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2013-04-01

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## Medical tourism? A case study of African patients in India

Ву

Allyson Molly Goldberg

A thesis submitted in partial satisfaction of the  $requirements \ for \ the \ degree \ of$ 

Master of Science

in

Health and Medical Sciences

in the

**Graduate Division** 

of the

University of California, Berkeley

Committee in charge:

Professor Stephen Eyre, Chair Professor Lawrence Cohen Professor Ndola Prata

Spring 2013

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#### Abstract

Medical tourism? A case study of African patients in India

by

Allyson Molly Goldberg

Master of Science in Health and Medical Sciences

University of California, Berkeley

Professor Stephen Eyre, Chair

To date, the limited academic literature on "medical tourism" has relatively ignored the vast number of patients from developing countries traveling abroad for medical care. This case study employed a mixed-methods approach to understand the motivations and experiences of African patients traveling to India. Twenty African hospital inpatients and their companions at two, linked private hospitals in India completed a brief questionnaire and a semi-structured interview, which was analyzed using a combination of grounded theory and thematic analysis. Both instruments revealed that patients were traveling for life- and/or quality-of-life saving medical needs, often with the goal of simply surviving. While improved health was participants' singular priority, and equipped, responsive hospital staff the most positive aspect of participants' experiences, challenges were numerous, including language/cultural barriers, high costs, long-term separation from family and work, and culture shock specific to a more advanced care setting. Being in India also inspired reflections on participants' own health care systems, particularly in the realms of patients' rights, the efficacy of health professionals, and "development." Notably, few patients identified with – or had ever heard of – "medical tourism" in the way it is popularly defined.

The implications of this study are numerous, including informing the experiences of future patient travelers from developing countries, their doctors at home and abroad, and health system improvement efforts in both African countries and India. Finally, this analysis suggests a strong future for the globalization of private health care services, raising questions in development economics and putting new perspectives on achieving health care as a human right.

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#### Introduction

In this era of globalization, "medical tourism," a new term describing the practice of patients traveling abroad for medical care, has emerged as a controversial and complex phenomenon. Worldwide, popular media and academic literature have generally characterized medical tourists as people who travel abroad for health care at lower cost than is available at home, health care that is unavailable at home, where waiting times are shorter, or where the opportunity exists for a combined, exotic vacation. Typically in academic literature, medical tourists are additionally characterized as patients who travel with the express intent of obtaining medical care. This differentiates medical tourists from expatriates and travelers who become ill while on vacation overseas. More than 50 countries nowadays court medical travelers, and India, Thailand, and Singapore are currently considered top destinations [1].

Among much of the literature on this topic, a prevailing conception is that medical tourism is a dramatically new global phenomenon. Indeed, the term was coined only in the late 1990s [2]. Yet as Pafford (2009) describes, for centuries patients have been traveling to healers in faraway places and to climates more conducive to their conditions, and in the last century, the wealthy and elite from abroad have been traveling to the U.S. for high-quality care at top medical institutions [3]. Therefore, what seems to distinguish this era that Pafford has thus termed the "third wave" of medical travel is the success of several developing nations as medical destinations, and the beginning of an overall shift in international patient traffic from the global North to the global South [3, 4]. U.S. literature on medical tourism, which is relatively coincident with the country's most recent health reform debate, accordingly reflects awe at the rapid improvements in health care that "destination" countries are making, as well as skepticism about and defensiveness against what may be an external threat to the U.S. health care system. In the title of their 2010 piece, Underwood and Makadon express a general ambivalence of U.S. authors about medical tourism: "game-changing innovation or passing fad?" [5].

Traditionally, the U.S. has been the leading global destination for health care [6, 7]. A 2008 report by the global management consulting firm McKinsey & Company suggested that the U.S. cares for approximately forty percent of all international patient travelers [8]. Since the rise of medical tourism, however, a global marketing campaign by international hospitals and reports of revenue from destinations like India, which expected an industry worth U.S.\$2.2 billion by 2012 [9], have made U.S. researchers and policy-makers particularly interested in tracking the absolute number of patients traveling into – and now also out of – the U.S. for health care. Currently, because there are no standardized pathways for medical travelers entering and exiting the U.S., no existing data collection mechanism, including through the government or an international regulatory institution, is fit to capture the whole picture. Likely, part of the ambivalence about medical tourism in U.S. literature stems from the fact that the extent of the phenomenon is still unknown.

Perhaps the most frequently cited statistics about medical tourists come from the Deloitte Center for Health Solutions (DCHS), a research arm of the U.S. firm Deloitte LLP, which specializes in audit, financial advisory, tax and consulting services. Their 2008 report on medical tourism reports that an estimated 750,000 Americans went abroad for medical treatment in 2007, and that in 2008, over 400,000 foreign patients would come to the U.S. for treatment [10]. Using data from the U.S. Department of Commerce's Office of Travel and

Tourism Industries, which conducts a continuous Survey of International Air Travelers into and out of the U.S., Johnson and Garman (2010) estimate that as many as 121,392 ± 10,878 Americans may have traveled abroad primarily for medical treatment, while 102,869 ± 13,699 international patients may have come to the U.S. Johnson and Garman's own estimates, which are based on "in-depth telephone interviews with 18 providers who were either ranked by [the] U.S. News and World Report [annual "America's Best Hospitals" report] or were identified by their peers or in the media as hospitals catering to international patients," suggest that 50,329 Americans traveled abroad in 2007, and 42,469 international patients came to the U.S. [7]. Finally, researchers at the University of Iowa (2011) estimated that in 2008 approximately 13,500 Americans traveled abroad for medical care using medical tourism facilitator companies to help arrange their journeys [11].

What these widely varying estimates make clear is that currently available data on medical travel to and from the U.S. are very limited in both scope and utility. Further, the diverse methods used in these estimates suggest that, beyond measurement challenges, there may neither yet be a universal definition for a medical tourist. Still, what is common across the majority of the above estimates is the finding that outbound medical travel exceeds inbound travel. While Johnson and Garman conclude that this imbalance nevertheless results in a trade surplus for the U.S. of up to \$1 billion, likely reflecting the specialized, high-cost treatments that many inbound medical travelers seek [7], at the least medical tourism is highlighting weaknesses in the U.S. health care system that may upset the global balance of medical travel.

This review of literature explores the recent rise of medical tourist destinations in the developing world by way of an historical explanation. Starting in the post-World War II era, the subsequent section details select developments in the U.S. health care system between the 1940s and 1980s that have contributed to its earning international renown and to its becoming the leading global destination for health care. In so doing, this section also offers a perspective on how the U.S. health care system came to be the most expensive in the world, ultimately pricing many of its own residents out of the market. The paradox between international renown and local unaffordability helps to foreshadow the rise of medical tourism.

The second section of this literature review begins in the 1990s in Thailand, the origin point of medical tourism. It then describes the spread of this trend to India, the ultimate focus of this analysis. Singapore, although an important medical destination both in the early years of medical tourism as well as today, will be minimally addressed due to lack of available data. Overall, although the development of medical tourism in these countries is believed to have had no direct relationship to changes taking place in the U.S. health care system, it is probable that high costs of care in the U.S. contributed to medical tourism's initial success.

Finally, the conclusion returns to Underwood and Makadon's binary question [5] and suggests that future research is needed before medical tourism can be truly understood, let alone categorized as either a "game-changing innovation or passing fad."

#### U.S. Exceptionalism and the Paradox of U.S. Health Care

The U.S. is a world leader in medical research and development. On a survey published in 2001, of the six innovations (developed between 1975 and the turn of the century) that physicians reported to be most important for patients – including MRI and CT scanning, ACE inhibitors (to lower blood pressure), balloon angioplasty (to open blocked arteries), statins (to lower cholesterol), mammography (for breast cancer screening), and coronary artery bypass grafting (to prevent heart attacks) [12, 13] – all but angioplasty were either created or improved upon in U.S. hospitals or by U.S. companies [13]. While most funding for medical research in the U.S. comes from private sources [13], the National Institutes of Health currently operates on a budget of more than \$30 billion for medical research [14]. In comparison, the European Union spends approximately one third that sum [15]. Emphasis on scientific advancement in the U.S. has made it so that people living in America typically have better cancer survival rates than Canadians and Europeans and have greater access – per capita – to technologies like medical imaging (e.g. MRIs, CTs) than Canadians or the British. Moreover, "[s]ince the mid-1970s, the Nobel Prize in medicine or physiology has gone to American residents more often than recipients from all other countries combined" [16]. Thus by many accounts, the U.S. offers the most advanced health care in the world.

The U.S. also spends more on health care than any other developed nation (17.9% of GDP in 2010 [17]). As was popularized during recent health reform debates, however, this spending does not necessarily translate into better health for Americans (e.g. [18, 19]). Why U.S. health care is so low value for money is a mystery that many health care experts have tried to explain. Perhaps most simply, based on their study of OECD nations, Anderson et al. concluded in 2003 that, "It's the prices, stupid" [20]. Many authors have also suggested that medical technological advancements – for which U.S. health care is also known as the most advanced in the world – are strongly implicated in increases in health care costs. Callahan (2008) goes as far as to suggest that "new or increased use of medical technology contributes 40-50% to annual cost increases" in the U.S., making it the largest source of cost increases [21]. Fischer, Bynum, and Skinner (2009) look instead, for example, at regional variation in health care spending within the U.S. and rather suggest that the feefor-service payment system and the use of advanced medical technologies are too simple to explain the recent, steep rise in health care costs [22]. They report the findings of a study that used clinical vignettes to elucidate physicians' clinical decisions and behaviors, and they conclude that differences among these individuals may shed more light on cost increases. For example, they found that physicians

in higher-spending regions...were much more likely than those in lower-spending regions to recommend discretionary services, such as referral to a subspecialist for typical gastroesophageal reflux or stable angina or, in another vignette, hospital admission for an 85-year-old patient with an exacerbation of end-stage congestive heart failure. And they were three times as likely to admit the latter patient directly to an intensive care unit and 30% less likely to discuss palliative care with the patient and family. Differences in the propensity to intervene in such gray areas of decision

making were highly correlated with regional differences in per capita spending. [22]

While the cause of cost increases is undoubtedly multifactorial, including other factors not mentioned here, there is a great paradox in the fact that U.S. health care is the most advanced in the world and, simultaneously, increasingly too expensive for many Americans to afford.

Recent health reform debates have shined a spotlight on this paradox. In 2010, the number of uninsured Americans rose to 49.9 million, or 16.3% of the U.S. population [23]. While the 2010 Patient Protection and Affordable Care Act (PPACA) was intended to be a step toward restoring equity in the health care system, the intense opposition that arose to the legislation may suggest that the design of the U.S. health care system – including its emphasis on medical innovation and infamous, fragmented health insurance system – reflects individualistic cultural values that have dominated in the U.S. for the past few centuries. Published authors have certainly suggested that comprehensive health reform will require a cultural shift (e.g. [21]). Yet, a more egalitarian system in which all people are able to contribute according to their means and access the most advanced health care in the world may defy the importance that Americans typically place on hard work and self-sufficiency. In contrast, the inequities in access and outcomes that currently characterize the U.S. health care system do not seem to exist as starkly in countries where historical events rather beget solidarity as a cultural value.

The health care systems with which the U.S. is frequently compared underwent major reforms in the post-World War II era, suggesting the postwar period as a time during which the course of U.S. health care diverged from that of other developed nations. Britain founded its National Health Service (NHS) in 1948, for example [24]. As highlighted in Michael Moore's film *Sicko*, Banks et al. (2006) found that despite that Britain spends less than half of what the U.S. spends on health care, per capita, among Brits of late middle age (55-64 years) there is lower morbidity due to diabetes, hypertension, heart disease, myocardial infarction (heart attack), stroke, lung disease, and cancer. The authors conclude that "[b]ased on self-reported illnesses and biological markers of disease, US residents are much less healthy than their English counterparts and these differences exist at all points of the SES distribution" [19].

Perhaps more illustrative than Britain's development of the NHS is the expansion of France's national insurance program beginning in 1945 [106]. In the French system, not only does every citizen have health coverage, but the sicker people get more coverage [25]. Although France's system is not inexpensive by global standards (yet is significantly less expensive than that of the U.S.), their national strategy has kept costs in check and health strong [18, 25]. In 2000, on the basis of its ability to balance good health outcomes with responding to the expectations of its population and achieving fairness in health care financing, the WHO recognized the French health care system as having best overall performance in the world [26].

In comparing the French and U.S. health care systems today, historian Dutton was quoted during a 2008 interview on National Public Radio as saying: "Americans assume that if it's in Europe, which France is, that it's socialized medicine. The French don't consider their system socialized. In fact, they detest socialized medicine. For the French, that's the British, that's the Canadians. It's not the French system" [25]. In fact, in

elaborating on how rife with choice the French health care system is, Dutton describes how the cultural values of liberty and equality are common to Americans and the French. He describes how these values arose out of Enlightenment-era political revolutions in both countries, but that the French alone have succeeded in incorporating individual liberty and social equality, as well as fraternity, into their health care system [25]. In fact, during postwar efforts at health reform in the U.S., the concept of national health insurance was shot down precisely by fears of equality and fraternity – looming threats of socialism, and the implications for racial desegregation that a national system implied [27].

While the impetus for Britain and France to create national health programs may have been independent, the immediate post-war era was also that during which the United Nations was founded. In December of 1948 the General Assembly adopted the Universal Declaration of Human Rights, and after much negotiation, in 1966 it adopted the International Covenant on Economic, Social and Cultural Rights (ICESCR) as well [28]. Article 12 of the ICESCR certifies "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." The Article further specifies among the steps to be taken to uphold this right "[t]he creation of conditions which would assure to all medical service and medical attention in the event of sickness" [29]. As of now, the U.S. remains one of seven countries that has not ratified the ICESCR [30]. A UN "convenant is a treaty which, under the rules of international law, creates legal obligations on all states that ratify it" [31], and as Alston (1990) recounted of the U.S. Senate Committee on Foreign Relations ratification hearings in November, 1979, there were "several discordant voices at the hearings, who warned that the Covenant, if ratified, might actually require that something be done" [32].

Overall, the top ten nations ranked by the WHO in 2000 for the best health care system performance [26] all have some version of a universal health care system. Further, all of those countries that are also OECD member nations implemented health reforms in the war/postwar period [33-36]. Since the 1970s, rejection of the ICESCR's tenets has affected U.S. policy [37]. While for decades the U.S. has been criticized by the international community for its exceptionalism and unilateral actions, in the case of the ICESCR, the negative consequences of non-adherence have allowed a highly unequal system to develop in the U.S. in which lack of access to affordable health care bears significantly upon the U.S. people. Moreover, as will be explained in more detail in what follows, because so many Americans have been left unable to afford U.S. health care services, this exceptionalism may have facilitated both inbound and outbound medical travel in the decades to come.

The U.S. health care system emphasized different priorities in the postwar era, priorities that were consistent with the standard that had been defined with the Flexner Report in 1910. This report, published by Abraham Flexner after assessing all of the U.S.'s 155 medical schools at the time, seems to have paved the way for the institutionalization of medical education (and more broadly, medicine) in the biomedical tradition [38]. In the postwar era, the success of military innovations such as the atomic bomb additionally inspired renewed confidence in science, and for the first time, government-led scientific research. Rather than a national health system, then, the U.S. pursued improved public health through research [39]. The budget of what is now the National Institutes of Health (NIH; it was singular before the major postwar expansion) increased 150 times between 1945 and 1961 [39], and as previously mentioned, the current budget is now over \$30 million [14]. Cumulatively over the last century, rigor and funding applied to the scientific

method have resulted in advancements in medical knowledge that have yielded incredible growth in pharmaceuticals and medical technologies, and have also contributed to the popular assessment that U.S. health care is the most advanced in the world.

However, some of the social and public health values underlying Flexner's report and the NIH expansion have paradoxically suffered as a result. Although improvement in public health was Flexner's motivation behind recommending medical education reform in the U.S., new, stricter state licensing requirements in the 1910s forced many medical schools serving minorities and disadvantaged areas to close. They also heightened the professional status of doctors, who were consequently training at more selective, more rigorous institutions [38]. The U.S. continues to face challenges overcoming these effects, particularly racial and geographic health disparities. Biomedical advances in medicine have allowed for highly specialized medicine to be practiced in the U.S., and emphasis on this advancement over equal access to it has meant that medical services continue to be rationed in large part by ability to pay. This has created a particularly favorable situation for wealthy, foreign patients whose own health care systems do not provide these sorts of advanced treatments. Moreover, perhaps to the surprise of readers versed in medical tourism, U.S. hospitals have been deliberately capitalizing on this fact since at least the 1980s.

#### Inbound medical travel in the 1980s

In 1986, U.S. hospital utilization was on a sharply declining trend. This trend occurred despite an increase in the U.S. population of 47.8 million, and an increase in the aging population, since 1965 [40]. In 1983, U.S. hospital usage had peaked, likely due to several adaptations implemented in health care services and payments that were meant to stem rising costs. One adaptation is thought to have been the institution of Medicare's Prospective Payment System, which began reimbursing hospitals for the care of Medicare patients by "predetermined, fixed amount[s]," according to diagnosis (i.e. diagnosis-related group, or DRG) [40, 41]. Many private insurers also adopted this method, which incentivized hospitals to discharge patients sooner, as they were no longer receiving per diem payments [40]. Other changes included the expansion of health maintenance organizations (HMOs), which have been shown to decrease hospital admission rates; the expansion of ambulatory care settings, including urgent care and surgical centers; the expansion of home health programs and nursing home facilities; increases in cost sharing, such as higher deductibles and copayments; utilization reviews; technological advancements in procedures that sped up recovery time; declines in use of hospitals by the poor, due to reductions in payments from many states' Medicaid programs; and an increasing number of uninsured [40, 42]. All in all, U.S. hospitals were losing money. Accordingly, within a few years, academic literature began featuring articles such as Berliner and O'Toole's (1988) in *Health Care Management Review*, entitled "[a]re international patients the answer to American hospitals' problems?" [43].

Foreshadowing the literature on medical tourism today, Berliner and O'Toole define international patients who helped to boost U.S. hospital revenues in the 1980s as patients paying full price for the cost of their care (i.e. not undocumented immigrants or visitors who fell ill while on vacation). They could be "referred to a specific physician or a specific service in an institution for a previously diagnosed problem" or they "may be seeking an

overall physical checkup and opt to obtain it at a renowned diagnostic center." In addition, they "may spend an extended period of time in a particular city on business or vacation and decide to get a medical examination at the same time" [43]. Among the hospitals that Berliner and O'Toole highlight is Cleveland Clinic, whose international patients "accounted for 5 percent of all admissions and 3 percent of all physician visits and, most important, generated 9 percent of the revenues at the clinic" in the early 1980s. To accommodate these patients, "[a]n international center with a fulltime staff of 12 [made] hotel arrangements, handle[d] currency transactions, provide[d] translation services, and schedule[d] appointments" [43]. Today, the Cleveland Clinic – which is only one example of a U.S. hospital seeking to benefit from international patients – now has a Global Patient Services Office with more than 70 staff members [44].

Aside from benefits to the hospital, Berliner and O'Toole reference a 1982 study by the nonprofit RAND Corporation, which demonstrated that international patients have a "beneficial impact on the overall Cleveland economy" by frequenting local establishments outside of the hospital as well. Further, they note that "[a] pleasant or familiar climate, the presence of tourist or business attractions, and the adequacy of hotels, banks, and restaurants may help to shift a potential patient from one institution to another." Shortly after, they note that Philadelphia started an "international city" initiative aimed at increasing – across several sectors, including medical care – the number of foreign visitors to the city [43]. Taken together, although officially nameless, it is difficult to distinguish this practice from present-day "medical tourism."

Finally, Berliner and O'Toole also mention some challenges of international patients – cultural and language barriers, the importance of having family and friends close by, the power of personal referrals, especially from doctors, and the challenges of traveling long distances. They discuss evidence from marketing studies undertaken on the attitudes of foreign patients and their physicians about U.S. medical care, and they discuss the best ways to increase referrals despite the above challenges. In particular, one conclusion they draw is that training international medical graduates from high-yield countries will promote significant gain, because the advanced technology used in U.S. health care can be easily and quickly exported. Notably, however:

[o]f course, this is only true for highly industrialized countries with large medical care systems. It is not necessarily the case in Third World countries where there is a continuing need for state-of-the-art medicine and the expertise that goes with it. Thus the primary competition with the United States for patients from Third World countries comes from Western European countries. [43]

The sentiment of the 1980s was not entirely promotional, however. As it is today, the treatment of medical travelers stirred up significant controversy. A *New York Times* article in 1985 recounts national upset over donated organs from American patients being given to wealthy foreigners who were, effectively, buying their way to the top of the transplant list. In the absence of any national guidelines, doctors and hospitals were responsible for allocating organs. In Washington between 1982-3, 25% of kidney transplants from cadavers went to non-immigrant aliens (i.e. foreign nationals on temporary, international assignments) [45]. Moreover, after the FDA's 1983 approval of

cyclosporine [46], an important immunosuppressant medication that eases transplant rejection and increased transplant success rates, the demand for organ transplants increased, exacerbating the organ shortage and this issue [45]. Doctors fell on both sides: in one camp, the American Council of Transplant Physicians and the American Society of Transplant Surgeons spoke out on the opinion that all available organs should first go to American citizens. Further, transplant specialists warned that the practice of giving organs to foreigners was undermining domestic organ donation initiatives. In another camp, the article highlights surgeons at Presbyterian Hospital, owned by the University of Pittsburgh, who reportedly gave foreigners organs "out of compassion. Many foreign patients became homesick, others were unable to afford the long wait" [45]. The shortage of donor organs continues to be a worldwide problem, and international organ trafficking and "transplant tourism" figure into some medical tourism literature. More broadly, what international organ "donation" connotes is that caring for international patients presents unique and controversial issues. Yet ultimately, money buys health care services. In a time of financial hardship, U.S. hospitals overtly sought to treat international patients who could pay.

Unfortunately for American hospitals, the need for cost-saving measures in health care – and thus of lost revenue – has only intensified since the 1980s. Between 1984 and 2010, per capita health spending in the U.S. increased from \$1637 [47] to \$8362 [48]. Lower reimbursement rates from insurers as well as an increasing number of uninsured patients have placed further financial stress on hospitals [49]. For years, the U.S. health care system has been widely considered "in crisis." Lack of access to health care, particularly for uninsured and publically insured patients, remains an extremely important problem. While comprehensive health care reform has so far proved impossible, some of the stopgap health legislation has further hurt hospital finances.

In 1986 Congress passed the Emergency Medical Treatment and Labor Act (EMTALA), a federal law that "requires screening and stabilization for all who seek emergency department (ED) care, regardless of ability to pay" [49]. This law constitutes a civil right that expanded the network of safety net providers for those most vulnerable to lack of health care access. In 1998, 93% of hospitalizations of uninsured patients started in emergency departments. These hospitalizations tend to cost more than for patients with private health care insurance [49], for one reason because those with insurance have more regular access to preventive care and can manage health problems before they manifest into serious conditions. In 1998, at least half of all uncompensated care provided by U.S. hospitals was from EMTALA-related services, and based on the average cost of hospitalization for an uninsured patient in that time, Fields et al. (2008) conservatively estimated that in 1998 U.S. hospitals lost more than \$8.35 billion dollars caring for the uninsured. As an unfunded mandate, the effect of EMTALA has been to increase the level of overcrowding in emergency departments across the U.S., leading to emergency department closures that undermine the law's intent. In sum, while intended to increase access to care, without more global improvements to the health care system, by overwhelming hospitals, the EMTALA initiative has since backfired [49].

Although U.S. hospitals now have even more reason to court patients from abroad, the ever-increasing costs of health care, as well as visa and other restrictions since 9/11 [6, 9], have forced many to seek treatment elsewhere. For example, MacReady (2007) notes that the number of patients from Arab countries who went to Bumrungrad International Hospital in Thailand, a "destination," was 5000 in 2001 and that "[b]y 2006, the number of

Arab patients at Bumrungrad had grown by nearly 20 times to 93 000" [9]. Moreover, recently Americans have started to seek care abroad as well. Still, it must be noted that rigorous research has not yet elucidated that health care costs and U.S. foreign policy are the most important – or certainly the only – explanations for changes in patterns of medical travel abroad. Again, medical tourism is not a universally understood concept.

Moving forward, although the growing inaccessibility of health care in the U.S. did not cause medical tourism to develop in Asia, it did provide hospitals in Southeast and South Asia with a ready early market of international patients. The next section describes the development of medical tourism in Thailand and follows its spread to India. Singapore, as well, developed a robust medical tourism industry during this early period, however there remains to date limited reliable data available on Singapore's industry, and thus it will not be emphasized in this account. While there are many parallels between international patient care in the U.S., Thailand, and India, the next section describes in more depth some ethical questions raised in this "third wave" of medical travel [3], in which foreign patients are courted by developing nations, and more specifically, ones with national health systems.

### The Rise of "Medical Tourism"

#### **Thailand**

In July of 1997, after a failed attempt to save the baht from speculative attacks, the Thai government decided to float its currency [50]. The baht was gravely devalued, sinking to half its former worth, compared with the U.S. dollar [51, 52], and the country entered a period of massive unemployment and under-employment that forced over a million new people into poverty. Over half of this million became extremely poor, living below 80% of the official Thai poverty line [52]. The health consequences of such a disaster are not difficult to deduce: there was a significant decrease in household health expenditures (24%) [52], patients reverted from the use of private health facilities to public sector ones [51, 52], and the poor forewent formal medical care and turned to self-medicating. Overall, the various consequences of this economic crisis in Thailand were both trying for the people and – after accepting a U.S.\$17.2 billion loan from the International Monetary Fund (IMF) – the government [52].

In the earlier 1990s, the private health sector in Thailand had expanded dramatically, and as Tangcharoensathien (2000) describes, by 1997 *Time Magazine* reported that there was a 300% surplus of private hospital beds in the country [52]. Private hospitals had also newly outfitted themselves with high-cost technologies such as MRI and CT scanners. An estimate of the debt burden of private hospitals in the year after the crisis hit amounted to U.S.\$1.3 billion [52]. Yet in the midst of the financial crisis, private hospitals were without the capacity to make returns on their construction and technological investments [2, 51-53]. Of research conducted in 1998-9, Tangcharoensathien et al. reported that "interviews of top managers of several private hospital chains revealed that approximately 40% of total pre-crisis private beds [would] be closed down by 1999..." [52]. If hospitals in Thailand were to survive financially, they needed a new strategy. So, about 15 years after U.S. hospitals began openly courting foreign patients, hospitals in Thailand began doing the same [2, 51, 53].

According to Margaret Talbot's account in the New York Times Magazine in 2001, in 1999 the Tourism Authority of Thailand directed travel agents to begin offering tour packages that included medical treatments, and they also coined the term "medical tourism." While private hospitals in Thailand were well equipped for a wide variety of medical procedures, internationally at that time, Thailand was best known for plastic surgery, and in particular, sex reassignment surgery. In a culture where "lady boys," or male-to-female transsexuals, "make up an unusually accomplished and accepted subculture," plastic surgeons were especially practiced at these procedures [2]. Even immigration officials "hardly blinked when a foreigner in a dress offered up a passport with a name like Chuck on it" [2]. The government was interested in expanding this potentially profitable industry, and so Thai Airways International, Thailand's government airline, "began offering travelers [the option to]...combine their Asian holiday with a comprehensive physical, including abdominal ultrasound, chest and barium stomach Xrays and a complete laboratory analysis of blood, urine and stool samples. They could get a written report sent to their hotel within three days" [2]. Talbot also suggests that the promotion of medical tourism was a beneficial strategy for Thailand to remake popular associations of the country - held since the Vietnam War - as a destination for sex tourism. In fact, in her article she quotes from an interview with the business director of Bumrungrad International Hospital in Bangkok: "[w]e do sex changes, but we are not going to speak about that. We don't want to be known for doing sex change operations. Sex tourism, sex change, nothing like that" [2].

Bumrungrad International Hospital in Bangkok most successfully embraced the concept of medical tourism [51]. Synthesizing Talbot's description, Turner (2010) neatly summarizes Bumrungrad's retooling strategy in three parts [51]. In the first, he explains how the hospital's executives (directed by Curtis Schroeder, an American [2]) exploited the low cost of labor and property in Thailand to be able to offer procedures at lower prices than those in nearby Singapore. Second, the physical hospital was made over in the style of a luxury hotel, including private executive suites, wireless Internet, catering from upscalestyle chefs in the city, and Au Bon Pain and Starbucks in the hospital itself [51]. Talbot further describes "250-thread-count cotton sheets and complimentary toiletries in baskets woven by Thai hill tribes" [2]. Third, the hospital put in place a customer satisfaction business model that gave patients agency in their treatment plans. For example, "[i]f a patient wanted surgery and hormone therapy to change from being male to female. Bumrungrad physicians did not introduce obstacles by making a psychiatric evaluation part of the process" [51]. (In the U.S., transgender patients must obtain referrals from at least one mental health professional documenting "persistent gender dysphoria," and in the case of some surgeries, must show "12 continuous months of living in a gender role that is congruent with their gender identity" [54].) Talbot quotes a woman who underwent sex reassignment surgery at Bumrungrad and rather "passed the [hospital's] 'real life' test of living as a woman for six months... As [the patient] put it, 'I don't want to pay some psychiatrist money I don't have to tell me something I already know'" [2].

In 2000, Bumrungrad International Hospital reportedly treated 165,000 foreign patients [2]. More recent estimates indicate that in 2007, the number of foreign patients was more than 1.4 million, of which about 420,000 were actually "medical tourists" (i.e. not expatriates living in Thailand or foreigners who become sick while on vacations there) [1]. In light of these numbers, a broadening of Turner's conclusion about Bumrungrad provides

a simple, helpful framework for thinking about medical tourism throughout the remainder of this analysis: given enough of the right incentives, patients in need of health care services beyond those available in their home countries will travel far to get them [51].

Despite the promotional tone with which much of the aforementioned literature is written, medical tourism in Thailand does not simply provide all parties with unqualified benefit. In 2011, NaRanong and NaRanong published an assessment of the economic impact of medical tourism on Thailand thus far. Their study was undertaken in three parts. In the first, using data from the Thailand Ministry of Commerce, they estimated the revenue and domestic value added to the country from medical tourism between 2008 and 2012. In the second, they collected data on the outpatient clinical encounters of 4,755 patients – Thai and foreign – in two private hospitals, in order to gauge the impact of medical tourism on the demand for physicians. Finally, in the third part, they used price data from several hospitals between 2003 and 2008 to gauge how trends in the prices of private health care services for Thai patients are being impacted by those promoting medical tourism [1]. Their analysis raises several important ethical issues.

First, NaRanong and NaRanong's estimates reveal that in 2008, Thailand earned approximately between U.S.\$1.93-2.17 billion dollars in revenue from medical tourism, of which U.S.\$1.23-1.39 billion, or 0.4% of GDP, was value added. They estimate that by 2012, the value added from medical tourism could reach as high as U.S.\$3.67 billion [1]. For Thailand, this can be considered a positive effect. However, in each of the two private hospitals chosen for the second part of their study, they noted that physicians spent on average longer with foreign patients than with local ones - 33.4 minutes compared with 32 minutes in one hospital, and 29.8 minutes compared with 25.3 minutes in the second hospital. Despite small absolute differences in time, both of these differences were statistically significant. Further, using these estimates, NaRanong and NaRanong conclude that "a full-time physician would be able to see only 14 to 16 foreign patients per day," which is significantly lower than the estimated 100 patients per day that general practitioners in Thailand's "gold card" national health care scheme may be expected to see, given mandated minimum physician-to-population staffing ratios. NaRanong and NaRanong's estimates additionally imply that, due to the demand for physicians among foreigners, "the actual demand for physicians [in Thailand] may be three times as high" as was previously thought [1]. Finally, increasing demand without accompanying increases in supply has the effect of raising prices. In the third part of their study, these authors found that between 2006 and 2008, the average price for five pre-identified procedures increased by 10-25% per year in the majority of hospitals they studied. The authors note that "[a]lthough data on prices alone are not sufficient to test the hypothesis that the recent rapid increase in the price of health-care services stems from the expansion of medical tourism, they are consistent with predictions based on economic theory" [1].

Overall, the findings from this study raise concerns that medical tourism is adversely affecting the health care system in Thailand, and particularly that it is decreasing access to health care services for local Thais. For the middle class in Thailand, price increases have made it "more difficult...to continue to seek treatment in high-end hospitals, on which they used to rely on a regular basis" [1]. The expansion of medical tourism has also exacerbated internal brain drain, in which "many highly skilled physicians and specialists...[have left] public and teaching hospitals" [1]. The authors predict that this will lower the quality of and/or access to health care in the public sector, which already faces

gross geographic disparities of this nature. In 2008, to combat the increased disparity that medical tourism had caused, the Ministry of Public Health nearly doubled physician salaries in community hospitals, and in 2009, did the same in provincial and regional hospitals. Hospitals were forced "to finance their pay hikes with their own savings" at first, until the government could allocate appropriate funds to contribute. Altogether, perhaps the most troubling aspect of these changes in Thailand is that medical education in the country is "heavily subsidized by Thai taxpayers" [1]. In essence, then, not only are Thai patients becoming out-priced by medical tourism, they are necessarily contributing to its success.

#### India

Reports of medical tourism from Bumrungrad International Hospital piqued the interest of government officials and private hospital administrators in India [51]. They were not in a situation of financial desperation, but in medical tourism, they foresaw a lucrative opportunity. In 2002, after undertaking a study to assess the potential of a medical tourism industry there, the Confederation of Indian Industry (CII), with McKinsey & Company, reported that the industry held great potential. This potential inspired a national initiative to make India a "global health destination" [55].

To foster this aim, the Government of India began offering 'M' (medical) visas to foreigners seeking medical treatments [55], as well as to their companions, and a number of hospital groups – including Apollo, Fortis, Max Healthcare, and Wockhardt – took charge of providing services to international patients [51]. Today, while hospital and regional specialties exist, on the whole, India is considered to provide the best value for medical services [56]. Prices for common procedures in India are often drastically cheaper than they are in the U.S. [6, 57], and they apply to a wide variety of medical specialties. According to CII estimates, 150,000 medical tourists sought medical care in India in 2005 [55], and an estimated 500,000 did so in 2007 [9]. In the spring and summer of 2011, India created more than 1,000 new jobs related to medical tourism [58]. This trend is expected to increase at a rapid rate, fueling an industry that is projected to earn U.S.\$2.2 billion by 2012 [9].

While the origin story of medical tourism in India is not as dramatic as that of Thailand, the subsequent development of India's industry might be considered more so. As with other developing countries, academic literature has repeatedly questioned the safety of India as a medical tourist destination, especially considering its high rate of infectious diseases and unsafe water supply (e.g. [57, 59]). In a telling example, the naming of and associated blame that came with the bacteria New Delhi metallo-β-lactamase 1 (NDM-1), the "superbug" first identified in a Swedish patient who had been hospitalized in India [60-62], made India and its medical tourism industry defensive [63, 64]. An article in *The Atlantic* recapitulated *The Times of India* on how "India's National Centre for Disease Control spent 'days openly denying' the public health relevance of NDM-1... [Further,] *The Indian Express* wrote that NDM-1 was a 'conspiracy to hurt Indian medical tourism'" [65]. Social inequalities and political problems in India have further led academics to question the ethics of practices such as organ trafficking and surrogate pregnancies in India (e.g. [67]).

Simultaneously, popular literature has entertained a variety of small dramas over India's medical tourism industry. These include a 2011 article in *The Christian Science Monitor* questioning Sonia Gandhi's travel abroad for medical treatment, "when India is itself a global medical destination" [68]; a 2011 uproar over Obama's statement that his "preference would be that [U.S. residents] don't have to travel to Mexico or India to get cheap health care. I'd like [them] to be able to get it right here in the United States of America that's high quality" [69]. Perhaps more significant, a *Times of India* report in March of 2012 described a group of about 40 police officers who descended upon Chennai's main Apollo Hospital to check the validity of their foreign patients' visas [70]. Without evaluating the seriousness of each of these stories, the media attention given to medical tourism in India clearly suggests the country's incredible potential in this industry. Bookman and Bookman (2007) describe how, forseeing this potential, the manager of marketing for Bombay Hospital predicted that in the 2000s, medical tourism would outdo the economic effects of India's 1990s "IT boom" by 10 to 20 times [66].

As in Thailand, these potential earnings for India raise complex economic development questions. Ideally, as medical tourism has impacted Cleveland, Ohio [43] and Thailand [1], the economic benefit of foreign patients will not be limited to private hospitals, but will positively impact the communities around them as well. In this way, medical tourism may hold promise as a tool for broad economic development in India. A particularly optimistic view is that earnings from medical tourism could be put directly toward improvements in the public health sector, which is in poor shape: a recent *Lancet* series (2011) highlighted severe shortages, particularly in financing [71] and human resources [72]. Further characterizing the Indian public health care system in an analysis that weighed the possibility of the Government of India more fully supporting the private sector as a provider of health care throughout India, a senior Government official wrote in a report:

The failure of [the] public health delivery system has been attributed to various factors such as being chronically under-resourced, under-staffed (Mullan, 2006), poorly managed, ridden with rampant absenteeism, low quality of service, overly centralized and inflexible planning and poor logistics in supply of medicine and drugs (Peters et al., 2002). Even worse, the salaried service providers have little incentives to be responsive to their clients with almost no means/instruments to enforce accountability. With roughly 80% of the overall budget being tied up in salaries of the staff and no corresponding emphasis on monitoring the quality of service provided, it has become more of a "public employment program" rather than a health delivery program to meet patients' needs and demand (Hsiao, 2001). [73]

At this point, there are no direct mechanisms established for linking the earnings from medical tourism with health or any other needs of the general population in India, or moreover, significant regulations on the private sector in general [74]. Hazarika (2010) notes that "there has been considerable resistance from various constituents of the private health care sector to accept in principle the applicability of certain regulations to their profession" [74]. Despite this, there are a few examples of private hospitals in India employing price discrimination to increase access to services for lower income individuals.

Richman et al. (2008) highlight Fortis Hospitals around New Delhi and Care Hospitals in Hyderabad as targeting different sections of the middle class in order to cross-subsidize care for lower income patients. They note that because the quality of care at these hospitals is high in all cases, "the differences in pricing strategies play out largely in areas not directly related to clinical care" (e.g. perhaps, the type of room a patient chooses to stay in). Further, "[t]he sliding-scale pricing is important because it attracts large numbers of limited-income patients, maintains a large volume of consumers, and supports the routines that continually seek to improve quality and efficiency" [75]. While Richman et al. intended their article to serve as a model that could increase access to services in the U.S. [75], it could also serve well as a model for the rest of India. One concern about medical tourism is that by concentrating wealth in the private sector, it will exacerbate the incredible inequalities that currently plague India [74, 76].

Authors from India have expressed similar concerns. As in the way that Thai citizens subsidize medical education for doctors who serve foreign patients [1], Hazarika warns that over 75% of the Indian health care workforce – after having undergone subsidized training in the public sector, primarily – is employed in the private sector, demonstrating that India is also suffering from a similar internal brain drain that could worsen. Based on a 2008 report from India's Government Planning Commission, the country's public health care system is currently "short of a phenomenal 600 000 doctors, 1 million nurses and 200 000 dental surgeons" [74]. While the cause of these shortages is likely multifactorial. including not only internal brain drain, but also factors such as international migration of physicians (external brain drain) and population growth, proponents of medical tourism rather suggest that it could stem the tide of Indian physicians leaving to work overseas [76]. It remains unclear whether slowing of external brain drain will reduce the private-public disparities in India or exacerbate them. Further, Hazarika cautions that the importance medical tourism may come to play in the Indian economy could lead private hospitals to "demand greater subsidies from the government," such as for "land [or] reduced import duties for medical equipment" [74]. Again similar to Thailand, this may create a situation in which taxpayer money is used to fuel health care for a private, international market, rather than to contribute to India's own social and health needs. Finally, since medical tourism caters to patients often requiring highly advanced, high-cost specialty care, it is likely to drive up the cost of health care services and, here too, place these services out of reach for much of the local population [74]. This would be particularly problematic for India, because its public health care services are already widely considered inadequate.

While these points are troubling in and of themselves, this discussion on economic development would be incomplete without complicating the picture with who the international patients in India actually are. Although India's early medical tourism industry began – as Thailand's did – by focusing patient recruitment efforts on the UK and the U.S., patients from these countries now comprise a relatively small segment of India's international patient population [82]. The reasons for this are undoubtedly various and may include, for example, the fact that the NHS only reimburses citizens who seek medical care within a three-hour flight of the UK. This policy emphasizes overseas options in other developed countries over India [77]. The 2010 Patient Protection and Affordable Care Act (PPACA) in the U.S. is also thought to have an impact on the number of U.S. patients seeking care, although the effects of this legislation on outbound medical tourism are controversial [78-80]. These Western patients not only make up a small percentage of India's

international patients registry, but research has documented that those who do seek care in India often wrestle with ethical issues of globalization and development during their stays [81].

Instead, India is now attracting patients mainly from its surrounding countries (i.e. those of the South Asian Association for Regional Cooperation, SAARC), Eastern Europe, the Middle East, and Africa [82-84]. In contrast to those from the UK or U.S., it has been suggested that these patients "often do not have home based alternatives [for health care], accept a more basic standard of customer care, and are more price driven" [82]. Again compared with U.S. and European patients, who often come for elective procedures, these patients tend to seek care for more serious medical conditions, for which treatment is the primary goal and tourism is relatively unimportant [82]. Large hospital groups such as Apollo, which claims the most international patients, as well as Max Healthcare and Fortis, have estimated that business from these patients is growing 30-40% per year [82].

Although numerous literature searches have revealed no empirical work specifically addressing the care of African patients in India, African patients are a particularly important market for Indian private hospitals [82, 107]. It has been suggested that over 20,000 African patients [85] – from various socioeconomic classes [107] – travel to India each year for medical care [85], and through its private hospitals, India has recently pursued massive expansion into the African continent. The BBC reported in 2011 that Primus Hospital in New Delhi opened a super-specialty hospital in Abuja, Nigeria [85], and Dr. Agarwal's Eye Hospital from India has partnered with the Thelish Eye Center in Kaduna, Nigeria [86]. Approximately one month after South Sudan became a nation, officials from Apollo Hospitals were in-country to meet the new government and become an official, overseas health provider [107]. In 2011, Apollo also signed an agreement with the Tanzanian Ministry of Health to jointly establish, via a public-private partnership, a hospital in Dar Es Salaam [87].

While the implications of medical tourism in India have been suggested, the rapid expansion of this "South-South" trade is a vastly understudied phenomenon whose consequences on African countries and African patients deserve further exploration. As wealthy patients from developing countries have been traveling to the U.S. for decades, so now are these same types of patients traveling to India. However, contrary to popular belief, perhaps, the care of many African patients in India is subsidized by African governments, some of which have formal relationships as payers to Indian hospitals [107]. Thus, the diversity of African patients in India may be more vast than typically thought, and several African countries are making significant investments in the Indian health care industry. It is not uncommon for countries providing public health care to buy goods and services from the private sector. Preker, Harding, and Travis (2000) suggest a matrix tool to help countries make rational decisions about which goods and services are best provided by the public sector, and which inputs are rather best bought [88]. Typically, however, private health care goods and services bought are acquired from private providers in one's own country. The acquisition of private health care services by African countries from India is a new phenomenon whose impacts on African patients and their health care systems have yet to be explored.

## Nature of the problem

Medical tourism is a rapidly growing phenomenon that now occurs in about 50 countries around the globe [1]. Although the term only came into existence when Thailand began courting international patients to its private hospitals in the late 1990s [2], U.S. hospitals had begun courting international patients more than a decade earlier [43]. While patients have been traveling for centuries in search of better medical care [3], the root of this recent and rapid expansion in international health service provision is in private business – specifically, private hospitals in the U.S. and Thailand that needed to expand their patient base in order to remain in good financial standing [43, 51-53]. While the U.S. can offer the most advanced health care in the world, since Thailand's hospitals demonstrated that enough of the right incentives can attract patients from the West, the medical tourism industry seems to have exploded worldwide [51].

The motivations of medical tourists have not yet been well elucidated by empirical research. Yet, what research does exist has prompted many authors to suggest that the term "medical tourist" does not quite apply to these patient travelers. Instead in the literature medical tourists have been referred to with terms such as "medical refugees" [89-91], "exiles" [92-94], and medical tourism has also been called "medical outsourcing" [95]. As with the measurement challenges discussed earlier in this paper, these alternatives suggest that medical tourism remains a poorly understood phenomenon. In fact, a 2011 review of medical tourism literature identified merely 103 papers on the topic:

The articles are characterized by a dearth of data, and discussions are mainly based on speculation rather than on substantive evidence. Only eight papers contained empirical data... However, 40 papers quoted figures on the volume/value of medical travel, although they did not conduct any primary research themselves. The references for the figures used in these papers were traced, and it was found that most were basing their statistics on interviews carried out by newspapers. [96]

Additionally, confusion over the definition of a "medical tourist" may reflect the fact that the rapid development of this global industry presents a moving target: academic research is not keeping pace.

In particular, what research does currently exist has focused on Western medical travelers and has relatively ignored patients from developing countries. The fact that India is considered to provide the best value for services [56], however, and that patients from developing countries make up the majority of India's international patient population [82, 84], suggests that current research is missing an extremely important part of the overall picture. As African patients represent a fast-growing segment of India's international patient population [82, 107], the case study presented subsequently focuses on them. Whether the provision of medical services to Africans in India represents a "game-changing innovation or passing fad" [5] is one of the research objectives to be addressed. Yet, what is clear up until now is that Underwood and Makadon's question is unanswerable without an exploration of non-American medical tourists.

#### Research aims

Given the dearth of empirical research that currently exists on medical tourism, and the magnitude of the suggestion that more than 20,000 African patients travel to India each year [85], this study aims to (1) characterize the demographic group of African patients seeking care in India; (2) understand how and why they make the decision to go abroad for medical treatment, and how and why they choose India as an overseas provider; (3) understand their hospital experience in India; (4) contextualize their experience within the concept of "medical tourism"; and (5) elicit their opinions about outbound medical travel from their countries and inbound medical travel to India. With a focus on African patients, this paper reflects a subset of data collected among various stakeholders in the process of medical travel from Africa to India, including medical and international patient service staff at these hospitals.

#### **Data and Methods**

*Field site and sample population* 

This study took place at two private hospitals in a South Indian city, over a four and a half week period in the winter of 2011-12. Both hospitals were part of the same hospital group and were administratively linked. Although the majority of patients at these hospitals are Indian, the hospitals serve over 14,000 international patients every year, and approximately a third of these international patients are African.

Twenty African hospital inpatients and/or their companion(s) participated in this study. While the focus was on patients, pilot work suggested that the patient experience – particularly at these hospitals – is inextricably linked to a companion. Hospital policy requires that patients have an "attendant," and all of the participants in this study were accompanied in India by at least one person from home.

Participants were selected as a stratified random sample by country of origin from lists of international patients that are maintained by the hospitals' respective international patient offices. To determine the strata, as well as each's size, aggregate data maintained by the international patient offices was used to generate a list of all of the African countries from which patients had come in the previous three months (September to November, 2011), as well as the number of patients who had come from each country in that time frame. The lists from both hospitals were merged, such that one list was ultimately used to determine sampling strata, and the number of African patients from each country was then calculated as a percentage of the total number of African patients to these hospitals in the previous three months. A sample of size of 20 was predetermined as a reasonable target that could satisfy the above research objectives, and the percentages calculated above were then applied to this sample size. Daily during the study period, then, African hospital inpatients were culled from daily lists of international patients in both hospitals, stratified by country of origin, and randomly sorted using the random sort function in Excel (RAND). Patients (and their companions) were then approached for eligibility and willingness to participate in the order of the randomly sorted stratum lists, up to the number required to fulfill each stratum's proportion.

Eligible participants were aged 18 or older and English-speaking. Potential participants were excluded if a medical condition or severe jet lag interfered with their ability to give informed consent. Participants were interviewed at a time during which they were free from obligations and procedures related to medical care, and also while self-reporting to feel alert and comfortable.

This study was approved by the UC Berkeley Committee for Protection of Human Subjects (CPHS protocol #2011-09-3573), as well as the assistant director of the joint international patient department serving these two hospitals, reflecting the extent of necessary and available approval for this type of research there.

### Questionnaires

Immediately before an interview, all participants were asked to complete a two-page questionnaire that elicited discreet information related to the research aims above. The questionnaires were piloted before use, at which time minor modifications were made. The final questionnaires included questions about demographic characteristics, previous travel to India, previous travel for medical care, pre-travel medical treatment at home, logistic information, and opinions about the quality of the hospital facilities, services, and care. Finally, participants were asked if they had heard of the term "medical tourism" and, if so, whether or not they would describe themselves using that term. Questionnaires for patients and companions were very similar, though not identical, and are included in the appendix of this report.

#### Interviews

In-depth, semi-structured interviews with all participants were based on an interview guide that was also piloted before use. Consistent with a grounded theory methodology, minimal modifications were made to the guide during the period of data collection as well, based on responses generated during earlier interviews.

Interviews lasted from 21 to 72 minutes, averaging 42 minutes. All were carried out in patients' hospital rooms, with some exceptions to ensure greater privacy and/or to accommodate participants' requests (e.g. guest room near to the hospital, where a patient was temporarily staying between periods of inpatient care). Interviews were audio-recorded in all but one case, and immediately following each interview, the interviewer recorded detailed notes about the interaction and the major themes that emerged.

#### Data analysis

Data from questionnaires were analyzed using descriptive statistics (i.e. counts and measures of central tendency) in Excel. Nineteen interviews were transcribed from the respective audio recordings, and for the one interview that was not recorded, notes written immediately after the interview took the place of a transcript in subsequent analyses. All transcripts were coded in HyperRESEARCH. The extract regarding patients' decision to travel abroad for medical care was analyzed using grounded theory [97], while the others were subjected to thematic analysis [98]. All results, and the relationships that emerged

between them, were subjected to re-verification with original data before they were considered final.

## **Participants**

In total, eight interviews took place with participants from Nigeria, six with participants from Tanzania, two with participants from each of Kenya and Mauritius, and one with participants from each from South Sudan and Uganda. Among all those who were approached for participation, in no case were both a patient and his or her companion(s) either found to be ineligible or did they decline. However, among the interviews analyzed, six patients and four companions participated independently, rather than in a dyad. One interview with a patient was excluded from analysis after the interview revealed that, although living in Nigeria, the participant was a citizen of the European Union and identified as such. Again, the total number of interviews entered into analysis was 20.

Among these patients whose experiences were studied through interview and questionnaire, twelve were male and eight female (overall mean age = 41.4 years). The medical conditions from which patients suffered were not specifically elicited in this study, however participants who volunteered medical information reported musculoskeletal problems requiring surgery, a facial trauma possibly requiring surgery, neurosurgical problems, prostate problems, suspected obstructive cholestasis (gallstone), and – most commonly (six patients) – cancer. One patient sought renal transplant (her donor was a family member), and one a general medical check-up. Patients' primary doctors in these hospitals were medical and surgical specialists in 17 of 20 cases, and general medicine practitioners in two cases. One patient's supervising doctor was not yet assigned at the time of interview.

Ten patients (exactly half) similarly volunteered their occupation during the interview: one ran a non-governmental organization (NGO), one was a taxi driver, one was a government lawyer, two held administrative positions in a government office, two were politicians, and three were students (including one medical student).

Although all patients in this sample were accompanied by someone from home, only 14 companions participated in an interview and questionnaire (four, independently). Seven companions were spouses of a patient, one a parent, and six were another type of family member (e.g. sibling, cousin). Three patients were accompanied by a friend. In addition to the medical student noted above, three companions identified themselves as medical professionals (two nurses, one family physician) in their respective countries.

## **Quantitative Results**

Seventeen patients and 14 companions completed a questionnaire (total n = 31).

Pre-travel experience

Sixteen patients reported on their medical care prior to arriving in India. All but one had previously sought care at home, and each of these patients had a doctor in his/her home country who knew that s/he was receiving care in India. As was revealed in an interview, the one patient who had not sought care before going to India traveled simply

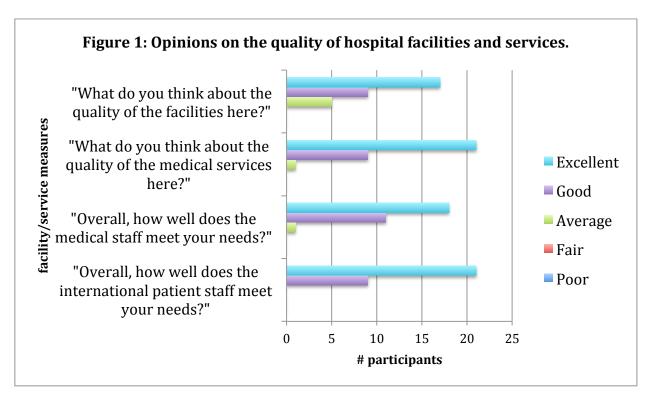
for a general check-up. Of the 26 participants who reported it, 23 traveled on medical or medical attendant visas, and three on tourist visas.

For 21 participants, this hospital trip was their first time in India. Ten had been to India previously. Of these ten, four were patients who had previously received care at one of these hospitals, and four were their companions. During the interview, a fifth companion revealed having previously undertaken academic studies in India, and the sixth did not specify. Further, of the 15 patients who reported it, a total of seven had previously received medical care abroad: again, four of these had been treated in India (three exclusively) and other destinations included South Africa, Saudi Arabia, and the United States. Five companions also reported having traveled abroad for medical care previously, and all five of these individuals had earlier accompanied the same patients they were accompanying during this study (again, four previously to India). It is unknown if these companions, themselves, were also patients abroad at some time.

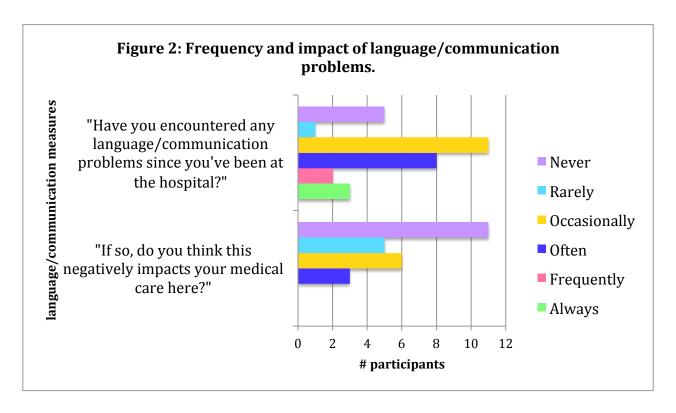
#### Hospital experience

While receiving medical treatment, all but one companion intended to stay in India for the entire duration of his/her patient's stay, and all of these stayed in the hospital on a cot provided next to the patient's bed.

All participants were asked to indicate on a Likert scale ranging from "poor" to "excellent," their opinions of the quality of the facilities and medical services in the hospital, as well as the degree to which medical and international patient staff met their needs. In each of these areas, all participant responses were either "average," "good," or "excellent," and no ratings were "fair" or "poor." The highest concentration of responses was on the upper end of the scale (see Fig. 1 – data not shown).

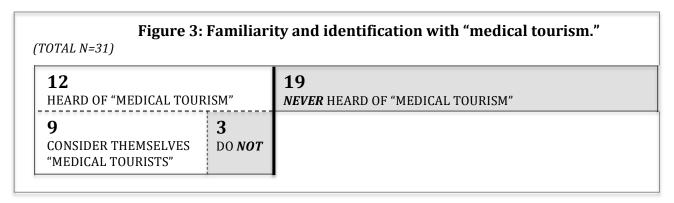


An additional Likert scale ranging from "never" to "always" asked participants to identify the frequency with which they encountered language or communication problems in the hospital, and additionally, the frequency with which they felt those problems negatively impacted the patient's medical care. A slightly higher concentration of responses to the first question fell in the bottom half of the scale, such that 16 participants reported language or communication problems "never," "rarely," or "occasionally," while 13 reported them occurring "often," "frequently," or "always." On the negative impact that communication challenges may have on medical care, 11 participants reported that "never" happening, while an additional 11 reported it happening either "rarely" or "occasionally." The highest score chosen for this question was "often," and was chosen by three participants (see Fig. 2 – data not shown).



"Medical tourism"

Twelve participants (five patients, seven companions) had previously heard of the term "medical tourism," while 19 had not. The questionnaire asked participants who were familiar with the term to additionally state if they considered themselves or the patients they accompanied "medical tourists," and nine participants (four patients, five companions) stated that they did (three did not). (See Fig. 3 – data not shown.)



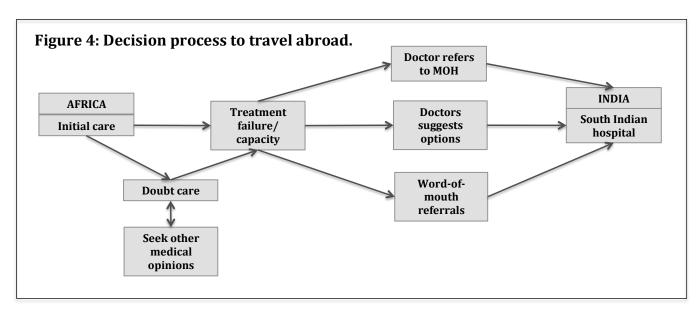
Eighteen participants reported having previously gone sightseeing or having future plans to sightsee during their stay, while thirteen did not. Of the 18 who did, 11 were patients and seven were companions. Six patients and seven companions reported no intentions of sightseeing.

## **Qualitative Results**

Sixteen patients and 16 companions completed an interview (total n = 32).

#### Deciding to travel abroad

For all the patients included in this sample, the decision process to go abroad for medical treatment began at the point in which medical care in their own country failed them. Participants were asked to "tell the story of how you made the decision to come to this hospital for medical care, and how the patient came to be a patient here," and their narratives described a process, first, of exhausting available or acceptable options for medical care at home, and then an options-weighing process that balanced the need for more advanced care with their ability to afford such treatment. The overall process they described is represented in the decision model below (Fig. 4).



As was elucidated by the questionnaire, all but one patient who reported on his/her care prior to India previously sought medical attention at home. Among the reasons that participants offered for why the care they needed was ultimately not available in their own country, inadequate facilities were nearly universally mentioned. In nine interviews, participants considered a lack of "equipment," "facilities," or "machines" the primary reason for a patient's treatment failure. In seven interviews, participants also suggested that doctors lacked appropriate specialty knowledge, training, or experience, and one specifically blamed the extreme shortage of qualified professionals. For three of these patients, human resources were thus considered the primary reason for treatment failure. Three participants additionally discussed unsafe or inadequate drug supply and distribution systems; two of these three considered the drug supply problem a primary reason for treatment failure at home.

Between the time that patients first presented for care and the time that they had exhausted appropriate medical options at home, most had doubts about the medical care they were receiving. Although some doubts were linked to reported mismanagement of a patient's current condition, others stemmed from the local reputation of their health care system's capacity and efficacy, and/or previously negative personal experiences. One Nigerian patient sought five medical opinions, including one in Israel, before deciding to pursue his treatment in India. Seeking multiple opinions was a common strategy, and many patients who made the decision to go to India on their own expressed, as another Nigerian patient did, "This place is more like second opinion, and final opinion, for me." Everyone in this sample considered the medical care in India an authoritative option. More broadly, once it became clear – either to participants or patients' doctors – that appropriate and/or acceptable treatment would not be found at home, no patient seriously considered the possibility of staying in his or her home country.

The choices to go to India, and specifically to these hospitals, represent additional layers of the decision process. For six patients, a doctor at home specifically recommended going to this hospital group, in all but one case through a program in which the national Ministry of Health sponsors overseas medical care there. For another three patients, a doctor who worked or had trained with this hospital group suggested it among options from which patients chose<sup>1</sup>. Thus, approximately half of patients (nine of 20) were directed toward these hospitals by a doctor.

Other participants did not have this same guidance. A Ugandan woman who was accompanying her young daughter on their sixth trip to India for leukemia treatment recounted the time, nearly three years ago, when she was told by her daughter's home doctors that her daughter would need to leave Uganda for further treatment. Her story rather elicits the feeling of an eviction:

[In the hospital in Uganda, the doctors] never had an opportunity to speak with you unless they were giving you bad news. So at the beginning, when they didn't even want to talk to us about the disease, for them to finally say

hospital.

1

<sup>&</sup>lt;sup>1</sup> The three patients whose doctors gave them options ultimately chose these hospitals after being reassured that the care provided at them was good: one patient's doctor had done training at one of the hospitals, and her husband reported that they knew "the outcome of their work had been very good." One patient's wife did word-of-mouth and internet research, and the last patient had a relative who had previously received successful treatment for the same condition at the same

you need to go somewhere... I was surrounded by like five doctors – the head of the department, and the next in charge, and the next and the next – and they were all looking at me. "So what is your decision?" I was like, "What decision?" "Will you take your child [abroad] or not?" I was like, "Where? Do you have a hospital you can recommend?"

Participants such as this woman relied on recommendations from family, friends, or other acquaintances who had had or knew of others' previous, positive experiences with these hospitals.<sup>2</sup>

Yet ultimately, the strength of the evidence on which participants based their decisions was quite weak. Reflecting extremely low expectations for the medical care they were pursuing abroad, many participants stated that they became resolved in their choice of hospitals because previous patients they had heard about had – as one Tanzanian woman with breast cancer said - "survive[d] up to now." Similarly, the same Ugandan woman described the decision period as one of intense vulnerability, recounting: "It was so overwhelming, really. You can imagine being at home with a child who you've been told has not healed and needs to go [abroad]. You are in a state of panic. There were so many plans – where are we going? How much money do we need? Was I [going] alone? Could someone else [go]? And then suddenly there's this facilitator in your face calling you 24/7..."<sup>3</sup>

Consistent with these feelings, while at the hospital a companion from Nigeria described deliberate efforts to collect information that he could distribute to people in need back home. As if to empower future patients, he said: "If people are ignorant, they are likely to be taken advantage of for their problem. They will be duped. There must be a proper channel to access health care in India."

Feelings of vulnerability were not limited to participants who chose these hospitals without guidance from a doctor, however. Adding to these feelings, for participants in all groups, were the burdensome costs of medical care abroad. Two patients articulated that treatment abroad would not have been possible without sponsorship from friends, and four other participants described both quality of medical care and cost as factors in deciding where to go, although they did not explicitly state that high costs would have prohibited treatment abroad. Costs will be explored in detail in a subsequent section, however it is believed that, in this sample, every participant's decision was based on a combined assessment of quality of care and cost, such that more advanced care was the motivation behind and priority in the decision process, and cost constituted the decision constraint. Feelings of vulnerability will also be explored more deeply in an upcoming section, as will participants' low expectations of overseas medical care, which these findings underscore.

<sup>&</sup>lt;sup>2</sup> One patient, a politician, sought the advice of the Indian ambassador to his country.

<sup>&</sup>lt;sup>3</sup> Aside from this woman's story, one other participant explicitly mentioned facilitators, and in a few other interviews, there were vague references to "third parties" who organized travel. Only two participants explicitly described being aware of the reputation of Indian hospitals before seeking care in India, and of using this reputation to influence their decision. Two participants described using the internet in their decision-making process.

### Enacting the decision

After making the decision, the task of simply waiting to go to India, ill, provoked considerable anxiety for participants in this sample. In eight interviews, participants expressed fears about the patient physically making it alive to India, or further, about making it in time to be helped. In four interviews, participants expressed fears about the severity of the patient's illness, and in two of these, fears that the patient could not be cured even in India. In the other two cases, fear was of the unknown: at home, a diagnosis had not even been reached. As one such patient said, "I was scared, because I didn't know how much [this condition] affected my body."

The length of time it took to enact a decision varied significantly between patients, often based on the severity of their condition. While the shortest intervals reported in this study were four to five days, some patients with lesser serious conditions who applied for sponsorship from their national Ministry of Health, for example, sometimes had to wait months before their case was approved and travel arrangements were made. A Tanzanian man who accompanied his elderly father to India described a sense of powerlessness while his father's file was being reviewed: "Sometimes you feel that you have to *do* something, but you have to be patient until their decisions are made."

Making arrangements on their own, other participants not only had to wait, but were tasked with the logistics themselves – i.e. communicating with the hospital in India to ensure the patient would be accepted by a doctor and expected, securing visas and airline tickets, and amassing the funds needed. Patients and companions additionally had to make arrangements to leave a job, academic studies, and/or family members (especially children), often without knowing how long they would be away. This was a hardship for many. Thus, although all of the patients in this sample were accompanied by a family member or friend, many international patients in the hospital came alone.

Cumulatively, coping through these emotional and logistic hurdles was trying for many participants. In some cases, those who had previously been abroad – especially for medical care – found their prior experiences protective against some of this stress. However, the most frequently mentioned sources of support during this time period were religious faith and continued reassurance from others who had had or who knew of previous, positive experiences at these hospitals.

In only one interview did participants describe questioning their decision to go to India. In this case, on top of emotional and logistic hurdles, this Mauritian patient endured excruciating pain during the airplane trip, significantly exacerbated during his transfer from the airplane to an ambulance in India, as well as during a bumpy ride in it from the airport to the hospital. His wife (W, below) and uncle (U) described the paramedics in charge of his transfer as "not careful," and described the Mauritian doctor who had had to accompany this acutely ill patient as "very angry" about this part of their experience. The patient and his family questioned whether they had made the right decision by attempting to travel:

U: It was such terrible, terrible pain, as if his head was going to burst in the plane.

W: When we came here, he had lost hope that he would be okay. He was very low. He was discouraged. He was crying like a kid. He said, "why did you bring me? I'll die here."

U: We were afraid we would lose him – we would lose him on the stretcher.

W: We thought we had made the wrong decision by coming here.

Fortunately, the patient survived the trip to the hospital, and felt as many participants did upon arrival – relieved.

Medical care and medical cultural differences

Satisfying immediate needs – equipment, expertise, empathy, and efficiency.

Again, the physical health needs with which patients arrived in India primarily included more advanced equipment and doctors with more specialized training. Ten participants described feeling particularly impressed by these aspects of the hospitals, one noting that, "People here are so well educated... They have like five oncologists, radio-oncologists, I-don't-know-what oncologists...in the same hospital!" The emotional needs with which patients arrived, however, were at least equally significant, and stemmed from mistrust of their own health care systems and fear about the unknown severity of the patients' conditions. Many participants arrived in India feeling great senses of urgency and anxiety. In eight interviews, participants described relief (and some excitement) at being attended to by a qualified doctor quickly after arriving. This made such an impression on a companion from Kenya, in fact, she remembers the exact minute – 3:27p.m. – that her husband was admitted to the hospital. A Nigerian patient described the same early moment, a bit star struck by her doctor: "[At the hotel], I was just allowed to put my things down, not even to change. I was taken straight to see the doctor – the surgeon, Dr. X – who is one of the top-most surgeons, orthopedic surgeons, in the world."

Beyond the need for immediate attention, another dimension of the anxiety that participants brought to India manifested as a desire for the patient's body to be thoroughly checked for any and everything that might be wrong. A companion from Tanzania explained this desire by contrasting it with medical care at home, where he described doctors providing symptomatic relief, but not necessarily determining the cause of one's health problem. Consistent with this, a Tanzanian patient with breast cancer said she trusted the doctors in India more because they checked her whole body, rather than just her left breast – she knew cancer to be a disease that can spread. Although the details of satisfying the desire to be thoroughly checked were not clearly explained by any participant, it was suggested that the authority of an attentive doctor and/or the number of diagnostic tests a patient underwent inspired further confidence in the quality of care at these hospitals.

A companion from Tanzania who accompanied a patient sent without a diagnosis described the emotional relief of receiving a diagnosis and treatment plan on the first day of her sister's hospital admission:

We arrived in the morning on the 8<sup>th</sup>, and on the 8<sup>th</sup> evening, we got to know what the problem was, how much she's affected. They started giving her medicines, and she started eating solid foods [for the first time in a month] – even before the operation itself. I don't know, maybe it's psychological. She felt cured already. But surprising, she could take solid food.

She further described the sensitivity with which her sister's doctor approached her: "The day we arrived, when Dr. X came he asked her, 'How are you?' She said, 'Fine.' And 'How is your family? How is your husband?' She started crying. She said, 'Doctor, please, help me.' That's when I [felt really justified in] the reason why we're here."

The feeling that medical staff in these hospitals were particularly caring was also more commonly and more lastingly held. In over half of interviews, participants described doctors and nurses as "more caring," "nice," "very friendly," or "restor[ing] hope." One patient described her relationship with doctors and nurses as "beautiful." While the importance of being cheerful is emphasized in nurse training at these hospitals, several participants also felt encouraged by the notion that the doctors and nurses caring for them were seemingly motivated by a genuine desire to serve patients, rather than the social status or income that may come with those professions. As one Tanzanian remarked, spelling a difference he perceived between India and his country: "Doctors in India, it's not that they are proud to be a doctor. It's a job, and you are his responsibility. And he is proud of how many patients he's attending and he is curing, but not proud that 'I am a doctor,' no. He is proud of you getting better."

Beyond the impression that doctors and nurses were particularly caring, equally common remarks had to do with the way that these professionals worked in their jobs. Participants frequently described doctors and nurses using terms such as "focused," "dedicated," "committed," "always busy," "time-conscious," and "hard-working." Many further described how attentive medical staff were, frequently coming and going from their rooms, and having clearly delineated roles within a team that made it possible to report a problem to a nurse and to be confident that it would be raised with the doctor, or for a doctor to set out a treatment plan and for a nurse to carry it out. A companion from Nigeria, himself a physician working toward a online public health degree in health system management, noted: "Here you see kind of a unity of purpose – just like a machine, in terms of their attitude to work. It is very, very good."

Many participants attributed the organization and efficiency of the hospital to strong protocols and management, attributes that they felt were missing from their medical system at home. Similarly, several also suspected that doctors and nurses in India might be paid much more generously than they are at home, in order to be so dedicated to them, and to their jobs. A retired nurse from Tanzania praised the fee-for-service payment system at these hospitals (in comparison to government-salaried doctors in Tanzania) saying:

If I were a Minister or if I were a President, I would have introduced this system, because even the doctor needs to [have a decent standard of living], and you can't just work on a small salary. Everybody who comes here is so excited [by] the way the doctors attend them. When you just arrive, the next hour the doctor is there. It's not that easy at home. Why are our doctors

[training at] this hospital briefly? Because they need extra money. I hope this will be improved.

A Kenyan patient similarly rejected a protocol in the government medical system at home that, as she described, requires patients to see a general practitioner for a referral before having access to a specialist. In comparison to her ability to see a specialist immediately in India, she felt that the system at home was "wasting time [because] it's not the right doctor."

Overall, that the attention patients received seemed prompt and appropriate, and – supporting this – that protocols seemed to be respected by hospital staff, engendered a comforting sense of equity in the hospital system: health care workers, with a higher calling to the service aspects of their profession, were paid adequately for the work they were doing, and patients were being treated in a just way. In total, participants felt that the hospitals were very responsive to patients' needs. A companion from Tanzania summed up this sentiment well, going further to say that this responsiveness inspired hope:

Every doctor here is committed to his job. He knows what he's doing. All nurses are committed to fulfill the patient's happiness. When you lose some hope, people [here] will come in and give you hope. It is better for life. Instead of being sad, you're going to be happier now. [Interviewer: The nurses and the doctors make you feel happy?] Yeah, because they care for my dad. Anything he wants, they will provide.

## Powerlessness and Patients' Rights.

While the equipment, expertise, empathy, and efficiency participants found upon arrival at the hospital was immediately reassuring, the vulnerable condition in which they arrived in India must be emphasized. Beyond first impressions, a few participants went further to speak of a re-empowering process that occurred in India by being explicitly given "patients' rights." One participant described a pamphlet about patients' rights that she received at the time her daughter was registered at the hospital, and several participants described, seemingly appreciatively, being updated daily on the patient's condition and the doctor's plan.

Two participants appreciated the transparency of the doctors, particularly when they felt that there was nothing helpful they could do for a patient. A Tanzanian woman explained this as important because, "As a human being, you're not supposed to give up." She explained that the opportunity to go to India – no matter the outcome for the patient – helps people to feel that they've done everything they could, even if nothing more can or should be done. A Kenyan companion contrasted the transparency of doctors in India with her experiences at home, where, she noted, "You feel you are being exploited."

The re-empowerment through patients' rights is perhaps best exemplified, again, by the woman from Uganda, whose daughter was being treated for leukemia. Beginning with her experience at home, she describes feeling exploited both by her own ignorance and a medical system that did not allow her the information or privacy she needed to understand what was happening to her daughter. Her early confusion evokes a feeling of deception. As unbelievable event after unbelievable event happens, it is as if someone is playing a sick trick on her:

[The doctor] asked me if I'd ever heard about leukemia, and I had read about it, and I was like, "It happens to children abroad. I've not heard of any child in Uganda with leukemia." So he says, "Your daughter has leukemia." I'm like, "Obviously this must be a joke, it can't be." Then he said, "You have to be admitted [to the hospital] tonight. Now."

So, we have an emergency wing for kids. When we [got] there, there [were] all these children in states of illness – very, very, ill children, but my daughter was just walking around. The doctor comes out and says, "Who is [daughter's name]?" I point her out and she says, "Come in." And I could see all the other moms starting to grumble, like, "This child who can walk is being given fast-track treatment?"

When [my daughter] had been there a night, a friend of mine who works in the States told me about a hospital called St. Jude. When we talked to our doctor about it, she was very dismissive, she was like, "Yeah, I know about that hospital, but there's nothing they can do there that you can't do here." That statement will never get out of my mind, because [now I realize] there's definitely a lot that they don't do.

The more patient-centered care in India did not diminish the challenges that this woman or others experienced at home, but she was particularly appreciative of the differences: "The fact that you are free to refuse, or free to discuss, I like that most."

### Medical culture shock.

Unfortunately in some cases, participants required a level of transparency and education that their doctors in this more advanced hospital may not have appreciated. In particular, two participants shared significant experiences of medical culture shock, both of which stemmed from not understanding the medical/surgical divide in specialty care. In these instances, rather than re-empowerment, misunderstandings about who was in charge of patients' care prompted fears that patients were being neglected or exploited.

One of these participants was the Tanzanian companion who earlier described her sister's miraculous ability to eat solid foods on her first day in the hospital, "even before the operation itself." On the day of the operation, however, she anxiously waited over 12 hours for her sister to come out of, what she was told, would be a six to eight-hour surgery. She was shocked when she came across her sister's physician in the hallway:

They told me it was going to be long – six to eight hours – but even if more than eight hours, it should have been over by two, ah? Then by five, six in the evening, seven – oh my God, you cannot say this is normal. And then again, I see Dr. X passing in the corridor with his phone, talking. I was like, "What?! Aren't you supposed to be in the [operating] theater with my sister?" He started laughing. He said, "No, some other people are doing the operation." I was like, "You're kidding me. You must be kidding me." Then another doctor

came from the theater. Dr. X asked him, in English, "What happened?" He said, "The operation is still going on." That was six in the evening. You know, at least if they had spoken in their local language, I wouldn't have understood. From then on, I didn't want any more explanation. I said, "Okay." Ah, I was confused.

A Nigerian patient, a nineteen year-old with cancer, transferred to one of these hospitals from a nearby Indian hospital, after misunderstanding the role of the various specialists working with him there. He had been admitted to the other hospital under the care of a medical oncologist, underwent surgery, and afterward, was deeply mistrusting of his medical oncologist, who re-assumed oversight of his care after the operation. Of the surgeon, he said:

I trusted him, but when he finished the operation, I just thought... Because back in my country, the one that does the operation is the one that knows what he sees there; he's the one that knows what is going on, he should be the one to continue with the treatment. For someone who didn't do the operation, who hasn't seen anything and doesn't know what is going on, he can't just take over me and continue what he doesn't know.

This patient's mistrust of the oncologist became even more entrenched over the fact that the physician did not check the patient's surgical incision site and that he referenced another doctor in describing his post-surgical plan for chemotherapy. These and other examples made the patient and his father feel that the doctor did not know what he was doing, and that he did not care about the patient, but was only focused on "money and chemotherapy." In contrast, at the time of interview, undergoing only chemotherapy at this new hospital, the patient rather described his oncologist as "much like a father, not like a doctor."

Medicine can be considered to have a culture unto itself. Thus for these participants, the culture shock they experienced was double-layered: the subsequent section deals with other cultural differences that impacted participants' experiences in the hospital in India.

## Other cultural differences

A few participants reported prior exposure to Indians and Indian culture, for example, through food, Bollywood movies, Indian professors at African universities, or higher education in India. However nearly all participants in this sample had very limited personal experience in India – many confined to the hospital – and thus the cultural differences they noticed are mostly extrapolated from their hospital experience.

#### Food.

Pilot interviews revealed that African patients had significant difficulty eating the hospital food, and so this topic was addressed with an interview question directly. In all but a few interviews, this question revealed many strong opinions, almost all of which were negative. While two participants acknowledged it unrealistic to expect either high quality

from institutional cooking or African food from a hospital in India, patients reported difficulties eating that ranged from becoming ill or being otherwise unable to tolerate the food, to "managing it," despite lamenting the lack of variety, perceived low quality, and intensity of spices. Several participants suggested the food as their greatest challenge during their hospital stay.

The challenges participants faced over food engendered and/or exacerbated significant feelings of homesickness in the hospital. A few patients outright refused to eat Indian hospital food, and in six interviews, participants reported cooking for themselves, either with ingredients they brought from home or with ones they had purchased in India. Cooking facilities were only available in some nearby guesthouses, however, so cooking was only an option during times of outpatient treatment, or if a companion was staying outside the hospital. Some inpatients found acceptable, alternative foods in nearby establishments. Yet, several participants noted that no matter their strategy, they were never quite able to replicate food from home. One patient lamented: "The rice they eat here is different from ours in Nigeria...a different kind of rice. Plantain – a different kind of plantain. [Interviewer: They have bananas here.] Banana, eh heh. Always their food is different." A Kenyan patient (P, below) and her companion (C) ironically noted the same:

C: We Kenyans, we are from British colony. So we eat British food. For breakfast, you have to have toast and milk and-

P: Milk, cereals, jam – all that!

C: But here you find the food is plates of potatoes, blah blah blah... The breakfast!

In two interviews, patients spoke of how the food they received at the hospital had a negative impact on their medical conditions. One patient with diabetes described that due to limited variety in the hospital diet, she felt compelled to deviate from her diabetic diet and "break the rules sometimes." A second patient, who was on dialysis for kidney failure, spoke with an extremely frustrated tone about how she felt the hospital food had compromised her health: "When I came, my hemoglobin was ten point – almost eleven. Since I've come here, it has gone to eight because of the food. In Kenya, we eat a lot of greens. But here, they don't have any greens. To them, cucumber is a green. And every day it is the same food that they serve."

The incredible dissatisfaction participants reported with Indian food, and the extent of their efforts to find alternatives, existed despite the fact that the hospital provided them with menus from which they could make selections. While the majority of menu options were Indian foods, menus also included a limited number of continental, Omani, and Tanzanian dishes. While some patients seemingly disliked hospital food as a rule, questioning about the menus revealed that only a few participants found them useful. Others rather noted that despite having options, they were unable to understand the menus, on which phonetic English spelled out the names of unfamiliar Indian dishes. Thus, a language barrier (to be further discussed, subsequently) compounded this cultural difference.

# Race and religion.

After food, no other noted cultural differences seemed as impactful on participants' experiences, however racial and religious differences – discussed by three participants each – posed significant curiosities and challenges. On racial differences, two participants described being the subjects of wide-eyed staring, "like they have never seen a black person." Although one participant seemed to feel the staring quite rude, particularly in comparison to a more discreet method of brief, intermittent glancing that she described from home, she attributed this behavior to Indians being curious about her – and although they could not speak English, she thought they were friendly. Another woman felt more intimidated by the attention, as well as perplexed, particularly after she unexpectedly found that South Indians also had very dark-colored skin:

When you're exposed to Indians back at home, the dark ones, they're just a few. Most of them are much lighter. Their staring and whistling is what scared me a little bit. You turn and someone is looking at you, and has nudged another one to look at you, and they point like they are not scared of showing you that they are actually looking at you and you're different. I used to get up in the morning and walk outside, but I got a little bit frightened.

She was also the subject of staring in the hospital, however after some time she realized it was her shorter skirt that attracted the attention:

You realize people are looking at you, and you're like, "is it 'cause I'm black? But they are so black." Then later you realize it's the skirt – everyone is wearing trousers or a sari. It was the first time I'd ever encountered that: there are no legs showing. None whatsoever. Did you notice that? [Interviewer: Different parts of your body are allowed to show here.] Apparently you can show your midriff. When the young girls from home are showing even a little bare midriff skin – zzo, look out! But you can wear a short skirt.

In addition, religion was revealed as a source of connection, curiosity, and division among participants in this study. Although South India is, itself, very diverse, one companion from Mauritius reported feeling culturally identical to Indians, because he was also Hindu. Another patient was interested in the way Indians (Hindus) prayed with so many religious statues, in contrast to his Muslim upbringing, and also in the fact that women working in the hospital left their long hair uncovered, even though – he suspected – many of them were also Muslim. Another Muslim patient was concerned – but unable to ask successfully, due to a language barrier – about whether the food he was being served contained pork. As before, this example highlights compounded cultural differences.

### Language barriers.

Only five participants stated that they had no trouble communicating with hospital staff during their stay. The rest reported difficulties with nurses and with non-medical staff

(e.g. cleaning staff, food service staff), but never with doctors. This section focuses on communication with nurses. The language barrier that participants described ranged from an inconvenience to a possible impediment to aspects of medical care. A companion from Nigeria, herself a nurse, said of the nurses involved with her friend's care: "They are very nice. Very nice. It's just that, most of them, they can't communicate."

The most common explanation participants gave for poor communication was differences in pronunciation. Participants described having to listen very carefully to understand nurses, as well as strategies of asking for repetition, of communicating nonverbally, of writing things down, or of the nurse finding another staff member who could communicate with them more easily in English. Many participants felt that, despite these extra efforts required, in the end, successful communication could almost always be made. However, a Nigerian patient highlighted one way that miscommunications may occur: "Well, you know, when *I'm* communicating with them, I assume that they should understand, since they speak English. It is when *they* are speaking, that I find their English is a bit difficult." A Mauritian companion knowingly experienced this kind of miscommunication, despite receiving confirmation that he was understood: "You tell them one thing, they say, 'yes, yes,' and then do another thing than what you have asked."

A few participants described how nurses with lesser English proficiency would attend to patients without speaking: "The ones that cannot communicate with you, they will just come, do one or two things, and just walk away." While many participants felt confident that nurses were nevertheless proficient at their jobs, even if not in English, two companions felt more strongly that verbal communication was an important part of patient care. One said:

They kind of ignore you, the nurses – yeah, until you engage them into a conversation. I tried and said, "So what is it you've come to do? And when are you going to do it, and what are you going to use?" So that you make them slow down and talk to you. Because when they are speaking to the Indian patients, you can hear them having a conversation. So I'm thinking they are either overwhelmed by the fact that you're a foreign person, or are imagining that they will not be able to communicate.

Compounding the low English proficiency of some nurses, and although all participants in this study spoke English, some Tanzanian participants described how several people from their country come to these hospitals without speaking any English – and sometimes, neither speaking Swahili. In these cases, the burden of communication falls on other Tanzanians in the hospital who can act as interpreters. Two companions, whose family member had been receiving treatment at the hospital for the last seven months, had become particularly experienced interpreters, even being notified by the international patient staff at the hospital when a new Tanzanian patient was admitted. One of these companions paraphrased a typical plea from these new patients when she would visit them in their hospital room for the first time: "Please, please – I don't understand these people. They speak very quickly, so we don't understand what they are saying. You have to be here..." Her brother-in-law continued: "I have been a translator, yeah. I've even been signing so many documents for the patients, after translating them, [translating] advice and [details] about the operation, about the doctor's advice [and their options]..."

He went on to tell the story of a non-English speaking patient who – despite understanding the doctor's advice and the benefits and risks of a second operation he needed – was simply too homesick to want to go undergo another procedure. This patient rather wanted to leave:

It was difficult for one patient – he refused a second operation: "The first is fine; I can go like this." It was a hard time for his doctor, but the doctor said to me, "try your very best to convince him to do the operation." I convinced him, and after that, he agreed. The doctor was very happy, and he came and hugged me.

Similarly, another Tanzanian participant told the story of a different non-English speaking patient who was so anxious to leave India that he began purging himself of his belongings, as if to physically and emotional be rid of his experience there:

Last Saturday night he was even returning some [U.S.] dollars. He told [some friends], "I don't want these dollars. Keep them. I'm going home." All he wanted was to go home. His dollars would have made him money. He said, "No, no, I want to go home." You know, he's local [not from a metropolitan place]. And so we said, "Listen, should we write anything for you, in case you get stuck at the airport?" He said, "Don't think I don't know English. I know the words 'yes' and 'name.' So I will reach home." When I was coming from shopping today, we asked [another Tanzanian], "Did [man's name] reach home?" He said, "I called his family. They said he hasn't reached home."

Overall, despite the burden of the language barrier, several participants expressed feelings that hospital staff were making genuine efforts to communicate with them, especially by trying to find individuals who could speak English more clearly, or who could act as informal interpreters. The Tanzanian companion first quoted above admitted that "small gaps" in communication persisted nevertheless, but he felt that these were unavoidable and no more serious than communication gaps that might exist in any medical encounter, even when everyone involved speaks the same language in the same way.

## Costs of care

As previously elucidated, the primary reason for the patients in this group to seek care abroad was to access more advanced care, and cost was a limiting factor in choosing a hospital overseas. Accordingly, care in India can be thought of as representing the best participants could afford. A Tanzanian woman who had previously received medical care in South Africa, the U.S., and Mumbai spoke of India's reputation in providing medical care of "good value": "There is a spread [advertisement] now that the treatment in India is advanced and affordable for people from developing countries." Speaking of the Ministry of Health program that was sponsoring her husband in India, she added that her government had reached the same conclusion: "I think they look on their budget, and given the prices in India, they can afford to save many patients. You know, if they had to send one patient to the States, it would really be the whole budget."

Overall, the participants in this study were either fully sponsored by their government or a private individual, partially sponsored/subsidized, or they paid out of pocket, sometimes fundraising to do so. Participants in all three of these groups expressed that treatment in India was not easy to afford.

First, for those whose governments offered the possibility of full sponsorship, there was no guarantee of being chosen for the program. This uncertainty represented a significant source of stress for those who applied. The Tanzanian companion, whose sister's illness had prevented her from eating solid foods for a month, described their experience obtaining government sponsorship as "struggling." If her sister had not been chosen for the program, she said they would have had to pursue an individual sponsor, as the estimated cost of her sister's care – approximately \$650, plus airfare, incidentals, and possibly lodging for outpatient treatment – was more than they could afford. Similarly, a Nigerian patient with a back injury, who had sought treatment at home for over a year before coming to India, described wanting to go abroad but thinking "there was nowhere I could raise that amount of money." She had already spent a good deal on physical therapy, x-rays, and an MRI in Nigeria. When she ultimately found an individual sponsor, she described the event as "a miracle." Overall, in speaking of advice they might give to future international patients to this hospital, several participants who had been "struggling" to secure sponsorship said that doing so was extremely important.

Patients whose care abroad was subsidized (but not fully covered) had significant difficulties affording the balance of the cost. A companion of the Mauritian patient, who questioned his decision to travel to India, offered these grave unprompted thoughts:

One thing that I'm a bit surprised about is the cost of treatment in the hospital. In this private room, we are paying 5,000 Indian rupees (~\$92) per day. It's costly: if you have no money, you die. This [surgery] will cost us – you know how much? Five hundred thousand Indian rupees (~\$9200). I say again: if you have no money, you die.

For patients paying any amount out of pocket, one piece of the financial challenge arose from the unpredictability of a patient's treatment course. These hospitals can provide a pre-arrival estimate of the cost of a patient's care, based on a doctor's review of medical records. However, these estimates are subject to change – sometimes to increase – once the patient is evaluated in person. Further, currencies from the African countries from which participants came often cannot be easily converted directly to Indian rupees, thus considerable amounts of money are lost in exchange. A patient from Nigeria characterized the circumstances of those paying out-of-pocket as "sacrifice." In the same vein, some participants reported anticipatory stress about the possibility of having to pay for follow-up treatment in India as well.

Further, beyond the costs of patient care in India were the costs of companions accompanying them. These costs not only included airfare, food, and lodging (up to one companion could stay in the hospital with each patient), but lost wages at home. A Kenyan man who went to India expecting to be his wife's kidney donor (but was found to be ineligible, for medical reasons) had to leave his wife in India when the cost for her care became higher than they had anticipated: "I work on contract, and we need money. We need money." He also expressed regret that he was not able to stay to see more of India, but

he did not want to spend the money, saying "the more we stay, the more we spend." The couple planned for their son to exchange places with him in India (as a potential organ donor), and after he would afford his son's airfare, the husband hoped that he would earn enough money to be able to return to India for the operation and to accompany his wife and son home.

Despite the difficulties that participants faced affording treatment, only the Mauritian family described above expressed that the costs were unreasonably high. In fact, several others suggested it reasonable, if not obvious, that higher quality care would come at higher cost. Moreover, since participants universally felt that patients were receiving high quality care, most considered the costs justified. Still, many maintained a cost-conscious mindset in India, for example, strategizing to buy food in street markets rather than in the hospital restaurant, and opting to stay outside the hospital (as an outpatient) when the patient's condition allowed.

## "Absorb[ing] the pain to come."

All of the previously explored aspects of participants' experiences were drawn together by the essential goal of obtaining needed medical care. As was briefly described in an earlier section, however, participants seemed to embark on this experience with unspecific and low expectations of the medical care patients would receive abroad. Their goal, simply, was to preserve patients' lives and/or the quality of their lives.

While for many, a largely positive hospital experience and improved health validated the decision to travel and justified the early sacrifices made, clearly participants endured additional hardships during the hospital experience. These not only included the aforementioned language barriers and cultural differences, but sharp reflections on an ever-globalizing world and the status of their own countries in it.

Reflecting on differences between nursing care at home and in India, one Tanzanian woman, herself a retired nurse, described something lacking in the connection with nurses at this hospital and invoked a development metaphor to explain her thoughts:

I see there is a difference. I don't know whether it's this communication problem, but sometimes you miss their attention. What I was feeling is, at home we have those long-serving nurses who are sometimes even better than doctors – you know, they have this experience for a long time. So there's a personal touch, apart from the training that you have to give a drip [IV] or give an injection; there's this tender loving care. Sometimes here I say, either they are too busy or because of the communication – the language thing – sometimes I miss that.

You know, these are the modern people. They are more technical. Like the manual [car]: it's like you train yourself on the automatic car, and you cannot drive a manual car. Here they are more automatic, the dot-com people. You know, they have the technology, but I miss that touch. We don't have much of the technology [at home], or the new facilities, but at least this – that nursing care – if you find the right nurse.

You know, it could be my fault. Some places, when you go as an African, you will come with a feeling, "oh, they don't care about me because I'm black." So maybe I'm misjudging them. But okay. The most important [thing] to me is that I get the treatment.

Her reflection on India's development suggests a modernity in which elements of humanity are lost to advancement. Pitting technology against old-fashioned caring, she suggests that something basic and important is lost in development, and that the hospital exemplifies this trade-off. Just as drivers of an automatic car cannot "go backward" to drive a manual, she suggests that a new generation in India may be too technologically advanced for experienced, caring nurses to survive as an asset in the new medical system. Her analogy might even be considered foreboding for India, because, as is commonly known, those who first learn to drive a manual car are thought to later be able to drive any vehicle.

Interestingly, her feelings about her experience are in direct opposition to a motto of this hospital group (to provide "tender loving care"). Yet as she suggests, perhaps a communication or cultural barrier stands in the way of these nurses demonstrating their ability or training to care. Further, her consideration that she may be misperceiving a racial bias not only implicates race in development, but suggests that in the globalization of health care, all parties stand to learn a great deal about cultural differences.

Ultimately, despite having thoroughly considered her observations and expressing strong feelings about them, this companion concluded – as did many other participants – that these differences, even shortcomings, in the medical care she perceived in India were unimportant as long as "treatment" was delivered. She went on to advise future Tanzanian patients that the most important strategy for being in India was simply to be cooperative with the medical staff there:

If you start being fussy about the food and the... These are minor things, basically. You put things in priority. The most important thing is having treatment, and you [have to] understand that the people taking care of us are also human beings. So if you become uncooperative, you may distract them from what they're supposed to be doing, and even your treatment may not work because you are stressed.

More broadly, a companion from Kenya framed this common idea as "working toward your goal" – defining a target and constantly focusing on advancing toward it – as a strategy to deal with "minor" challenges and to keep things in perspective. She and others described this strategy with pride inasmuch as it had helped her and her family to overcome what may have otherwise seemed like insurmountable challenges. Another Kenyan patient, the one whose husband was soon to return to Kenya to work, described her coping strategy similarly: "What you usually do, you focus. Why are you here? I'm here for medical [treatment]; forget about everything [else]. That is how. You focus on living."

Again, however, the focus required to cope with this experience was not just one to withstand cultural differences, but to withstand a realization that there are, as one patient described, "degree[s] of developing countr[ies]." Several participants were surprised and uncomfortable with the dirtiness of the city streets in India (and some with the lack of cleanliness in the hospital as well), but overall, India was more developed than many

participants had imagined. As one patient from Nigeria said, "You know the way Third World countries are. I was thinking India to be like that: poor organization, bureaucracy, and the rest of it. But the experience put that away. The experience was quite different." A few participants did not even consider India a developing country.

The development differences upset several participants. Many were dismayed that so much money from their country was being spent in India, and some worried that even the loss of revenue at home would not be enough to spur improvements there. The Nigerian physician said: "I met another Nigerian yesterday who said that it didn't take them [Indians] six months to put up this structure [building]. He has been coming and going since two thousand and nine. So I said, 'they are making a lot from me.' We should be playing the medical role India is playing in Asia; we should dominate health care for the whole West African sub-region." Instead, several participants lamented the brain drain from their countries, noting that their "very good doctors," who prove themselves by working overseas, unfortunately stay overseas. The same nurse from Tanzania explained part of India's success in medicine through her impression that, in comparison, Indian doctors who train abroad rather tend to return home.

Some participants also described positive impacts that more interaction between India and African countries may have, beyond Africans obtaining medical treatment. These included the fact that African health care workers (such as the ones in this study) would be exposed to new approaches, that Africans would have opportunities to travel abroad, and through travel to India, that African students may be exposed to educational opportunities there. One patient, a politician, considered that his trip to India could also serve a diplomatic purpose.

However, enthusiasm for these positive, potential outcomes did not stand up to those that most participants expected for India – namely, continued economic development and international notoriety in the medical field. Several participants felt India to be a somewhat insular nation, noting that no foreigners seemed to be employed at the hospitals, that it was difficult to find restaurants in the city serving non-Indian food, and that newspapers reported mainly on local and domestic (not international) issues. One patient, in particular, came to understand his observations as Indian nationalism and expressed, somewhat jealously and competitively, that the commitment of Indians to their country would further enhance India's development.

These realizations make observations like that of the Tanzanian nurse even more poignant. In addition to her "automatic car" analogy, other participants were extremely frustrated in this advanced-care setting by what they perceived as little focus on some basic elements of good hospital care that, they feel, are better attended to in their home countries. Two participants gave lengthy examples of poor cleanliness, expressing frustration that nurses and other hospital staff did not recognize these problems and, in most cases, were dismissive unless the participant demanded that something be done. Another example, described in one interview, was directed at the common sense of nurses, who would reportedly leave the nursing station unattended if patients called all of them to separate rooms simultaneously.

A Nigerian patient summed up the challenges of Africans' experiences well by relaying the sentiment of previous Nigerian patients of this hospital, whom he had met at home before going to India. He said they were "just lamenting. They're feeling bad about the situation back home. Because you spend more to come here, the risk of flying is there...

It's not something palatable, but the drive to live is so much in human beings that they will absorb the pain to come."

"A class thing."

While "lamenting" the global injustices of their situations, some participants also reflected on the local injustices they observed in India. Most striking to them was the metropolitan poverty, and a few participants bemoaned the fact that the hospital services they were receiving were likely inaccessible to most Indians. As the companion from Uganda said:

It's just shocking, really shocking. You know, when you look at the kind of wealth in India and how it plays out on the street, it's really strange. Our families on the streets, I think, only come out at night. You wouldn't know we had families on the streets the way you do here, which is very upsetting when you imagine that this country has lots of money. They have a nuclear program; when we were here in June they launched a submarine. You have a Hyatt just, I-don't-know-how-many-meters from here; you have a Sheraton on the other side [of town]. So when you see such names popping up, I was imagining a New York of sorts, ah? And if you put all of those buildings together, it would be almost like New York. But they are so far apart, and then you have these pockets of real dirt... It's mind-boggling, side by side. The culture shock is in terms of knowing that India has more money than we do. You expect things to be better.

The two companions from Tanzania who had become unofficial interpreters were similarly frustrated with the situation, and also that the poor in India seemed not to be as so. They explained the cycle of poverty in India as a human rights issue:

[None of the poor in India] can change their lives because they believe they will remain poor. It's not true! You can struggle: how can you believe that you were born poor and you will never achieve? I think they use this caste thing – the higher ones and the middle one – they must force the lower classes to remain there, because they can benefit from them. I think that's a big problem they have. I don't know when they will wake up. We don't want them to change everything in their culture, but some things like this, which are going against human rights, they need to change.

Ultimately, in two interviews participants suggested, with regret, that these hospitals were too expensive for most Indians to afford. As one Nigerian patient put it:

My worry is that [this hospital is] catering to a particular target group. And if it's catering to a particular target group, it's probably the high-end target group and the middle class. So the majority of Indians will be left out of this beautiful facility, except if they have outreach to the various rural communities and make their services available to them. Then there will be

some meaningful impact on the entire nation. But I have been concerned – I have been actually saying, "Oh my God, this is a class thing." In a business, you want to make money, and if you go to the low-income people, you won't get the money to buy the equipment. So, you've got to be tough on who you want your clients to be. That's what I suspect this is all about.

This patient's concerns are not unlike some in the literature on medical tourism, and will be explored in the upcoming discussion. Finally, however, the next section deals with the way these participants understand the phenomenon of medical tourism, and the way they see themselves in it.

### "Medical tourism"

As was apparent from the questionnaire, less than half of the participants in this study had ever heard of "medical tourism," and even fewer identified with the term "medical tourist." In interviews, participants were asked what they thought these terms meant.

Of the nine participants who had previously heard of "medical tourism," and also considered themselves or the patients with whom they traveled "medical tourists," all who spoke in depth about the concept had somewhat unique definitions. These are captured in the table below. As participants' words reveal, "medical tourism" was generally considered a variation of regular tourism, thus the quotes also highlight the way participants conceive of this more general concept. A few participants emphasized the opportunity for personal growth, sometimes considering the medical experience tourism. Some rather emphasized tourism as a revenue-generating opportunity for India, while clearly expressing that their priority to was to obtain medical care.

# Definitions of "medical tourism" from participants who had heard of "medical tourism" and identified as "medical tourists."

"You come from one country to go to another country for medical treatment. It's good experience. You meet so many challenges. It makes you bright in your health. This is a medical tourist. We learn more about health care in another country, see what they doing."

"We heard the term in our country, that they're having medical tourism. I didn't know what it meant, but I thought what it meant is opening more doors. India now, to get a visa for medical things is so easy. So I think they have [made] their doors more wide [open] to let more people come to [their] hospitals. You know, each country has their own way of [promoting] tourism. With them, I think the best tourism is: let people come to [the] country for medical [care], and maybe they will be able to see other things. I think they sat down and said, "Okay. Let's open [more doors]" – as [my husband] said, [as source of foreign] revenue."

"That's a new terminology, because of globalization. There are people connect[ing] the dot. Tourism is synonymous with the Europeans. They travel to interesting places all over the world. But for those also accessing medical care in another country, then they [are] called a medical tourist. And it has serious economic implications for the recipient country."

"First [primarily] you are here [for] medical [treatment]. But you see a lot of things, and you need to go out. We've been to the beach, we compared our place and here, we found 'wow, wow, wow, wow, wow, wow, '[We] will be able to tell [people back home] 'I've been to India.' [We're] medical tourist[s]!"

"As I understand the word 'medical tourist,' it [is] someone who goes for medical attention to different countries, though it can be for many different reasons. I go to a country because I feel they have better facilities than my country, and still, next time, even if I'm convinced with their [medical care], I'll not like to go to the same country. I would like to change – I do it for medical purposes, but I combine it with tourism, because after I finish my treatment, I will later go into town and see. I'm trying to go to New Delhi or Mumbai – after I finish [treatment], we need to just see. And before [needing] [an]other visa."

Still, the priority on medical care did not necessarily prevent those participants with more stable or lesser serious conditions from taking advantage of opportunities available in India, beyond medical treatment, during their stays. The physician from Nigeria spoke enthusiastically about new glasses he purchased at a nearby optic center, with special lenses unavailable in his country. Further, "as a doctor working in a developing country, [he'd] heard much of the X Medical Center," and he considered his experience as a companion "an adventure" through which he could observe and learn from the hospital's management protocols. The nurse from Tanzania and her husband found and attended a meditation retreat outside the city during the weeks in between his cancer treatments at the hospital. Yet overall, emphasizing the lesser priority that these activities held compared to patients' medical treatment, none of them were pre-planned: the Nigerian physician's glasses had broken in the airport en route to India, and the Tanzanian couple simply took advantage of available time. As the nurse concluded, "[the] tourism is mostly medical."

Three participants who had previously heard of "medical tourism" denied that they were "medical tourists," and two of these described the term in ways most consistent with its current understanding in academic literature – specifically, that "medical tourism" combines medical treatment with a sightseeing or relaxation vacation, and is for people with elective or non-urgent medical problems.<sup>4</sup> Yet, their understandings of the term are neither very consistent, and they also express that "medical tourism" is not necessarily a benign or easy experience.

To explain her understanding of "medical tourism" a patient from Nigeria described a program called "Health Spa," a kind of reality TV show in which patients with not-so-serious conditions are flown to a beautiful place for an all-expenses-paid recovery. Interestingly, although she considers the subjects of this show "not ill," she describes their experiences on the show as designed to allay fears of death (and of course, cure them quickly):

If you know you have anger syndrome, or you [over]eat... To me, you are not ill. But there is a beautiful resort for you – [a] beautiful environment with tennis courts and music halls and dance halls, and they treat you individually on your particular ailment – it might be psychological – and then you join the others and you share, and you go on sightseeing... That's my idea of medical tourism. It's fun...making ill health fun, and getting well by the end of two weeks or three weeks of a tour – coordinating different things that make it less fearful that you're doing to *die*.

This patient did not consider her medical experience tourism, because she was engaged solely in medical care, without tourist activities simultaneously. However, she expressed interest in visiting other cities in India as a "pure touris[t]," if time after discharge from the hospital, and her medical condition, allowed.

Similarly, the woman from Uganda – who rather described her daughter as a "medical evacuee" – asserted that tourism is an activity undertaken for pleasure, and that

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<sup>&</sup>lt;sup>4</sup> The third, a companion from Nigeria, described that his brother intended to undertake what he considered "medical tourist" activities by touring hospitals, but this companion was confused about whether his brother could truly be called a medical tourist, due to the type of visa on which he traveled.

with her daughter's condition, tourism was the last thing on their minds. She hesitatingly concluded that someone traveling for plastic surgery might be considered a "medical tourist," but had a strong opinion about the inaccuracy of the term:

I really [think] who[ever] coined that one should change... Plastic surgery: you meet the city, you sightsee before, you sightsee after. So it's really pleasure, but even plastic surgery – apart from disfigurement – it's a really personal thing... So that one would be medical tourism. But in our state?

Unlike the previous patient, this woman suggested that medical care and tourism need not take place simultaneously in order to be "medical tourism," but she emphasized that tourism describes a set of activities undertaken for pleasure, and that she and her daughter were not in India for pleasure. She further described, as a companion, several barriers to being able to undertake any significant activities outside of the hospital, all of which further underscore the priority of the patient receiving medical treatment. These included the realities of being exhausted from sleepless nights with a sick patient, and the fact that having only one companion means that that person cannot "take time off." In addition, she expressed concerns about safety outside the hospital, about getting lost, and about rather wanting to go home once the patient was able to travel:

It's hard getting around. Apart from the auto drivers, someone has to give you directions of where to go. And then of course when you read all these things in the [news]paper, it also becomes an issue, like, "If I go, will I be safe, will I come back?" The least you can do is maybe go to the shops and stuff like that, which I wouldn't really call sightseeing. But you can't if you are alone. Maybe if you're two [companions], you can take time off. Another thing: at the beginning, she was on the medication like every four hours, or every six hours, so the time we were in the ICU was totally sleepless. You kind of get exhausted – very, very, very exhausted.

There were four participants who, on questionnaires, reported never having heard of "medical tourism," but in interviews nevertheless considered themselves or their patients "medical tourists." Two patients made this determination based on a guess of what "medical tourism" meant. In both cases, their definitions concretely described the fact of getting medical care abroad. These quotes are shown in the table below.

# Definitions of "medical tourism" from participants who guessed about what the term meant, and who also identified as "medical tourists."

"Medical tourism, it's like the way I came here. It's like tourism in a medical way. I came to be treated in a different country than where I am from. It's also a different experience, as I have explained. If I hadn't come here, I wouldn't know all this; it's part of tourism."

"Medical tourism is when you get medical [treatment] from outside. Isn't it? Yeah. Something like that."

Overall, those participants who identified as a "medical tourist" often described "medical tourism" as fulfilling concrete and practical goals (e.g. patients receiving medical treatment, India earning foreign revenue) that stem directly from the fact of foreigners obtaining medical care in India. From their perspective, the opportunity to be a "medical

tourist" seemed coincidental – sometimes serendipitous, sometimes simply a nominal convention. Those who did not identify with the term rather seemed to consider "medical tourism" something more extraordinary and deliberate, perhaps superficial or superfluous to medical care. In total, among all of the definitions that participants offered, was there no clear consensus on that of "medical tourism," and among the many that emerged, none that challenged the priority of medical care for these participants.

#### Discussion

Given the clear articulation of participants in this study that medical care was the singular priority for their travel to India, it can be easily concluded that the health care available to them in the African countries from which they came was not adequate in meeting their needs. In interviews, participants raised several issues that help to explain their insufficiency, for example, poor facilities and lack of equipment, brain drain, poor government oversight and management, and underpayment of health care workers. These findings are not novel, and the political, social, economic questions that underlie them are complicated and better addressed in other papers (e.g. [99]). However, the ways that these problems manifest in the patient experience in African countries directly influenced the experience and opinions of African patients about the health care they received in India.

In particular, the responsiveness participants experienced from the hospital staff was a dominant, positive feature of their medical experience. This feature was supported, they felt, by hospital protocols that helped to ensure a sense of equity, such that all patients' needs would be attended. Responsiveness to patients' expectations is a key criterion of the WHO's ranking of health care systems around the world, along with fairness in health care financing and good health outcomes. In the 2000 ranking, the highest-ranked African country from which participants came was Mauritius (ranked 84th), and the lowest was Nigeria (187th). India was 112th [26], a ranking that highlights the uniqueness of these private hospital facilities, and the relatively small reach that they have within India. Although a few participants in this study were so impressed with their hospital experience that they did not consider India a developing country (and some authors have suggested hospital environments abroad are specifically designed to suggest this, e.g. [100]), others clearly identified the inequalities they knew to be manifest in India and expressed genuine concerns that these facilities were likely inaccessible to much of the Indian population. Published authors have also raised concerns about the potential for the treatment of international patients to exacerbate health inequities in "destination" countries (e.g. [74, 100]), and similarly, these findings raise questions about the extent to which other positive aspects of participants' experiences are replicated in the public health sector in India – namely, a respect for patients' rights (see, e.g. [101]). Autonomy – along with a sense of equity – in this health care setting was an important part of overall healing for participants in this sample. Initiatives to raise the quality of care in these hospitals to "international standards," including the protection of patients' rights, will be explored further in a forthcoming analysis.

Despite the burdens that participants in this study faced affording the cost of their treatment, support for this hospital's fee-for-service system is a finding with significant implications. As has been demonstrated, perhaps most famously in the U.S., the fee-for-service payment system has been implicated in rising health care costs [102]. As earlier

discussed, increases in health care costs have been without equivalent improvements in health outcomes [18, 19] and have also significantly compromised equity in the health care system (commonly considered a reason forcing an increasing number of Americans to seek health care abroad). Yet as participants in this study suggested, in many developing countries in which government salaries for health care workers are low and slow to materialize, fee-for-service payments in the private sector make it more possible to retain health care workers. These hospitals in India are just one example. Thus, although international comparisons may seem to make it clear that a fee-for-service system is a risky strategy for ameliorating absenteeism and brain drain, they illustrate the urgent need for adequate health care services in these countries, and foreshadow the consequences that may occur if these needs are not adequately and more quickly met. In support of this idea, fairness in health care financing is another major criterion on which the WHO rests its ranking of health care systems [26].

Further, in the U.S., the fee-for-service payment system has been implicated in the provision of a significant amount of unnecessary medical care [102]. In the context of international medical travel, and in light of the findings of this study, a worthy consideration is whether – particularly given the vulnerable state in which patients travel abroad, and the cultural and linguistic barriers they face – international patients are at increased risk for overtreatment. Yet, patients are not to be exclusively considered victims in a fee-for-service system. As the results of this study show, patients' own concerns about their health – perhaps heightened due to mistreatment or under-treatment in their own health care systems – often manifest as a desire for more diagnostic testing and procedures. Moreover, it is understandable that patients coming from lesser-equipped health care systems want to take advantage of all of the resources they can while they are available to them. (This fact has been capitalized upon by international hospitals such as these, which offer multiple packages of comprehensive preventive health exams.) How Indian doctors consider the needs and expectations of these international patients, keeping in mind their abilities to afford the procedures and to find adequate continuing care for health conditions in their own countries, will be included in a forthcoming analysis.

Among the negative experiences that participants had during their hospital stays, language and cultural barriers played a significant role. There is an extensive literature in the U.S. on the importance of culturally-competent medical care for reducing health disparities, protecting patients' rights, and achieving positive health outcomes (e.g. [103]). In this study, the rather dire health situations in which patients arrived in India caused them to subjugate these factors in their experiences, however from the perspective of the hospital, cultural competence – broadly, not just of doctors and nurses – should represent a quality of care issue to be continually addressed [104]. This effort is substantiated not only by the rapidly increasing globalization of India's health care system, but also justified by an opportunity to strengthen and protect important, positive developments in the hospital again, for example, respect for patients' rights. Moreover, given the diversity of India, this issue is thought not to be unique to international patients, or even, simply, patients. Although it would have been difficult for participants in this study to perceive these differences, the likely cultural and linguistic barriers that exist among hospital staff may be important areas to address, particularly for working toward goals such as staff retention and improved quality of care.

Returning to equity, the contrast between that which participants perceived in the hospitals in India and the exclusive opportunity that they were afforded to be able to seek treatment in India is a notable paradox. These participants were, simultaneously, privileged enough to be able to travel abroad, and so underprivileged that they had to. For those who traveled with government sponsorship or subsidy, again, questions are raised about how distributive justice is preserved in some African health care systems where a significant amount of money is being spent outside the country. During their hospital stays, participants experienced this dissonance, struggling with an individual desire to survive and yet the realization that pursuance of their survival may have contributed to a broader phenomenon in which the globalization of health care services suppresses development in their countries. A recent news report conveyed concerns of Nigeria's Senate Committee on Health, for example, that the country is losing N80 billion (more than \$507 million) annually to outbound medical travel [105]. Although the practical impact of this loss of resources has not yet been assessed, as some participants discussed, the level of health care they received in India is currently unavailable to the majority of Indians as well. The perspective of these Indian hospitals and some of their doctors as actors in this international dilemma – and, it may be argued, stewards of some of these health care resources - will be included in a forthcoming analyses.

Although more advanced, private health care facilities do currently exist in some African countries, India's experience in rapidly developing its private medical industry, as well as participants' personal experiences in these hospitals, may provide helpful perspectives on African health development. Compared to India, the African countries from which participants come do represent a different "degree of developing country." Further, as the Tanzanian nurse suggested, perhaps the ability to "drive a manual car" puts Africans in a unique position to be able develop economically and technologically, without losing that "personal touch." As for the individuals who participated in this study, an important future question is the impact that the technological and medical cultural differences they experienced during their hospital stay will have on their approach to and opinions about future health care experiences at home.

Finally, as was clear from the disparate definitions elicited for "medical tourism," there is no singular understanding of the term among this sample group. Although a clear definition neither exists in the literature, a clear finding in this study is the fact that participants were traveling for serious medical needs, and that obtaining treatment was the sole priority of their travel. Any "tourist" activities in which participants engaged were spontaneously and carefully planned around medical treatment, if they were pursued at all.

The motivations of these participants were not necessarily significantly different from those suggested of other "medical tourists" in the literature – namely, those traveling for health care at lower costs than is available at home, with shorter wait times than are available at home, or for procedures unavailable at home – although individuals who participated in the few empirical studies that exist on medical tourism (e.g. [81]) did not necessarily have an opportunity to accept or reject the term. Instead, much of the literature on this topic, which is speculative in nature, assigns them this label. Again, the term "medical tourism" traces back to the 1997 Thai financial crisis and the directive of the Tourism Authority of Thailand in 1999 for travel agents to include medical treatments in tour packages as a way to save a private hospital system that was rapidly devaluing [2, 51]. At that time – and as these data show, through to today – the success of "medical tourism"

rested on the novel concept that the *choice* to obtain, or where to obtain, medical care could be influenced by incentives [51]. Incentives did not play a significant role for the participants in this study, however, because in the life-threatening or quality-of-life-threatening situations in which many found themselves, they did not have a choice but to travel abroad. As was stated earlier in this paper, medical care at these hospitals in India was simply the best they could afford.

More broadly though, that the net flow of global patient traffic is shifting from developed to developing countries is a novel phenomenon. While this shift opens the possibility that patients from equipped and accessible health care systems may be incentivized to go abroad for medical care, the extent to which any patient travelers feel that they truly choose between near-equivalent health care options at home and abroad requires further empirical study. If the term "medical tourism" is preserved to describe those patients whose medical care choices may be incentivized, medical tourism might be considered a "game-changing innovation" [5]. However, those patients who are simply seeking otherwise unavailable, yet necessary, health care are not "medical tourists." They are simply *patients* seeking health care abroad.

### Limitations

The fact that the participants in this study were limited to English-speakers excluded a significant portion of African patients at these hospitals. Given the likely demographic and socioeconomic differences between English and non-English speakers, it is probable that this study neglected a set of experiences that may be different from those who met inclusion criteria. Further, due to the varying levels of English fluency among participants in this study, it is possible that some meaning was blunted or misinterpreted from the interviews.

In addition, although this study was not intended to produce generalizable findings, it should be noted that these findings are, indeed, limited to the participants of this study. Their further exploration would be valuable for substantiating their validity among a broader population.

### **Conclusions and Implications**

This study is the first known empirical work addressing the experience of African patients and nations in the South-South trade of medical services. Questionnaires and interviews with patients and their companions from six African countries suggested that patients in this demographic group are traveling to India after exhausting available or acceptable options for medical care at home, and that they seek treatment for conditions that are life- or quality of life-threatening. This is in contrast to much of the secondary and speculative literature on patient travelers (so little empirical work exists), for whom incentives are typically employed to influence patients' *choice* to obtain care abroad. The patients in this study cannot be considered to have had the choice but to go overseas. Rather, they traveled for necessary medical care, a practice that is neither novel nor tourism.

These findings suggest several areas to be further explored within these hospitals, as well as by researchers more generally. Quality improvement measures in the hospitals,

for example, might take the form of African language interpreters, cultural sensitivity and diversity training for staff, and more culturally appropriate food options for African patients. More broadly, future research questions might include:

- For African countries, what is the long-term cost/benefit ratio of sending patients abroad for medical care? At what point would it become more cost effective to bolster the capacity of health care services at home?
- What impact does the experience of receiving treatment in India have on African patients' future expectations of their health care system, as well as their health careseeking behaviors, at home?
- What impact is international revenue having on the prices of private health care services in India?
- What impact do international patients have on the availability of health care services for India's own population?

Finally, Underwood and Makadon, as many authors, suggest a dramatic characterization of medical travel in binary frameworks: good or bad? "[G]ame-changing innovation or passing fad?" [5] This study sheds light on what may be the true novelty of medical travel – not "medical tourism," but the redirection of patients around the globe from developed to developing countries for care, and particularly, a new South-South trade in medical services. For those who believe health care a human right, the opportunity for patients in need to obtain health care services is incontrovertibly positive. However, research on this topic cannot afford to ignore the quality of patients' experiences, nor issues of distributive justice in health care. The "innovation" of developing countries as health care destinations has tremendous potential for health and economic development, and its ongoing impacts in these areas deserve urgent attention.

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Appendix – Participant questionnaires	
	Participant #

# Patient Questionnaire

Thank you for taking the time to fill out this short questionnaire. It asks basic questions related to your experience at comfortable answering, and please answer as accurately as you can.

DIRECTIONS: Circle or fill in the answer below that best matches your experience.

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	PLEASE CIRCLE OR WRITE YOUR RESPONSE	
<b>1. Which country are you from?</b> (please write your response at right)		
2. How would you describe your gender?	Male / Female / Transgender / Other	
3. How old are you?	years	
4. Did you come to Hospital with a companion/attendant?	YES / NO	
If yes, how is this person related to you?	Spouse or partner / Parent / Child / Other family member / Friend	
5. Is this your first time in India?	YES / NO	
6. Before this, had you ever traveled abroad for medical care?	YES / NO	
If yes, was it for you or someone else?	MYSELF / SOMEONE ELSE	
If yes, was your trip to Hospital?	YES / NO	
If yes, which country(ies) did you travel to? (please write your response at right)		
7. Did you seek medical advice for your condition in your home country, before coming to ?	YES / NO	
8. Did you receive treatment for your condition in your home country, before coming to ?	YES / NO	
9. Before coming to India, did you discuss this trip with your doctor(s) at home?	YES / NO	

10. Do you have health insurance?	YES / NO	
If yes, are you using your health insurance for this care?	YES / NO	
11. When did you first consider travelling abroad for the medical treatment you are now receiving at Hospital?	Date (dd/mm/yyyy):/	
12. How long do you expect your <u>total stay</u> in Hospital will be?	months weeks days	
13. Which type of visa are you traveling on now?	MEDICAL VISA / TOURIST VISA / Not applicable	
14. Overall, how well does the medical staff at Hospital meet your needs?	Poor / Fair / Average / Good / Excellent	
15. Overall, how well does the International Patient staff at Hospital meet your needs?	Poor / Fair / Average / Good / Excellent	
16. What do you think about quality of the medical services here?	Poor / Fair / Average / Good / Excellent	
17. What do you think about the quality of the facilities here?	Poor / Fair / Average / Good / Excellent	
18. Have you encountered any language/communication problems since you've been at Hospital?	Never / Rarely / Occasionally / Often / Frequently / Always	
If so, do you feel that this negatively impacts your medical care here?	Never / Rarely / Occasionally / Often / Frequently / Always	
19. Have you ever heard of the term 'medical tourism'?	YES / NO	
If yes, would you consider yourself a medical tourist?	YES / NO / DO NOT KNOW	
20. Have you done, or do you plan to do, any sightseeing while you are here?	YES / NO	

When you are finished, please return this questionnaire to Allyson. Thank you!

Com	panion	Q	uestion	naire

Thank you for taking the time to fill out this short questionnaire. It asks basic questions related to your experience at comfortable answering, and please answer as accurately as you can.

DIRECTIONS: Circle or fill in the answer below that best matches your experience.

DIRECTIONS: Circle or till in the answer belov	PLEASE CIRCLE OR WRITE YOUR RESPONSE
1. Which country are you from? (please write your response at right)	T LEASE CINCILL ON WRITE TOOK RESTORSE
2. How would you describe your gender?	Male / Female / Transgender / Other
3. How old are you?	years
4. How is the person you are accompanying related to you?	Spouse or partner / Parent / Child / Other family member / Friend
5. Is this your first time in India?	YES / NO
6. Before this, had you ever traveled abroad for medical care?	YES / NO
If yes, was it for you or someone else?	MYSELF / SOMEONE ELSE
If yes, was your trip to Hospital?	YES / NO
If yes, which country(ies) did you travel to? (please write your response at right)	
7. Did the patient you are accompanying seek medical advice for his/her condition in his/her home country, before coming to ?	YES / NO / DO NOT KNOW
8. Did the patient you are accompanying receive treatment for his/her condition in his/her home country, before coming to ?	YES / NO / DO NOT KNOW
9. Before coming to India, did the patient discuss this trip with his/her doctor(s) at home?	YES / NO / DO NOT KNOW

10. When did you first consider accompanying the patient for the medical treatment s/he is now receiving?	Date (dd/mm/yyyy):/	
11. How long do you expect the patient's total stay in the hospital will be?	months weeks days	
12. Will you be staying in India for as long as the patient you are accompanying?	YES / NO	
13. Are you staying in the hospital with the patient you are accompanying?	YES / NO	
14. Which type of visa are you traveling on now?	MEDICAL ATTENDANT / TOURIST / Not applicable	
15. Overall, how well does the medical staff at Hospital meet your needs?	Poor / Fair / Average / Good / Excellent / Not applicable	
16. Overall, how well does the International Patient staff at Hospital meet your needs?	Poor / Fair / Average / Good / Excellent / Not applicable	
17. What do you think about quality of the medical services here?	Poor / Fair / Average / Good / Excellent	
18. What do you think about the quality of the facilities here?	Poor / Fair / Average / Good / Excellent	
19. Have you encountered any language/communication problems since you've been in ?	Never / Rarely / Occasionally / Often / Frequently / Always	
If so, do you feel that this has had a negative impact on the medical care the patient is receiving?	Never / Rarely / Occasionally / Often / Frequently / Always	
20. Have you ever heard of the term 'medical tourism'?	YES / NO	
If yes, would you consider yourself the companion of a medical tourist?	YES / NO / DO NOT KNOW	
21. Have you done, or do you plan to do, any sightseeing while you are here?	YES / NO	

When you are finished, please return this questionnaire to Allyson. Thank you!