced forest-based tribes. In the initial years, with the naivety of the inexperienced, we believed that by correcting the dehydration of the doe-eyed six-year-old Mare and giving her a free course of antibiotics, we had made health care accessible to her. Much to our dismay, within a month, Mare was back in the outpatient clinic, with diarrhea all over again and looking thinner than ever. We realized that it was a losing battle to keep her healthy as long as she continued to drink water from the same contaminated stream, live in unhygienic surroundings, and eat only the paltry meals that her family could barely afford. We gradually began to connect these living examples to what our preventive medicine text books had stressed all along—there are many social determinants of health which, if left unaddressed, do not permit realization of the vision of health for all.

Such instances continually pulled us out of the hospital building and into the villages and tribal hamlets. We discovered that our textbook of *Preventive and Social Medicine* (Park, 1986) (P&SM as we used to call it), was our most valuable possession.

We devoured the descriptions of national health programs, sanitation procedures, water treatment protocols, and maintenance of cold chain for vaccines with a completely new perspective. We discovered the *Manual of Basic Techniques for a Health Laboratory*, (World Health Organization, 1980) detailing how to set up a laboratory with low cost, reliable and simple methods. We learned to drive a jeep to haul supplies and patients. To step up the level of clinical care, some of us pursued post-graduate programs and equipped ourselves to provide more specialized care too. It has been over two decades since we embarked on this journey. We have encountered a variety of perplexing dilemmas with no clear solutions. We have sometimes been compelled to adopt health practices that were not really evidence-based, seemingly irrational, inequitable and even downright unethical. This narration describes only a few of our thousands of cases, and hopefully conveys our periods of self-doubt, despair and hope, as well as, the challenges we face to reconcile with the difficult choices we are forced to make every day.

Unforeseen Challenges in Saving Mothers and Children

High maternal and child mortality rates have been one of the most disturbing aspects of the health care scenario in rural India. To ensure immunization of all children, health workers with vaccine carriers go from village to village and hamlet to hamlet to reach those infants that would have missed visits to the immunization clinics. Our grass-root workers facilitate these visits by identifying households with such children. Occasionally, they encounter families who spirit away the infant into the adjoining woods as soon as the health worker is seen approaching, and blandly proclaim that the child is not at home. Despite reassurance and counseling about the safety and necessity of the vaccine, their apprehensions and misconceptions are insurmountable. What is the extent of the responsibility of the health worker? Is it ethical to hunt down the child and force the administration of the vaccine in view of the public health gains, besides the child's welfare?

A few months ago, a pre-term neonate was admitted to our hospital, but worsened and needed referral to a higher centre in the city. The family refused to go despite repeated persuasion and detailed explanation about the technical limitations of care at our centre. From the family's perspective, the variety of social, cultural, and monetary challenges they would face in the city were themselves limitations for care. We were compelled to retain the baby and continue giving the best care we could.

Two years ago, we received by ambulance a woman well into the last month of her sixth pregnancy. She was very sick with abruptio placentae, when the placental lining separates from the uterus, and deranged coagulation of blood, a serious problem where the blood does not clot properly. Her baby had already died but still remained in the uterus. Our hospital was not equipped to deal with the situation, and we referred her to a higher centre in Mysore. As we feared, her family members were neither keen on the transfer nor willing to accompany her. As the support systems in most Indian hospital are quite skeletal, it is imperative for two to three family members to always be with the patient to make the rounds of the pharmacy, the blood bank and even the cafeteria to buy food for the patient. A kind neighbor from the hamlet and one of our own health workers volunteered to accompany her, fully aware of what it entailed. After the patient was admitted to the ward, our health worker spent all night visiting various blood banks in Mysore arranging for blood products, money to pay for them, and transporting them to the patient's bedside—all this, in addition to donating his own blood to one of the blood banks. Yes, it is a painful truth that replacement donors are still very much in vogue in India. Ultimately, the patient slowly limped back to a stable state, and we can say with deep relief and gratitude that her five children have been restored back their mother. To cap it all off, the neighbor and the health worker were handed the dead fetus to arrange for the funeral, which they fulfilled in the same selfless manner. Interestingly, they had no clue how to go about it and merely followed the actions of another family who were involved in a similar rite. Considering

the local cultural nuances surrounding death and funeral rites, no words can really convey the extent of appreciation for the commitment shown by these two, clearly extending far beyond their designated duty. Isn't this what compassion and humane care are all about? How do we capture this in a medical school ethics curriculum? If someone were to ask the question, "What does it take to save a mother's life in rural India?" the complexity of the answer is self-evident.

Perplexing Cultural Nuances

A few months ago, one of our doctors was on his weekly visit to the tribal hamlets. He spied 23-year-old Radha, curled up and motionless on a straggly mat in the corner of a hut's verandah, looking very sick. With coaxing, he discovered that she had not eaten for the past two days but was unwilling to come to the hospital. Her husband, sitting at the doorstep, wore an disinterested air. He reluctantly parted with the information that her mother had left some porridge for her. He had made no attempt to feed his wife and merely shrugged when requested to bring his wife to the hospital immediately. Our doctor was in a dilemma and a thousand thoughts flitted across his mind. Would it be culturally and socially appropriate if he ventured into the hut (despite the husband sitting on the doorstep), got the porridge and forced a couple of spoonfuls into Radha's mouth? Should he brush away her refusal and take her to the hospital? How should he reconcile the imperative to respect the patient's choices and his duty to provide care? If he walked away, she would likely miss the only opportunity she would ever have, to reach the hospital. Was it really a voluntary choice on her part not to come to the hospital, or had she been compelled to remain at home? Does a doctor's duty to a patient start only when the patient solicits care?

Between The Devil And The Deep Sea

Many medical professionals have frequently observed that antibiotics are overused and misused in India. Doctors in our hospital are periodically

cautioned to adhere to antibiotic policy and guidelines. Many babies and young children come to our hospital with respiratory infections which can be viral and therefore would not need antibiotics. However, there is always a possibility of secondary infection which precipitates rapid deterioration. Due to socio-economic and geographical challenges in the area, some families may not be able to bring a worsening child back to the hospital in time when such an infection arises. Doctors face the predicament of whether they should initiate antibiotics for prophylaxis, or should they prioritize the public health agenda of restricting overuse of antibiotics? We often feel justified in initiating the antibiotics "just in case," but are nagged by the thought—are we contributing to the emergence of drug resistance? Are we slipping into irrational health care? But haven't we actually made a rational choice?

Amateur Health Economics

While we are aware of the multi-dimensional nature of our work, we discover more layers every now and then. Most of the patients coming to our hospital are daily wagers. A visit to the hospital therefore entails loss of that day's wages and other indirect and social costs. If repeat visits are necessitated for investigations and review, these costs go up further. Developing systems to reduce turnover time in the hospital and complete most components of care in a single visit is a constant endeavor. Well-endowed hospitals and patients can approach medical services like a menu without a price list. Standard algorithms for diagnosis and treatment can be adhered to with textbook like precision. Resource-poor settings present many challenges for practice. Those algorithms remain mere theoretical frameworks. It is not infrequent to see patients ask the doctor how much tests cost and then request that he choose those that fit their budget. The same goes for medicine prescriptions. The doctors have to cleverly stretch, twist, and even circumvent standard procedures to make judicious choices for care that still suit the patient's ability to pay. Perhaps we should have procedures that also incorporate these realities!

Emerging Challenges

Besides direct patient care, a variety of other dilemmas came our way. The advent of multicentric clinical trials into India brought stringent norms for informed consent. Many years ago, we embarked on a collaborative research study with an American hospital in the local community. Having heard many stories about abuse of research participants in other studies, we were pleased and much relieved to note that providing information to participants and obtaining informed consent was strongly emphasized. However, we were shocked to see a six-page informed consent form, which included adverse effects like thrombophlebitis and hematoma for a simple procedure like a phlebotomy (the drawing of blood). While we appreciated the spirit of transparency inherent in the process, there is definite merit in the argument that by information-overload participants can be alarmed into refusal. In fact, some of the community representatives on the ethical review board felt the extent of information was ludicrous and that it should be more moderate. After much debating and negotiation, we were finally able to convince the Institutional Review Board at the U.S. hospital to modify the consent form. It was an important lesson for us to ensure contextually appropriate adoption of international guidelines and norms and not succumb to pressure from the “experts.” The informed consent process has undergone a serious transformation in the past decade and is now more flexible and contextually appropriate.

Being an organization involved concurrently in clinical care, public health and research, we often face unusual dilemmas. While conducting an epidemiological study related to diabetes, we went to all households in the village, offering risk assessment and a screening blood test to all consenting adults. Whenever a participant refused to participate, we explored the reasons for refusal. A sixty-year-old woman consented for risk assessment but on being offered a blood test, she refused and bluntly told us that it made no difference to her. She felt she could not afford the medicines anyway and her daughter-in-law would not accommodate her diet requirements. Should the research team make more concerted efforts to make her agree to the test, so that

she could at least know her diagnosis? Or should we respect her refusal? Is it the responsibility of a researcher to address social reasons for refusal to participate in research? What do organizations like ours do when we also have a role in public health for the very same community that we are studying?

The Journey Continues

Presently our organization delivers a combination of preventive, promotive, curative, and rehabilitative healthcare. The past two decades have taught us that the medical doctor is positioned really well to make a huge difference, beyond the boundaries of healthcare alone. We came into the medical profession with a virtue-based ethic. We realized that in practice, what works best is a consequentialist approach. Many decisions we made and still make are based on potential consequences, and often involve a trade-off with something else of value. Each passing day we realize more that healthcare means not merely providing rational and evidence-based medical care, but also *facilitating processes that improve the quality of life of people in need in a contextually appropriate manner*. Indeed, this is our driving mission.

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Lives Saved, With a Little Help from Friends

Prasanta Tripathy

In November 2000, Jharkhand was carved out of Bihar, a state in eastern India, to be a separate state to fulfill the aspirations of its people and

allay their feeling of alienation. It was a good time for me to reflect on how best I could contribute. In 2002 Ekjut, a registered development organization, was set up by myself and other like-minded colleagues. Ekjut, which means “togetherness,” was the outcome of a longstanding desire to do something on our own, something that was close to my heart—doing something for and with the people I had grown up with. An invisible cord kept me attached to this region of India and after stints with a few development organizations within and outside the state, my wife, Nirmala, and I decided to relocate to a village near my hometown, Chakradharpur.

Chakradharpur is a small railway township in South Bihar where I spent all my childhood and days of schooling. Beyond the periphery of this township and its satellite market place, live indigenous people, the Adivasi, in villages and hamlets. Even as children we could appreciate the government policy that protected them in the sense that their ancestral lands could not be acquired by Dikus, the non-tribal people living in the towns and cities. The un-spoilt bounties of nature protected and preserved by the original inhabitants of the land—the Adivasi people—was there for all of us to see and enjoy.

A rumor that a doctor couple was building a nursing home led to a regular flow of men, women and children to our unfinished home with all kinds of ailments, including medical emergencies. It was becoming increasingly difficult to cope with the workload of constructing the house and at the same time—overwhelming to see children dying in our home, which was never meant to be the hospital that the villagers thought it to be. They were reluctant to visit the government hospitals, which were primarily meant to serve poor people and their attitude could be summarized in just one word—fatalism. We wanted this to change—they somehow needed to understand their rights and entitlements. The public health care system had to be strengthened and Nitmala and I wondered how our work could make this happen.

The Adivasi people were soon to become partnering communities with Ekjut. It did not take us

long to realize how unprotected they were. We had a vague idea that we wanted to build healthier communities. Providing full-time curative care was not an option; it was also beyond our means. Knowing that strengthening the health system would take time, we hoped that our community-based work would strengthen the demand side, since even the minimum services that were available were grossly under-utilized.

India is home to about 10 million tribal people. We had seen and also knew that their health status was poor and that tribal people have the disproportionate burden of child mortality, malnutrition, malaria and death in childbirth. But we could not find a reliable existing data base that could guide our work. The health status of women and children soon became Ekjut’s main concern.

We wanted our work to generate knowledge that would be relevant in a wider context. Adivasis are not a monolithic entity and our evidence needed to grow from working with several different tribal groups. We needed to build our research capabilities and willingness to work with several different indigenous groups, as well as, the poor people living alongside them in different districts. A collaboration with University College of London was soon to follow. Professor Anthony Costello who was my teacher more than a decade back, invited me to partner with his department and jointly bid for a grant. This grant was likely to come at the confluence of several interesting developments. First, the self-help group movement in India had made a substantial jump and such groups existed in almost every village. Second, a grassroots organization called PRADAN was working with women’s groups to strengthen their livelihoods in several states of India including our district. PRADAN shared with us that they realized that the savings accrued by the women’s groups members were being frittered away for irrational medical treatment and people were being misled by the “crookery and quackery” of informal and private medical practitioners. Third, a visit to Narangabeda, a neighboring village with an existing women’s group and our interaction with its secretary helped us to understand that the health situation of women

didn't seem to correlate with the small increase in income. They were happy to allow us to pilot a monthly meeting with their groups deliberating on health. Invitations for conducting similar pilots came from two more villages. Finally, the possibility to work with Professor Costello's wonderful multi-disciplinary team using his principle of, "No survey without service," was an attractive proposition.

We decided to work with the self-help women's groups while opening them up to broader range of people. Extending the scope and methodology of our work to benefit people living in the underserved areas of three bordering districts of Jharkhand and Orissa states was aided by a parallel and pre-existing approach of participatory learning and action and the use of simple storytelling. We co-crafted contents of a meeting cycle, integrating our domain knowledge of health, applied some creativity and proposed applying this community mobilization approach in about 200 villages and to evaluate the impact of the intervention. We successfully bid for the grant and completed a cluster-randomized-controlled trial—comparing the difference between communities where our Ekjut team worked with women's groups and where it did not.

The participatory meetings provided a forum for communities to develop a common understanding of maternal and neonatal problems, as well as, locally acceptable and sustainable strategies to address them. The combination led to an astounding reduction in newborn deaths by 45 % in the last two years of the trial that ended in the middle of 2008. The reality is that the newborn death rates after this impressive improvement—about 30 per thousand live born births—was still relatively high in comparison to better off places. The groups had succeeded in plucking the low hanging fruits and the poorest benefitted the most. The question we asked ourselves in 2008 was—should we try additional "packages" and intervene further in our intervention villages and see if we are once again successful? We decided to go to newer areas instead, so that quick gains could be made by other communities in similar circumstances.

Ekjut continues to work with more than 1,000 women's groups in many underserved areas in

several districts during its tenth year. We went on this expansionist spree because we knew from experience that successful research findings are not easily accepted and take many years for policy makers to adopt. Before we did this we extended the benefits to the villages in our controlled areas, as we had commitment to them that we would do if we found the intervention effective.

It was also proving difficult to convince professionals that this almost dumb-foundingly simple method was able to reap more benefits than the usual public health delivery mechanisms. The latter seek impact through linear administration of programs—from implementers to recipients. The Ekjut trial adopted a circular method, where implementers, facilitators, group and community members themselves became planners, designers and recipients of learning.

In the coming days we will continue to look at the role participatory interventions with women's groups can play to improve the quality of health services and health and nutrition beyond the peri-natal period. We will also look at the role of such groups in influencing other developmental issues such as women's decision-making power. It is our strong conviction that the voice and agency of people should guide the decisions that shape their lives.

Ethical Consideration

While informed consent provisions in our studies ensure that women who agree to be interviewed are able to make a free choice for giving us legal permission to interview them, we had to be completely sure that we never take advantage by misleading them into believing that the invitation to be interviewed during the study would somehow lead to an opportunity to receive some kind of medical services from Ekjut. All our data collectors are from the communities of the interviewed women because of our apprehension that an external researcher might be viewed as someone in a position of authority and there could be reluctance to refuse participation, if they wished.

During the entire course of our work, we debated the idea of "obligation" to the community. Should

this be judged from the end of the project findings only? We cannot guarantee that our interventions will always be successful. There was less argument about the fact that community empowerment (which was our ‘intervention’) can be an end in itself and any positive results would be a bonus.

We must also be concerned about our other obligations to the communities because we employ longitudinal surveys and therefore feel obliged to communicate the results—like the status of health of the vulnerable—at appropriate points and at earliest possible times to the participants and government agencies.

Maternal deaths may be a rare event for a village or a hamlet but in our office we couldn’t be blind to the regular reports that were pouring in. We had to break the rule of waiting for our trial to be over and published a paper about the high maternal mortality in our districts. We engaged with print and television media, hoping to influence and improve the services available in these regions. We also shared our findings with Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, during his mission to India in December 2007 to examine maternal mortality through the lens of the right to health. Witnessing high levels of maternal mortality also made us think more generally about the need to use data collected during trials for advocacy when gross inequalities in health are visible. Trials tend to focus on a small number of outcomes but collect a lot of other data which sometimes does not get used. We felt that using this information would be important because mothers gave their time to participate in surveys and the data could be used productively for advocacy to bring attention to pockets of the disadvantage, which do not always get picked up in national surveys.

In spite of the growing consensus around the four cornerstone interventions to reduce maternal mortality—family planning, skilled birth attendance, effective referral networks and emergency obstetrics care—we found these aspects grossly lacking in Indian villages. In subsequent years, some attention to these has led to a reduction in

maternal deaths in India. Overall coverage of services has improved during the last five years but the coverage estimates can be misleading if distribution is not taken into account. Soumik Banerjee, a young engineer working with indigenous people, keeps sending case histories of maternal deaths among the underserved populations where he works. They live along the slopes of a hill called Sundar Pahari (literally meaning the beautiful mountain) in another district. Therefore, we know that things may be bad in other underserved pockets.

The average state and national coverage of services in India appears to be improving and even may be adequate in some places, but is insufficient when analyzed in detail and from the perspectives of the poor and marginalized. This uneven coverage can only be dealt with by increasing public sector investments in health and education in the underserved areas.

More encouraging for us has been the fact that community mobilization through women’s groups seems to have hastened the speed of decline in maternal deaths in hundreds of villages where the groups are active. The increased self-efficacy, problem-solving skills and strengthened network of marginalized communities might be helping people to make the best of available services and making more timely, and thus life-saving, decisions.

There is a commitment from the government of India to invest more in public health during the next Five-Year Plan, its twelfth such plan, and focus on universalization of healthcare services. Our work in the underserved pockets of several districts of two states proves that together with universalization, efforts should also be made towards enabling marginalized communities to come together, listen to their voices, and ensuring that these are acted upon to address inequities in health.

Ekjut has also found it difficult to communicate the state of under-nutrition among children to their parents and to the communities. Even in seemingly homogenous societies, the poorest carry the heaviest burden of disease, malnutrition and premature deaths. Our team members have come up with interactive games and stories that help to sensitize better-off people towards building inclusive

societies, but the concern remains that the structural problems can't be permanently addressed through mere improvement of people's conditions—their overall status must improve.

It is possible to mobilize volunteers in health promotion programs—if we avoid victimizing and stigmatizing individuals; are sensitive to ethnic and cultural practices; are willing to assist communities in making friends with one another; and help them come up with their own stories of change to replace the old ones when necessary. After all, story telling originated in the forests and hills.