

## Letter from Ganiyari

### THE ART OF LETTING GO AND THE MANDATE OF GOING FURTHER

In rural India, people get to the hospital on foot or by bicycles, rickshaws, public transport, hitchhiking, taxis, but rarely by the public ambulance, and even more rarely, the private ambulance.<sup>1</sup> People get help from the family, friends, compassionate lorry drivers and even empathetic complete strangers. I have seen two healthy individuals sandwich a very sick loved one between them on a motorcycle when that sick individual was no longer able to sit upright. I have met a father who walked through the night with his suddenly paralysed son in his arms, stopping only once inside the doors of the Emergency Department.

While there are a lot of ways and many different people who can get you to the hospital in rural India, there is only one group of people who can take you home: your family. This reality is a mix of legal precedent and cultural tradition. When you are alive, a diversity of options listed above—some expensive, some reasonably priced, some free—are available to you. But when you die, there is no train or bus or friendly lorry driver; there is only one option. Your family must arrange a ride in a private vehicle capable of transporting a dead body. (Colleagues tell me that in some parts of India some hospitals have the capacity to transport dead bodies, but the publicly available information that I could find about transporting the dead in India relates only to air travel.<sup>2</sup>) Such vehicles and the rides they provide are few and far between in the central eastern states, including here in Chhattisgarh.

Such transport is often prohibitively expensive.<sup>3</sup> In a bad monsoon year, these expenses can consume an extended family's entire savings. If this happens, sadly, it leads to a vicious cycle of food insecurity, malnutrition and further illness.

#### *Letting go*

We are presented with a dilemma that I never faced as a trainee in a tertiary care hospital in the USA: in an acutely sick individual with a treatable condition (and, therefore, not a palliative case), when and how do you decide that enough is enough? We can treat pulmonary tuberculosis, severe sepsis and exacerbations caused by asthma, but we are not always successful. This fact is frustrating, horrifying and undeniable. When does one tell the family: 'It's time to go to the train (or the bus) station. It's time to take your loved one home before he dies...'

You can die on the train or bus if you boarded alive, no extra fee.

Such statements run counter to the intrinsically aggressive narrative of my medical training. While I hesitate to speak for all of us, one strives and struggles until the patient dies (provided that it is the patient's or their loved ones' wishes). Even in neurologically devastated patients, where few effective treatment modalities exist, research has shown us that meaningful, reliable commentary about a person's cerebral function often cannot be made until 72 hours after a cataclysmic event.<sup>4</sup> In such cases, in the USA we continue to aggressively treat for an additional three days. In rural India, such a 72-hour period seems an unimaginable luxury. Families want to take a loved one home for understandable last rites and a desire to avoid additional expense. Doctors are aware of the constant demand for beds. In Ganiyari, we cannot afford to leave someone with a minimal chance of recovery in a bed for even a day.

You might ask counter questions: 'Does this really happen? Is this really a decision you have to make? Would you really tell the family of a 15-year-old with an APACHE II score of 70 that "it's time to go home"?'

I will probably never be willing to do anything other than 'rage, rage against the dying of the light'<sup>4</sup> for a child or adolescent or parent with young children. But one would be amazed at the number of highly functional middle aged and elderly adults who come to the hospital in rural India with treatable conditions who, despite our best efforts, move ever closer towards death.

In the process of creeping towards death, the patient is usually exposed to more treatment modalities and is generally started on more powerful and expensive medicines. In most cases, the bill for these treatments and medicines will be partially or completely covered by out-of-pocket expenses of the family in question.<sup>5</sup> With each additional expense, the chance for indebtedness increases. At its best, Indian healthcare operates under the following tacit agreement: doctors promise to do what is necessary and prudent but not more while patients agree to trust that the expenses the doctors place upon them are justifiable.

I would like to think we are operating under this tacit agreement in Ganiyari. But, even at its best, it is hard to accept the reality. It is awful watching someone leave the hospital hours from death with a problem you believe you can still intervene upon though you also know, prognostically, there is no hope. But it is equally awful imagining a grieving family having to bear the onerous burden of paying for transport home in addition to the expenses they've already incurred. Nothing in my medical training prepared me to navigate these realities.

#### *Going further*

Thus far, my narrative has largely focused on medical professionals and our struggles, leaving the patients and their families as passive actors. Though done for the sake of clarity, this omission is unfair.

As these events play out with a loved one, I wish I could better explore the thought processes of the apparently stoic spouse or child. How much of this desire to go home to die is truly financially motivated? I have certainly conceptualized it as such in this piece. All over the world—both where I trained in the USA<sup>6</sup> and in India<sup>3</sup>—medical care is a major cause of bankruptcy. However, this conceptualization may simply be how I best understand the struggle these individuals face. Given the woeful state of affordable, accessible medical care in most regions of Chhattisgarh, how much of this is a matter of patient expectations? With the preponderance of premature death in this part of India, my patients and their families are probably just as good as this foreigner at seeing when death is coming. Can these families also read the tired lines etched on my face, which say that many of the best medicines for the extremely ill, both palliative and non-palliative—narcotics or blood products—are either not available or substituted with lower quality alternatives? Am I couching a family's end of life discussion as a cultural or financial quandary when it simply amounts to, 'Why die uncomfortably in a hospital when you can die uncomfortably at home?'

I still believe it is our duty, as rural medical professionals, to tell families when we think it is time to take their loved one home. But, as difficult as this process is, we as doctors must avoid thinking that our responsibility ends there. We must think about

why this individual got sick, and we must also think how that illness is situated within the individual's community. When we think about the individual's community, we must recognize that this community also includes our own hospital.

As we reflect on end-of-life care in Ganiyari, we turn a discerning eye towards our own healthcare institution and its strengths and weaknesses. Some of these weaknesses can be addressed internally; this is why we have a monthly morbidity and mortality conference. Some of these weaknesses have a locus of control outside of our campus. It is there the work of advocacy begins. In Chhattisgarh, such work would address the well-intentioned but misguided local and national regulations of narcotic pain medications (which, despite 2014 legal loosening remain effectively off limits in much of our state<sup>7</sup>). We would also question the onerous restrictions related to blood banking.<sup>8-10</sup> There are justifiable concerns about opioid addiction or the spread of blood-borne illness; nonetheless, at the end of life, concerns about addiction or misappropriation seem laughable.

Further, we must strive to make our hospitals and clinics places that challenge expectations—our own and our patients. The hospital here in Ganiyari is completing construction of a rural intensive care unit (ICU). In Haiti, highly active antiretroviral therapy (HAART) radically altered how patients thought about and acted towards their HIV infection, leading to the so-called 'Lazarus effect' where the sick seemed to rise from the dead.<sup>11</sup> While this was a pharmaceutical intervention, supply chains which got those drugs to Haiti, hardworking Haitian healthcare professionals treated those patients, and word of mouth at bus stops and in marketplaces spoke of individuals cheating death. Advocacy was the fertile soil in which those supply chains were conceived and implemented; those bus stop and marketplace conversations were the fertile soil in which expectations were forever changed. Can we perhaps strive for a similar 'Satyavan/Sati-Savitri effect' here once the ICU is fully functional? It will not be easy, but it will not be as hard as some (hypothetical) Bengaluru- or Mumbai-based intensivists gasp at the idea of a rural ICU.

#### *The boundaries of our collective profession*

I admit three things. First, as a doctor for four years, I do not have enough experience to accurately predict death more than a few hours before its occurrence. Second, I have not found a way to deal with these situations except with gut feelings and expert advice on a case-by-case basis. Third, this is real. The conversations, the

decisions, the need for advocacy, and the call to challenge our patient's possible expectations about care and its quality as they enter our hospital—all this is real.

It is challenging to let a patient go home with a possibly reversible condition. When I took the Hippocratic Oath, I never imagined I would one day be letting the ultimate harm—death—happen to an individual so as to avoid another harm—indebtedness—for the living who remain. But that is not where the challenge stops; it is only the end of the beginning. We must also be advocates and challengers of expectations—advocates whenever what is happening for our patients differs from what is possible; challengers whenever our communities accept as natural a reality that is remarkably unnatural. It is hard to let go, but it is critical to not stop there.

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TIMOTHY S. LAUX  
*Jan Swasthya Sahyog, Ganiyari*  
*Chhattisgarh, India;*  
 HEAL Initiative  
*University of California San Francisco*  
*San Francisco, California*  
 USA