THE NEGLECTED STEPCHILD

A PUBLICATION DEDICATED TO GLOBAL SURGERY
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SURGERY
Neglected Surgery (In Numbers)
Benjamin Price puts together a series of harrowing facts demonstrating neglected surgery on a worldwide scale.

Forgotten Fistulas
The Association pour la Promotion de la Santé Humaine (APSH) describe their dedicated efforts to assist those with obstetric fistulas in Burundi.

Finger On The Pulse
Dr. Hitendra Mahajan remembers anaesthesia before Lifebox and the positive changes occurring to promote safer surgery in India.

Connecting The Lights
One.Surgery releases a new research index, aiming to connect and distribute global surgery research all over the world.

From Rust to Repair
An interview with Keith Miles, Executive Director of Miles International Surgical Initiative. We discuss that surgical instruments are also in a deep state of neglect.

Surviving Without Surgery
Sara Smeets, a medical student describes one case she encounters in India, realising that despite great facilities, more is needed to access surgery.
THE PATHOLOGY OF NEGLECT

August 2018

Dearest Readers,

From removing tumours to restoring sight, and from road traffic accidents to the road to recovery, surgery transforms and saves lives. However, for surgery to be effective, safe treatment should be available within a suitable time frame that does not compromise the outcome for the patient.

For too long, conditions imminently treatable by surgery have been neglected across the world. Millions of people have and continue to suffer needlessly, unable to access the surgical care they desperately need.

The child with club foot, without treatment, becomes permanently disabled, undergoing a lifetime without the ability to walk or work. The baby, with an untreated cleft lip loses their beautiful smile, disfigured with each year of neglect. The mother, who gives birth but becomes incontinent, raises her family in physical pain and socially abandoned. The parent, unable to recover from an accident, loses their livelihood, sending their family into poverty. The adult, who slowly becomes blind as the cloud of cataracts cover their vision, now requires a full time carer.

Without essential surgical care, these easily treated conditions have become disabling and life threatening. Providing these surgical services requires a commitment from many differing stakeholders, all working together, slowly alleviating the burden of neglected disease one operation at a time.

One Surgery aims to address this neglect occurring in global surgery by giving those people involved - from surgeons to patients, from healthcare organisations to individual heroes - a voice to share their stories and thus a chance to finally be heard and inspire others towards this remarkable effort.

With love always,

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NEGLECTED SURGERY (IN NUMBERS)

BENJAMIN PRICE

Benjamin is a final year medical student at the University of Melbourne and the current President of the Surgical Students Society of Melbourne.

PHOTO BY ANKIT RAJ
Sometimes numbers are meaningless - anonymous little black characters displayed in a plain white circle afloat a dimly lit background. But sometimes numbers describe much more than this - each figure representing a silent voice, a daily struggle to survive and a sobering picture of healthcare without surgery. Benjamin Price portrays this stark image with the powerful, heart-breaking numbers of on-going neglected surgery.

**1**
This is the number of surgeons, anaesthetists and obstetricians per 100,000 members of the population in parts of Africa.

**2**
The number of operating theatres per 100,000 people in low and middle income countries.

**830**
The number of women who die every single day as a result of pregnancy and delivery complications, equating to 303,000 every year.

**5626**
The number of patients per 100,000 people who require surgery and fail to receive this treatment in Western Sub-Saharan Africa.
NUMBER OF LIVES THAT COULD BE SAVED EACH YEAR IN LMIC IF FATALITY RATES AMONG SERIOUSLY INJURED PERSONS COULD BE REDUCED TO THOSE IN HIGH INCOME COUNTRIES.

THE COLLECTIVE NUMBER OF DISABILITY ADJUSTED LIFE YEARS CAUSED BY 3 CONGENITAL ANOMALIES IN LOW AND MIDDLE INCOME COUNTRIES - CLEFT LIPS AND PALATES, CONGENITAL HEART ANOMALIES, AND NEURAL TUBE DEFECTS.

THE NUMBER OF NECESSARY SURGICAL PROCEDURES NEEDED THAT ARE NOT PERFORMED IN SOUTHERN ASIA EACH YEAR - THE REGION WITH THE GREATEST MAGNITUDE OF SURGICAL DEFICIT WORLDWIDE.

THE NUMBER OF PATIENTS WHO RECEIVE SURGICAL CARE EACH YEAR, FOR WHOM THE EVENTUAL OUTCOME IS FINANCIAL DESTITUTION.

THE NUMBER OF CHILDREN BORN EVERY YEAR WITH CONGENITAL TALIPES EQUINOVARUS, ALSO KNOWN AS ‘CLUB FOOT’. 80% OF THIS COHORT WILL BE BORN IN LOW AND MIDDLE INCOME COUNTRIES, AND MANY WILL NEVER RECEIVE SURGICAL TREATMENT, DESTINED TO A LIFE OF DISFIGUREMENT AND STRUGGLE.
The number of women worldwide who suffer from obstetric fistula, one of the most debilitating complications of childbirth. Almost all of these women live in Sub-Saharan Africa and South Asia.

This is the number of people globally with visual impairment secondary to cataracts. Despite being surgically treatable cataracts remain the leading cause of blindness in low and middle income countries.

This is the number of people who suffer from inguinal hernia globally. The majority of these individuals live in countries where the surgical burden is maximal, and the availability of mesh repair is minimal.

REFERENCES:

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FORGOTTEN FISTULAS

by Claude Kubiwana and Nkurunziza Willy

Claude Kubwimana is the president and legal representative of the Association pour la Promotion de la Sante Humaine (APSH-Burundi), an organization that focuses on the support of women in Burundi.

Nkurunziza Willy is the head of communication for APSH-Burundi.
IT IS ESTIMATED THAT MORE THAN 2 MILLION YOUNG WOMEN LIVE WITH UNTREATED OBSTETRIC FISTULA IN ASIA AND SUB-SAHARAN AFRICA, RESULTING IN INCONTINENCE, SHAME, SOCIAL STIGMA, AND OTHER HEALTH PROBLEMS.

Burundi, a land-locked country in the Great Lakes region of East Africa, is as beautiful as it is poor. The country has a population of approximately 10 million people, interspersed throughout its rolling, undulating landscape. It has one of the severest hunger and undernourishment rates of all 120 countries ranked in the Global Hunger Index, and an average life expectancy of only 58-62 years. In Burundi, 41 babies out of every 1,000 live births die in the first four weeks of birth.

An obstetric fistula is an abnormal connection between the vagina and rectum or bladder that is caused by prolonged obstructed labor, leaving a woman incontinent of urine or feces or both. They are also often associated with significant social stigma, leaving women isolated and vulnerable. Many neglected women are either degraded or even completely abandoned by their spouse and community.

Association pour la Promotion de la Santé Humaine (APSH) in Burundi is one of the only organisations that focuses on the support of women’s health in Burundi. Throughout the country, there is only one centre, Urumuri (meaning ‘light’ in the Kirundi language), that provides medical care for women with obstetric fistulas. ASPH supports this centre perform the heavy task of providing adequate surgical care for these women.

For example, a thirty-three year old woman in Burundi had a painful and difficult home delivery. The child survived, but his mother developed a large fistula where faeces and urine passed through one way. Without treatment or medical advice, her situation worsened. Eventually she developed a suffocating odour that her husband could not
Tolerate, resulting in her isolation at home. Fortunately, APSH found out about her case, and supported her transport and successful surgical repair. Her complete recovery has since enabled social reintegration.

However, with only one fistula repair centre throughout the country, women often have to travel many miles to reach the facility and receive adequate medical care. It can often take over 12 hours to arrive at the centre, patients either making the journey on foot, bicycle or sometimes on a traditional stretcher. Some of the women undertake the heavy journey unaccompanied. This lack of access and transport can have terrible consequences.

On the 22nd of March, 2018, a woman gave birth with great difficulty to a baby of about 3.1kg. Sadly, the child did not live long due to fatigue following the difficult birth. There was no midwife present, and the mother developed fistulas of both the perineum and the bladder, and excessive bleeding further complicated the delivery. Her village was very far from the nearest medical centre, but neighbours carried the patient on a traditional stretcher to Urumuri. Tragically, she died on the road to the centre due to excessive blood loss. Two lives were lost that day because of the lack of access to early intervention and distance to the nearest centre.

Urumuri currently has three surgeons and two anaesthetists working at the facility, treating an average of 32 fistulas per month. APSH is now also providing women with accompaniment and orientation during the journey to the centre. In the future, the organisation wants to increase awareness of fistulas, so that women can receive prenatal consultations/postpartum care, and enroll in the healthcare system, so that complications can be prevented or dealt with earlier. Although the road to the centre is long, and often impassable, running through hilltops and mountain peaks, by developing a reliable outreach programme, APSH is confident that more women in need of treatment can be reached.
Unfortunately, even when women succeed in reaching Urumuri, appropriate surgical care is not always possible and surgery cannot always be performed. Both the centre and APSH-Burundi are in need of more specialists and appropriate materials.

APSH has now sounded the alarm with regards to these problematic situations in Burundi. They hope to receive help, including moral support, materials and/or financing so they can continue to address and improve this urgent surgical need for women with fistulas as soon as possible.

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ALTHOUGH WE ARE BORN WITH THE SAME ANATOMY, THE SAME PHYSIOLOGY AND WITH THE SAME LOVE IN OUR HEART AND TEARS IN OUR EYES, IT IS OUR ENVIRONMENTS THAT ULTIMATELY DICTATE HOW WE BREAK AND FOR HOW LONG.

Saqib Noor
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<td>Tropical Surgery, Obstetrics &amp; Gynecology CME Conference - Houston, USA</td>
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<td>NOVEMBER</td>
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<td>7th International Society of Obstetric Fistula Surgeon’s Conference - Karachi, Pakistan</td>
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DR. HITENDRA C MAHAJAN, A CONSULTANT ANAESTHESIOLOGIST IN NASHIK, INDIA, REMEMBERS ANAESTHESIA BEFORE LIFEBOX.

LIFEBOX IS AN NON-GOVERNMENTAL ORGANISATION DEVOTED TO SAFER SURGERY AND ANAESTHESIA IN LOW-RESOURCE COUNTRIES.
In the last 20 years of my professional career as an anaesthesiologist, I have witnessed many changes in the way anaesthesia is delivered in India.

In 1996, when I underwent my post graduate training, we shared just one pulse oximeter between five busy operating theatres. Around twenty patients per day underwent anaesthesia and our only pulse oximeter was rotated to those high-risk patients that needed it the most. Incredibly, for the remaining patients, continuous “finger on pulse” was the best monitor we could offer to our patients.

In 1998, when I started freelance private practice as an anaesthesiologist, I used to visit many smaller hospitals where ether (an anaesthetic agent no longer used in developed countries) was the main anaesthetic agent available. Our equipment to deliver anaesthesia was also extremely simple.

Fortunately, I had purchased my own pulse oximeter after securing a bank loan of Rs. 50000 ($750). It took me a further five years to acquire a Boyle’s machine to deliver anaesthesia and more robust equipment to monitor the patient during surgery.

It was fun to move from one theatre to another with two bags, one having drugs and anaesthesia equipment and the other was a well protected bag to carry the monitor!

From the time of surgery to the point the patient emerged out of anaesthesia, I monitored the patient continuously, but after I left the hospital, my patients were cared for by nurses in post op care, again without basic monitors. I still skip a beat when I think about the tremendous difficulties we had caring for our patients post-operatively.

Thankfully now the situation has changed. In my operating theatre I have the latest anaesthetic machine with advanced monitors. Post-operatively, my patient will go either to the recovery room or the ICU. Both are well equipped with monitors and ventilators and my patients are well looked after by trained doctors along with nurses.

Sadly, the situation is not the same all over India. According to the WFSA workforce map, there are only 1.27 anaesthesiologists per 100,000 population in India.
Among those, not all the anaesthesiologists are as lucky as me to have access to a modular operating theatre and a well-equipped recovery room or ICU backup. Still many theatres are working with either simple Boyle’s machines or just an O2 cylinder. They totally rely on the visiting anaesthesiologist for the pulse oximeter which they bring with them. After the operation, the anaesthesiologist departs with the pulse oximeter, again leaving the patient at the mercy of clinical monitoring performed by nurses. In India it is common to see very well-equipped hospitals at one end and at the other end, hospitals without a basic pulse oximeter.

As an anaesthesiologist who has practised without any oximeters to now having access to the best equipment, anaesthesia safety has always been close to my heart. I feel passionately for propagating perioperative safety and advocating for this cause is of utmost importance. Hence in 2010 when I was the organising secretary of the state level anaesthesia conference, I set the theme of conference as ‘Safe Anaesthesia Saves Lives’.

I also started the oration in the conference, which was devoted to propagating safe anaesthesia but I knew this work alone was not enough to promote safe anaesthesia in India.

In 2016 while attending the WFSA world congress of anaesthesia at Hong Kong, I came across Lifebox. Hearing them talk about safe anaesthesia and attending their pulse oximeter distribution workshop was inspiring. It was something, which was matching to my motto in life, and I became hooked on to Lifebox.

After hearing Lifebox chair, Dr. Atul Gawande talk, I became determined to spread safe anaesthesia throughout India. In 2017, we organised the first Lifebox workshop in Maharashtra at the Indian Society of Anaesthesiologists (ISA) state conference, under my presidency. Dr. Someshwar Patange truly made great efforts in completing the formalities for this.

In the one-day Lifebox pulse oximetry workshop, delegates were taught about oxygenation, hypoxia, treating hypoxia and the WHO safety checklist. Apart from imparting knowledge, the hospitals also received a good quality of robust pulse oximeters. This would help the hospitals in need immensely and improve perioperative safety in India.
Since then Lifebox has distributed more than 500 pulse oximeters to hospitals in need and trained in excess of 600 healthcare professionals in different parts of India.

The success stories we now hear are heartwarming. In one of the sub-district hospitals at Girnare near Nashik, a patient was operated for caesarian section and the entire hospital was very happy and comfortable to perform the operation as they could monitor the patient with the pulse oximeter. At the end of the operation, they realised the baby was not comfortable as it had a borderline respiratory problem. The hospital was in a dilemma whether to transfer the baby to a higher centre or not. The Lifebox pulse oximeter with a neonatal probe came to their rescue. The pulse oximeter helped them to monitor the baby in the most scientific way and prevented the transfer of the newborn to a higher centre simply for monitoring. This transfer had its own risk and would have led to separation of the mother and the baby. They supplied oxygen to the newborn and after a few hours his condition improved.

Apart from improving quality of care, the healthcare providers are also more confident. In Kalvan sub-district hospital near Nashik, a nurse found out that one of her patients, who had just had a hysterectomy under general anaesthesia, was gradually dropping her oxygen saturation levels from from 98 % to 95 % on the monitor. Clinically the patient appeared fine, but as per the training received in the Lifebox workshop, she started oxygen for the patient and called for help. The doctor on call diagnosed a developing tongue fall and immediately inserted nasal airway for that patient and advised the nurse to continue oxygen and monitor the patient closely with the pulse oximeter.

After that, the patient maintained 100 % oxygen saturation and was conscious after five hours. Thus, with the help of a simple pulse oximeter, a potential catastrophe was averted.

The disparity in India between the urban and rural set up is large and so is the need for improving surgical and anaesthetic safety. Our intention as responsible public health professionals should be to standardise care without compromising safety. A small step in that direction is training all the doctors and nurses involved and providing simple tools that will ease delivery of care. I am thankful to Lifebox for making this possible and I am proud to be associated with the Lifebox project.

Long live safe surgery and safe anaesthesia.

Dr. Hitendra C Mahajan, M.D is a consultant anaesthesiologist and chief anaesthesiologist at Ashoka Medicover Hospital, Nashik.

Further information about Lifebox can be found at the Lifebox Foundation website - www.lifebox.org.
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Research is a form of electricity, a light that guides us to the future of patient care. Yet much of the world of global surgery remains in darkness, lacking the infrastructure to be truly on the research grid. One Surgery is releasing an index to help provide some connectivity.
Medical research, the scientific art of advancing knowledge for the benefit of patients, is a fundamental duty of the healthcare industry and an activity that is critically necessary in every sphere of the profession.

Within the specific field of surgery and anaesthesia, the vast majority of research activity occurs in highly developed healthcare settings, with only a small percentage of research dedicated to advancing the knowledge of surgery within low and middle income countries. Although there is an increasing focus on the topics of global surgery, with a surge of current research activity, not all scientific work is available or readily accessible when published. Even if an article is freely available, it may not easily be discovered by those who would benefit the most.

Medical advances have traditionally been published in printed journals for hundreds of years but current dissemination of research occurs in many formats, across various media and online platforms, making it difficult to find.
Research, like a light, needs to be switched on in areas of darkness, and crucially, despite an increase in global surgery research activity, it is unclear how much of the knowledge is filtering down to the clinicians and healthcare professionals working within low and middle income countries.

One Surgery is launching a new global surgery research index - an ambitious attempt at collecting all the worldwide publications relating to the field and placing them in an easily accessible format, lovingly archived and coded to be filtered down to relevant stakeholders who may benefit most from the work.

The Index allows articles to be shared, bookmarked and annotated (publicly or privately), keeping readers across the world instantly up to date with all latest global surgery research relevant to their field.

With an expanding index and growing archive of publications, One Surgery hopes to slowly connect research, lighting up one article at a time, building a robust infrastructure which will slowly power further advancements and collaborations of surgical research in previous areas of darkness and neglect.
FROM RUST TO REPAIR

Keith Miles, Executive Director of Miles International Surgical Initiative, discusses neglected surgical equipment with One Surgery.
Q: Miles, it’s great to have you join us at One Surgery. Miles International Surgical Initiative (MISI) provides support for an essential but often forgotten aspect of surgery - provisions of high quality surgical instruments to perform safe surgery. How did MISI start in this crucial global surgical activity?

Thanks for inviting me to discuss these often forgotten aspects of surgery. MISI started organically, when one of our founders volunteered for Mercy Ships in Benin, Africa. Standing on the deck of a Mercy Ship hospital, my older brother and MISI founder Willie Miles looked out on the horizon as thousands of people lined up to receive medical care. It was a transformative moment for him, realising that all these patients would need not just healthcare staff to receive appropriate surgery, but also strong, reliable equipment. What started off as a two-week mission became a lifelong passion to help surgical teams provide life-saving surgical care across the world. He wasn’t a surgeon, a doctor, or a nurse, and he wouldn’t be the one performing life-changing surgery that restored sight, or corrected deformities. However, what he could do was make sure the staff had the best surgical tools at their disposal. As a surgical instrument consultant, he managed surgical instruments inventories, and refurbished those instruments in dire need of attention. He would make sure the instruments cut, bit, grasp, and function to the surgeon’s expectations and thereby reduce the amount of complications that can arise. Once he returned from that life changing experience, we formed MISI.

Q: It is has been reported that 80% of medical devices in low income countries are donated or second hand - often provided without spare parts or technical support. What are the worst examples of neglected instruments you have witnessed (that were still in actual clinical use)?

Unfortunately, I have a long list of neglected instruments I have witnessed being used. I’ve seen osteotomes and elevators with the distal tips gouged out, scissors covered in rust, drill bits and reamers damaged beyond recognition, Kerrison ronguers with bone and tissue jammed in the shaft still being used on patient after patient. The list goes on.
Q: How difficult is it to restore instruments that are in a state of neglect?

The most important question to ask when attempting to restore neglected instruments is if the instrument should be repaired in the first place. Patient safety should always be at the forefront. Sometimes it is best to remove instruments that may pose a greater harm to the patient due to the increased chances of infection or malfunction during use. Often when our technicians work in resources deprived medical facilities, they have to walk a thin line between the needs of hospitals and safety of the patients. Most of the time those needs are in perfect alignment. There have been situations that require bending “best practices” to ensure surgical procedures can be performed. At times like that, we just do the best we can with what we’ve got. Neglected instruments pose a greater challenge to restore, often from improper handling or through the sterilisation process. This leads to degradation such as corrosion, pitting, rust, and cracks that compromises functionality.

"When surgical instruments do not receive proper care and handling due to a lack of resources or knowledge, the instruments and by extension, the patient suffers."

Q: Hospitals in high-income countries occasionally donate equipment that are sometimes expired or obsolete. How do you feel we can ensure the appropriate equipment gets filtered to the services that truly need it the most?

I think there is a misconception among some hospitals in high-income countries that donate medical supplies to low-income countries, that anything is better than nothing in regards to the equipment and instruments being donated. While that may have been true 25 years ago, medical facilities in developing countries now perform complicated surgical procedures, and they need more sophisticated equipment to ensure success. One way to filter medical supplies to the appropriate facilities is to work with reputable organisations that provide surplus equipment.
Q: What is the best tips you can give to surgical teams in these settings to maintain their equipment?

There are a few tips I’d like to pass on to surgical teams working in developing countries. First and foremost is to keep the surgical instruments moist until they can be transported to decontamination area after each and every procedure. Allowing saline, blood, or another bio burden to dry on surgical instruments will increase the rate of degradation exponentially. These substances are corrosive to metal. Then, once surgical instruments are in the decontamination area, begin the sterilisation process as soon as possible. Secondly, apply a surgical grade lubricant to the instrument on a regular basis. It needs to be a silicon free, water soluble mineral oil. This will also prevent rusting, staining and will restore articulation to moving parts. Lastly, don’t rely on the central sterile staff to check surgical instrument functionality. It should be everyone’s responsibility to make sure that the instrument is ready before it reaches the surgeon’s hand.

Q: What have you enjoyed personally about working in resource poor settings?

The most enjoyable part about working in these areas is the freedom to perform my craft in its purest form. MISI programs are free of charge, so when we make recommendations about process improvements, suggest new techniques, or take instruments out of service - it is accepted based off technical expertise and a genuine desire to help. It’s really refreshing and rewarding to just focus on providing a high-quality service, and not have to slide a bill across the table at the end.

Q: What has been your greatest challenge in the MISI project thus far?

One of our biggest challenges has been generating enough support for our programmes. MISI performs an essential service to hospitals and clinics that provide free surgery in impoverished areas of the world. We fund most of our programmes through our limited social enterprise income and donations. We may be the only organisation providing free on-site surgical instrument repairs in the world.
We have a growing list of all the hospitals and surgical centres that have reached out to us, in desperate need of our services. So our greatest challenge is choosing which facility we service next. We just continue to do the best we can with the resources available.

Q: What are MISI's on-going projects and how do possible partners contact you for further collaboration?

One of the biggest projects we have going on right now is our surgical instruments repair labs. The project involves setting up repair labs at hospitals or surgical centres in low-income areas and sending a master technician to perform the repairs and offer educational services to the staff. We're currently preparing for our first repair mission for CURE Ethiopia - A CURE International hospital. CURE International has over 9 hospitals in developing countries and we're honoured to lend our support. In addition, our instruments procurement programme for surgical mission teams is helping put the right instruments in the hands of surgeons. We help collect and then repair surgical instruments for missions around the world. We're always looking for partners to collaborate on our mutual goal of providing safe essential surgery into resource limited areas.

"We have a growing list of all the hospitals and surgical centres that have reached out to us, in desperate need of our services."

You can reach MISI through their website:

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By email at:

info@misi-online.org

Or follow on Instagram:

@miles.misi
SURVIVING WITHOUT SURGERY

SARA SMEETS, A THIRD YEAR MEDICAL STUDENT FROM HASSELT UNIVERSITY, BELGIUM DESCRIBES THE STORY OF A GIRL SHE RECENTLY MET ON HER ELECTIVE PLACEMENT IN JAIPUR, INDIA.
As a medical student, I have always dreamed about being active in global surgery in my later career and participating in reducing health care inequality worldwide. To start learning about global health care, my home university in Belgium offered me the opportunity to do an internship at the Mahatma Gandhi Medical College and Hospital in Jaipur, India, where I spent two weeks in the paediatric department and two weeks in the orthopaedic department.

This was a wonderful experience where I learned about conditions I would rarely have encountered in Belgium, but also about the Indian culture, society, education system, health care system and sadly, the poverty many patients face. We made many new friends as we were overwhelmed by the hospitality and kindness, as well as by the passion of the doctors to pass on their knowledge. I encountered many stories of hope, but was also touched by shocking stories from patients who had no money for better treatment. The internship made me realise that the availability of extensive medical knowledge, skilled surgeons, necessary resources and technologies are not always sufficient to give everyone access to surgical care, especially not for the less fortunate part of the population.

Prior to the internship, I was curious about the differences between surgery in Belgium and the Mahatma Gandhi Hospital in India. The surgery room, skills and amount of knowledge of the surgeons, as well as the surgical procedures and instruments were quite similar to those in Belgium. Of course, I only have the viewing experience as a student and I cannot compare with other hospitals in India which I did not visit.

However, one of the most touching cases that demonstrated lack of access to surgical care was the story of a girl who was nearly my age. She suffered from end-stage chronic kidney disease (CKD) and had been treated for six years with continuous ambulatory peritoneal dialysis (CAPD). She was now admitted to the paediatric ward to have her medication adjusted from paediatric to adult dosages. The nephrologist-paediatrician proudly explained how the girl had been treated with CAPD without any complications, having normal growth and development.

"The surgery room, skills and amount of knowledge of the surgeons, as well as the surgical procedures and instruments were quite similar to those in Belgium."
I was surprised that the treatment showed such good results, since CAPD is a technique where the patient has to perform under very hygienic conditions with the necessary skills and perseverance.

For years, she and her parents were taking turns at night waking her up every few hours for the exchange procedure of the dialysis fluid. However, CAPD is not a permanent solution and usually does not last for lifetime. In high-income countries like Belgium, it is mostly used as a temporary therapy to bridge the time to kidney transplantation. When I asked whether and when this patient would get a kidney transplant, the doctor replied that unfortunately for this patient it would not be possible for several reasons. It shocked me because, just as in my home country, all necessary skills and tools as well as highly trained surgeons were available in the hospital.

The main reason why the girl could not have a kidney transplant was that the family could not afford it. According to the doctor, the family was not that poor, which was illustrated by the fact they were able to pay all necessary drugs and equipment for the CAPD. But sadly, due to these costs, they could not save the large sum of money required for a kidney transplant. Another reason was that no one in the family was willing to donate a kidney. Doctors in the hospital told us several times that health literacy among the patients is often very low, especially among the poorer or rural population. The lack of education in this part of the population may lead to difficulties for patients to understand their disease or why it is important to adhere to the treatment. Although in this case treatment adherence was not the problem, the family believed that if they would donate a kidney, they would not be able to perform the hard work on their farm anymore. The doctors could not convince them otherwise.

A third reason was that even if a donor kidney would be available in the Mahatma Gandhi Hospital, for example, after a car accident, the patient would
never be able to reach the hospital in time. The family lived in a rural farming village in northern India close to the border with Pakistan and would have to travel for at least 15 hours to reach the Mahatma Gandhi Hospital, while a donor kidney should better be transplanted within a few hours.

Luckily, the nephrologist-paediatrician explained that this patient showed exceptionally good results with CAPD and that he once reached a survival time of 20 years with CAPD with another patient like her. He hoped to reach this long survival time with this girl too, although it is exceptional. Even though CAPD is not a permanent solution for children with end-stage CKD, it was often the only solution he could offer.

I realised that if the girl was born in my home country, she would probably already have had her kidney transplant, because our health care system provides substantial financial support trying to guarantee health care access for everyone. So, there we were, two girls of nearly the same age, one born in India without access to the necessary surgical care, the other born in Belgium with the extensive access to health care that everyone should deserve.

This girl still hoped to live for several years because she showed better results from her treatment with CAPD than most patients, but what about the children who cannot afford a kidney transplant and for whom CAPD therapy does not work so well, or for whom even the CAPD treatment is too expensive?

The inequality in health care access, especially this case upsets me. It is a global problem. It shows that even the availability of the required medical knowledge, skilled surgeons and surgical equipment is not sufficient. Creating a world with access to surgical care for everyone requires more than that, such as financial support, patient education and the right geographical distribution of all resources. Cases like this must convince us to keep dedicating ourselves to more equality in health care access worldwide.

"Even the availability of the required medical knowledge, skilled surgeons and surgical equipment is not sufficient."
Ours is a circle of friendships united by ideals

Juliette Gordon Low

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