

## **Is Dying Colorblind?**

### **A Brief Reflection on Disparities in Hospice Care Amongst Indian Americans**

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## **Dedication**

*For Neil Ghiso, whose bravery and struggles inspire me more than words can express. Even though I never had the privilege of coming face-to-face with him, his story has given me the strength to overcome my own medical problems and continues to make me a better physician on so many levels.*

## *Preface*

I was graduating from medical school terrified of death and dying; terrified I would fail a patient who lay dying in front me; terrified that I would become one of the physicians I had hated when I was faced with my own grim diagnosis a few years ago. Neil Ghiso's touching words that "caring – just caring" is the essence of a good doctor resonated with me as the road to residency lay ahead. Now was the time in my career when I could shape the physician I would become for the next several decades, and the path ahead was well-paved for me by former Ghiso fellows. The Neil Ghiso Fellowship provided me with a wonderful and timely opportunity to face my demons, not only to become a better person but also a better physician so that I may someday better serve a patient in his/her final hours.

I sat down and tried to decipher the origins of my fears and apprehensions about dying and sought to mold my Fellowship experience to explore these worries, both from objective and subjective points of view. As a physician, the death of a patient represented failure for me, regardless of the *quality* or circumstances surrounding the death. How my medical education instilled this overpowering desire to prioritize small medical triumphs over a dignified death mystified me. Was keeping the patient's body alive really a better outcome than allowing him to make peace with his family before he passed?

On the brink of my beginning my fellowship, I often reflected on my grandfather ("Daddy" as everyone called him), who had been maliciously kept alive for far too many days by us, after his devastating stroke. I wondered what thoughts entered his head in his last months, when he lay trapped within his own body – unable to speak or move, crying out in anguish every few minutes as the bedsores touched his bones. Afterwards, I regretted our hasty rejection of

hospice services and pain medications, lamenting how he died alone, rattling the rails of his metal bed, like a caged animal, held captive by his selfish family.

Death has no color – black, white, Latino, Indian – death comes to us all. Yet, I was alarmed by the disproportionate presence of Caucasian patients (~80%) pursuing hospice facilities in the United States. What, I wondered, became of the minority patients who silently suffered at the end of their lives? And, what were the major barriers to receiving compassionate care for this patient population?

The care of minorities, especially end of life care, was a vast and infinite topic, rich with multiple possible dimensions to explore. It was a topic that would inevitably enter into every physician's career. Yet, we physicians were unaware and untrained to provide care to minority patients at the end of their lives. Only through education and awareness of cultural, spiritual, financial, language and other factors that enter into patients' decisions could we embrace our patients' beliefs and value system to provide them with optimal care. Of the many choices for possible projects, I chose to focus in on a single population and single topic: the Indian American first-generation immigrant group and their aberrant attitudes towards hospice care. This choice was a direct result of my personal reluctance to provide my grandfather with the comfort services he so desperately needed. Applying directly to me and my family on multiple levels, I found that studying and researching these ideologies was very exciting and relevant to my own experiences.

Due to the extreme specificity of my topic, however, I struggled with lack of studies and resources to explore barriers to good end-of-life care for Indian Americans. There was an alarming dearth of studies in all minority patients, let alone the Indian American immigrant population. In the end, I found that extrapolation from other minority groups, especially African Americans, and studying the model of hospice care in India proved to be invaluable to my work.

Furthermore, by researching the ideological hurdles to accessing hospice care in India, I was able to transfer many of those concepts to Indians in America. I had the privilege to work with scholars from many different disciplines: Dr. Sarita Bhalotra of Brandeis University, whose expertise lay in health services research and was able to offer insight into minority hospice care in the United States; Dr. Muriel Gillick of Harvard University, a geriatrician who specializes in aligning patient values and expectations with the care they receive and was able to provide me with objective data that systematically studied the issues favoring aggressive care amongst minorities; Dr. H. Jane deLima of Harvard University, who has spent a considerable amount of time researching and working in hospices in the founding state of Kerala, India and provided a unique perspective into fundamental problems within the infrastructure and belief system of the indigent population; Dr. JoAnne Nowak of Harvard University who facilitated the honor of visiting a dying patient at home and was able to provide me with statistics from Partners Hospice, of which she is Medical Director.

In addition to these objective findings, I yearned to explore the humanity and personal face of end-of-life care. I wondered what it really like to see a patient dying with home hospice. During my childhood in India, I had seen numerous examples of terminal patients fighting for their lives with aggressive chemotherapies and invasive procedures, but had never witnessed a peaceful death. Inpatient hospice facilities were a black box for me, and I sought to learn which, if any, patients would be better suited for inpatient versus home hospice. I had numerous unanswered questions, both from a personal as well a professional point of view, and decided that my Fellowship ought to include home visits and inpatient hospice visits as well.

After attending an inspiring lecture by Dr. Rita Charon of Columbia University, as suggested by Dr. Robert Buxbaum, I stumbled upon the exciting field of “Narrative Ethics”. The

central philosophy of the field revolved around an inherent and deep-seated appreciation of the patient perspective, which often took the form of literary writing or other modes of artistic expression. Moved by the idea of exploring the patient's feelings through writing, I worked with Dr. Laurie Rosenblatt of Dana Farber Cancer Institute to try to incorporate a series of brief seminars on "Narrative Ethics" into the second-year Harvard Medical School curriculum. Unfortunately, however, the idea was met with some resistance from the administration, who clung to their dogmatic ideas that compassion was not a necessary component of pre-clinical education. On a personal front, however, I was able to write and submit an essay for publication about my extended illness and the lack of compassion I faced during my encounters, and how that altered my subjective perception of suffering. For the first time since my recovery, I was able to confront my emotions and my personal coping mechanisms against disease, and I felt empowered by my writing.

What follows is a brief report of my findings and experiences. The once-in-a-lifetime opportunity that this Fellowship offered me to explore compassion and improve patient care on so many levels is truly unparalleled. I have benefited from my experience as a Ghiso Fellow, not only as a future physician, but also a patient. What truly inspires me about this Fellowship is the incredible emphasis placed on the patient and on compassionate care at the end of life. Modern medical school curricula fail to appreciate the importance of physician attitudes and behavior on outcomes, and emphasize only the medical and scientific aspects of care. In addition, patients are often avoided and discounted at the end of their lives by their caretakers due to fear, lack of knowledge, and lack of education on compassion and the dying process. Unfortunately, it is the one time in the life of the patient when the role of the physician is of utmost importance and is indispensable. Through my Fellowship, I have discovered how to listen and how to observe,

how to understand unspoken words, and most of all, how to embrace my patient wholly (emotionally, physically, spiritually) as he/she makes his/her peace and leaves this world.

## The Color of Death

### Chapter 1

Imagine a cachetic man, his insides riddled with metastatic lung cancer, his bones causing him excruciating pain, unable to eat, drink or speak, his brain full of cancer. He lies still, except for his labored breathing, unable to move, waiting...and hoping for the sweet relief of death. His mind fills with memories of his youth, when his body had not yet failed him. His wife, a svelte woman in her sixties, can't help but wonder how the face she admired everyday for the past forty years has now morphed into a gruesome image of death. She can't help but pray for relief of his suffering. After all, there's nothing else she *can* do – there are no pain medications, no way to help him breathe easier, there's nothing to help him!

A common scenario throughout India, even in 2007, many people continue to suffer at the end of their lives, due to multiple barriers to accessing good hospice care. These barriers include, among others, financial, educational, cultural, and logistical difficulties for access of services (1). The idea of hospice, a collection of services guided by a philosophy of compassionate care at the end of life, didn't even enter into Indian medical care until 1986, lagging far behind the first American hospice facility by over twelve years.

America opened the doors of its first hospice, The Connecticut Hospice, in 1974, funded in large part by the National Cancer Institute. The need for hospice care was long overdue in America and came about primarily through efforts of Dame Cicely Saunders, who was also responsible for the first hospice facility in the United Kingdom and for initiating the modern hospice movement. Hospice services included attention to many types of pain, including physical, psychological, social, emotional and spiritual pain, as well as holistic healing, focus on

quality of life, and the family as the central care-giving unit for patients whose life expectancy was under six months. The concept of compassionate care and services at the end of life quickly gained popularity in this country, proliferating rapidly, with the presence of over 3,200 current hospice facilities in the United States today. Medicare services dignified the importance of this care by expanding coverage for its members in 1982, with Medicaid following soon afterwards in 1989. Even the United States Post Office widely publicized the concept with inception of a commemorative stamp in 1999 (Figure 1).



**Figure 1. The United States Postal Service Hospice Care Commemorative Stamp.** The artwork depicts the importance of dying at home, surrounded by friends and loved ones, and the butterfly depicts spiritual release, the final transition of life. The release of the stamp emphasizes the concept that all Americans should die well.

Western cultures have continued to expand funding, services, coverage and facilities in end-of-life care. As a matter of fact, the expansion has been so robust, that hospices are currently under-utilized, even in the United States. This has not been the case in the developing world, especially India, where there are palliative and hospice services in a mere 11 of the 29 states (2). The enigma of lack of end-of-life facilities in a country where 80% of cancer patients present with incurable or widespread disease continues to baffle the world (1). Even more shocking, however, is the finding that when Indian patients immigrate to the United States, they still refrain from accessing the abundant hospice services that are so readily available. As a first-

generating Indian American, I too started my Fellowship with apprehension and fear surrounding the idea of hospice care. Reflecting upon the origin and history of hospice care, however, helped me to understand the reluctance of third-world citizens in choosing hospice, and the transference of these hesitations to U.S. immigrants from India.

The hospice movement originated largely outside of the medical establishment, and was driven primarily by nurses and chaplains, rather than doctors. This explains why current hospice care is more than just physical support (i.e. relief from pain), but also encompasses spiritual and cultural domains (2). As a result, hospice care has evolved to provide all-encompassing care for patients in the last six months of their lives. In doing so, however, they inadvertently relieve the physician of his/her responsibility to the patient to understand and incorporate spirituality into medical treatment options. As a graduating medical student, I can confidently say that I do not recall a single session where the notion of spirituality, religion and dying was presented to us.

Sulmasy suggested that:

In today's medical culture, even a deeply concerned clinician might tend to "problematize" the spiritual aspects of a patient's care, casting them as ethical problems (eg, "code status" and "futility") or as psychosocial problems (eg, "denial" and "disposition"). Spirituality cannot be reduced to these categories, however. Spiritual and existential well-being are major components of health-related quality of life, especially at life's end (3).

Because dying is so inexorably linked to religion and spirituality, it is impossible to dissect these two entities and futile for physicians to attempt to avoid addressing spiritual components of end-of-life care. The fear of embracing a patient and his/her spirituality is pervasive amongst doctors in the medical community, and leads to poor outcomes for patient care – a trend that needs attention and reversal. Now at the end of my medical school training, I almost left medical school with immense trepidation about addressing a patient's spirituality – we were never taught how to do that! Interacting with patients at the end of their lives through this fellowship, discussing spiritual issues and appreciating the importance of consolidating

medicine and religion, however, I feel newly empowered to discuss religion and spirituality with my patients.

Religion is so inherent that patients consistently make end-of-life medical decisions based on their religious predilections: Catholics are less likely than Protestant Christians to pursue life-prolonging treatment, Jews have a greater preference for the use of feeding tubes, and African Americans show consistently greater resistance to limiting life-sustaining treatments and signing advance directives compared with other racial groups (3). Amongst Indians, 80% of whom follow the Hindu faith, sickness and suffering are thought to be the quickest way of purging sins from earlier births, and relief of this suffering is believed to prevent the penance necessary for complete absolution (2). In addition, there is a conceptual and logistical hurdle to accessing opioids. Alarming, India is the world's largest producer of morphine, yet only 3% of India's cancer patients have access to adequate pain relief, largely due to stringent governmental restrictions on dispensing of morphine and individual attitudes regarding fear of narcotic dependency (1, 4).

When I look back on my multiple surgeries, I remember reluctance in pushing the button of the patient-controlled-analgesic pump, even when the pain seemed unbearable. Perhaps this cultural belief could lend insight into one of the many barriers Indians in America face when considering palliative and pain services. The lack of historical use of opioids in palliative services in India has introduced a fear among first-generation Indian Americans regarding the safety of these substances. Understanding these fears will allow me, as a physician, to be cognizant of the religious and cultural context of my patients, educating them and providing them with services that they feel comfortable using.

Culture, a constellation of shared experiences, values and rituals, inherently defines how terminal patients view end of life. Krakauer et al. suggest that the documented greater preference among African Americans than among European Americans for aggressive life sustaining treatment and against the use of advanced directives is a direct consequence of shared meanings and values formed by a shared historical and social experience – their culture (5). The same can be extrapolated to Indians: decisions are often based on historical experiences or distorted notions that no longer apply. A survey of over 2000 patients revealed that whites trusted their physicians more than non-whites, and other ethnographic studies based on patient interviews have demonstrated that that patients worry that “doctors could not be entirely trusted to know when, and if, to stop life support because their motives might be tainted by economic considerations” (5). In addition, historical precedence of medical racism, where human experimentation was disproportionately carried out on African Americans, and minority populations were routinely prescribed decreased analgesia, has continued to propagate the notion amongst minorities that doctors cannot be trusted. This same mistrust could also be a part of the Indian American community. All of this translates into a deep-rooted mistrust for the motives of doctors, and the belief that recommendation of hospice care is motivated by financial incentives for physicians.

Furthermore, the culture of India, a rapidly developing country, which continues to push forward in order to improve technology, is not favorable to palliative services, which emphasize comfort care over cure. Prominent attitudes among India’s population result in a large thrust in oncology towards curing disease rather than appreciating the importance of quality of life (1). The individuals who have the financial resources use these resources for pursuing a cure rather

than improving quality of life (Dr. Jane deLima, personal communication). Thus, the culture is just not amenable to “giving up” which is what hospice care is deemed equivalent to.

First generation immigrant Indians, who are now part of the dying geriatric population, also refrain from accessing hospice care due to pre-existing notions they hold, carried across the miles from India. India opened its first hospice in the state of Kerala in 1986, when a pain clinic was established as part of the vast Regional Cancer Center that stood within the capital city of Trivandrum (2). It was somewhat unsuccessful due to the widely-held notion that pain is a natural and expected consequence of disease (2). A Western-style inpatient hospice named *Shanti Avedna Ashram* was also concurrently opened in Mumbai in 1986, but occupancy remained disappointingly low, because of the widespread belief that any *Ashram* was appropriate only for the underprivileged and destitute. When the name was subsequently changed to *Shanti Avedna Sadan* (meaning peace, without pain, at home), there was a dramatic increase in use and number of patients served, because the connotation was no longer one of poverty (Figure 2). Many of these ideas, however, that inpatient hospice facilities are places for the destitute continue to pervade the thinking of many immigrants.



Figure 2. Shanti Avedna Sadan in New Delhi, India. The first such inpatient hospice was opened in Mumbai, and has since gained popularity throughout the country.

Perhaps even more than cultural and religious biases and medical mistrust, though, is the lack of knowledge of disease, hospice facilities, what they offer and how they can be incorporated into a dignified death. In India, the belief that cancer is contagious is still widespread amongst the illiterate and often leads to patients hiding their symptoms or presenting very late to their doctors. Dr. deLima related a story to me of one of her patients whose daughter was engaged to be married. As soon as the mother was diagnosed with cancer and began seeking hospice services, the bridegroom and his family ended the relationship altogether, convinced that the woman's cancer may spread to them. Within the United States, there is some degree of self-selection, since the majority of immigrants are educated. But, wrongly-held beliefs regarding cancer and palliative care are still quite prominent.

There is an undue importance placed on the family unit, and it is often a matter of pride to care for a loved one. Hospice services, both inpatient and outpatient, shift this balance of responsibility slightly: even though there is a lot of emphasis on the family members as caregivers, the notion that a nurse or social worker enter the house to care for a beloved elder is deemed disrespectful.

For me, the best way to address this lack of knowledge was to immerse myself within home hospice visits and observe, firsthand, how the presence of absence of hospice services can impact the dying process amongst minorities. That way, I would be better equipped to inform my patients and gauge which patients would be appropriate candidates for these services. I was unable to single out any Indian American patients currently enrolled with these services to visit, but went to the home of an African American patient. What follows is an account, motivated by the "Narrative Ethics" genre of medical writing describing my subjective account of a home

hospice visit of an Armenian patient who silently struggled with Alzheimer's disease, enrolling in hospice just months prior to her 100<sup>th</sup> birthday.

## Chapter 2

Entering the parking lot of the apartment complex, I was struck with the dullness of the red brick buildings against the drab afternoon sky. Towering ominously over the parking lot, were three identical buildings, which looked old and dingy. We entered the once closest to us. As I walked in to see my Armenian patient – let's call her Ellen – I cringed at the “Dead End” sign in the cul-de-sac to the right that greeted all visitors to the building. We entered Ellen's small, dark apartment, her final home, and I could instantly smell a musty odor that made me slightly sick to my stomach. Looking around, the apartment was complete with more comforts than any modern-day hospital could have provided. There was a lounging wheelchair in the corner, “The Cadillac” as Ellen's attendants liked to call it. It was equipped with an automatic gear shift, a thick plush velvet cushion, and reclined to almost 180 degrees. There was a walk-in closet stuffed full of medical supplies, dressing changes, gloves, diapers, anything that Ellen could ever need. The yellowing walls had old pictures, reportedly some of Ellen's favorites. And Ellen lay motionless amidst it all, hardly moving except her occasional grunt of displeasure. Her 24-hour attendants were wonderful, giving her every move the utmost attention. She was clean, well-dressed and well-groomed – she even had her nails manicured. Yet, there was a chill in the room. Ellen's family had divided her wealth and moved on with their lives, justifying their lack of presence by compensating her with 24-hour services and equipment. They visited rarely, leaving this woman to die alone and miserable, despite all the comforts around her. I left Ellen with a sense of pity and awe. Few minorities had the privilege to die with endless

resources, yet one could hardly call her dying process dignified. Cast aside, she was nothing more to her family than the money she once owned. And, in this case, I found that hospice services could do very little to provide this woman with affection, or the closure that she needed to leave this world with peace. Perhaps that's why she has not been able to let go – dying slowly in that apartment for the past ten years. As I left her apartment, I felt relieved. The cold winter air chilled my bones and all light had lifted from the sky to give way to the early evening dusk.

References

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