

## The experience of a European nephrologist at the SIUT: the largest Nephrology-Urology Transplantation Unit in South East Asia

### Editoriali

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#### ABSTRACT

An Italian nephrologist, during her long experience in the Middle East, is a guest at the SIUT (Sindh Institute of Urology & Transplantation) in Karachi, the largest centre of nephrology-urology and transplantation in South Asia. She discovers the “SIUT model” which guarantees a constant quality of health care, fighting organ trafficking despite the poor economic conditions of the country, Pakistan.

## Introduction

The Islamic Republic of Pakistan is a federation consisting of four provinces. Its capital is Islamabad, and the country borders India to the east, China to the north, Iran and Afghanistan to the west, and the Indian Ocean to the south. With a population of nearly 229 million – over 60% of whom is under the age of 27 – it is the sixth most populous country in the world. Pakistan has a fast population growth rate and is expected to have a doubling of the population within 30 years [2]. The United Nations estimates that Pakistan will be the fifth-most populous country by 2030. Its geopolitical location is strategic, as it is at the crossroads between Middle East-Central Asia and South-East Asia; along the oil and gas routes from Central Asia to the Indian Ocean. Therefore, it lends itself to being a hinge for pan-Eurasian integration, attracting interest from China and the Middle East, and making it a very unstable geographic area, in particular, because of its proximity to Afghanistan.

The languages spoken are Urdu, English, and numerous local languages due to numerous ethnic groups constituting the population. Agriculture is the backbone of Pakistan's economy; the key industries of Pakistan rely on the production of wheat, rice, and cotton. The agricultural sector generates more than 20% of the national GDP, employing about 41% of the national workforce and providing livelihoods to almost 67% of the population [3, 4]. The economic growth of Pakistan, in the pre-Covid era, reached between 4.5 and 6%. The adult literacy rate is only 56%, the Gross National Income (GNI) per capita is USD 1,500; spending on health is only 0.7% [2].

According to UNICEF reports communicable diseases and malnutrition still dominate today, half of the women of reproductive age have anaemia (50.4%), haemorrhages and hypertensive crises are common and predictable incidents in maternity are too often fatal; the last recorded maternal mortality rate was 276 per 100,000 live births. The neonatal mortality rate remains stably high; and so is the growing number of stillbirths: 43/per 1000 live births. In young people and children, diarrhoea and respiratory diseases remain the main causes of death. From the data provided by the WHO: Pakistan is one of the three countries where polio is still endemic, and so it is for hepatitis B and C with 7.6% affected. Pakistan ranks fifth in tuberculosis cases in the world; it has a focal geographic area of endemic malaria and has an established HIV concentration among the high-risk groups, the estimated coverage of antiretroviral therapy is only 9.0%; there are high rates of unshielded blood transfusions. There is no vaccination plan adequate for the number of the population. There is a progressive increase in chronic kidney disease, affecting about 17 million people. This increase is linked to inadequate access to health care with consequent diagnostic delays. In Pakistan one in ten adults has hypertension and it is in seventh place in the world for incidence of diabetes. In recent years, the diagnosis of celiac disease has also increased a lot. The most frequent renal diseases are diabetes, hypertension, and kidney stones but autoimmune nephropathies are also frequent. The WHO also reports that Pakistan's health indicators showed improvement from 1990 to 2015, despite numerous challenges, political, social, geological, and internal and border conflicts. The average life expectancy increased from 59 years in 1990 to 67 years old in 2015; 50% of the people live below the poverty line on less than 1 \$ per day, and they have to think about where the next meal comes from, so for these people, the medical treatment becomes a luxury. Karachi, the former capital, is the most populous city with 14,910,352 people and an urban agglomeration of 24 million inhabitants (data updated to 2017). It is the city where SIUT was born and developed, in the province of Sindh, which is the most urbanized part of Pakistan, with 48.8% of the urban population [3]. The high population density in Karachi is determined by immigrants from other provinces of Pakistan and migrants from countries such as Bangladesh, Myanmar, and Afghanistan, looking for economic opportunities. Importantly, most of them settle in Karachi City, which represents 64% of the urban population in Sindh province and 21.7% of the Pakistan population.



Fig. 1: map of Pakistan.

In a country like Pakistan and a large and difficult city like Karachi, one wonders if the treatment of chronic kidney disease can be provided despite numerous challenges, including high cost, quality assurance with the enormous workload, respecting the dignity of the patients, religious diversity and prejudices while fighting organ trafficking; the answer is 'Yes' and this is reflected in the SIUT model.

### The SIUT and its model of care

The SIUT was born and remained in the old congested part, the "Old City" of Karachi. It is a symbolic place so that it would remain accessible to the people living below the poverty line.

The SIUT is the only institute of its kind in South Asia. It treats patients from all regions of Pakistan and neighbouring countries free of charge. SIUT is also a teaching hospital that trains doctors and nurses and is home to cutting-edge technologies. It has an excellent team of skilled healthcare professionals and is thus an island of excellence and humanity in an ocean of corruption and commercialization. It was born as a unit of urology with eight beds, inside the Civil Hospital of Karachi in 1971; it gradually began to expand clinically and physically then in 1991 gained the status of an autonomous institution.

In 2005, the SIUT Trust was recognized as a trust to provide medical facilities and financial assistance to those in the terminal stage of kidney disease. It is also a Unit for biomedical ethics and culture; it was designated in 2018 as a WHO collaborative centre in bioethics and the only one teaching Medical Ethics.

Today SIUT is a "Centre of Excellence" known for high standards of professional ethics, with a team of medical professionals, dedicated and motivated, tireless as I have never seen before, with no timetables, whose life is SIUT. When it was created in 1971 was a small department but today is a hospital with 1,000 beds and structures spread over 400,000 square meters. SIUT is constantly expanding: 16 wards, a big Outpatient Department, 4 auditoriums, and laboratories of immunology and immunopathology, 4 ICUs dedicated only to transplant patients, 6 theatres, a big library, a huge

number of doctors, nurses, dieticians, psychologists, social workers, pharmacists, drivers and many other professionals; there is a Shared Electronic Health Record, which connects the various departments with radiology, laboratory etc. to the network. There are also SIUT satellite centres in different areas of the region, which provide health services even in remote locations. They work all together, each in compliance with the SIUT philosophy, perfectly integrated into the organizational system and united for the same purpose of providing a free health service of quality to all.



Fig. 2: Part of the SIUT building.

The SIUT looks like a miracle to the eyes of a western observer, but behind this miracle, there is a man, the urologist Prof. Syed Adib-ul-Hasan Rizvi, a young doctor who, after his studies in the UK, contrary to many of his colleagues, decided to return to Pakistan with a container full of medical equipment and to give birth to that urology department of only eight beds from which everything starts, aware that there could be no urology without nephrology. Now he is 83 and, despite his age, in the morning is the first to arrive and he is the last to leave the hospital.



Fig. 3: Prof. Syed Adib-ul- Hasan Rizvi.

Prof. Rizvi's philosophy is: *"to provide all patients with complete and modern medical services free of charge"*. Rizvi believes that healthcare is a birthright of every man, woman and child, regardless of the cost. Treatment should not be denied to a person because he is poor and cannot afford the cost of medicine, it must never be ethnic prejudice but equal treatment for everyone, regardless of the patient's background, caste, creed, religion, or gender. All this to Europeans may seem obvious but it is not so outside of Europe. Prof. Rizvi has also always maintained that *"health professionals take care of the patient, providing not only free care and treatment but also social and health advice so that the patient and the patient family can cope with the emotional stress caused to them by illness"*. It is thanks to him that the SIUT model and its philosophy exist.

**SIUTs Model**  
Community –  
Government Partnership

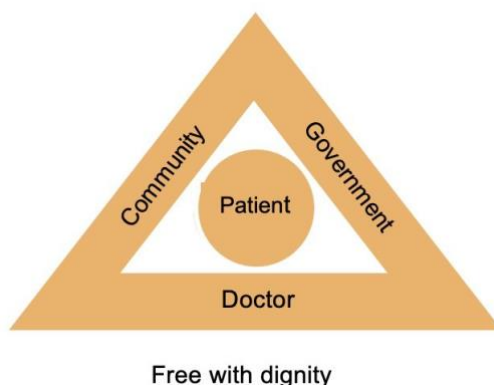


Fig. 4: The SIUT triangle.

**The SIUT philosophy is that every human being must receive the right care**

- Free with dignity regardless of caste, colour, creed and religion
- Must be open all day and everyone can enter
- The service should expand according to the patient's needs
- You have to work hard to keep up with technology
- It must be autonomous, transparent and accountable to the government and the community
- Oppose the marketing of medical care

The patient is the fulcrum of the model, and the medical community that takes care of him is his supporter.



Fig. 5: Two of the entrances to the Outpatient Department.

The role of physicians is complex, from providers of care to advocates for all their patients' extra-health needs. The seemingly non-medical problems affecting an individual's health here are not ignored, as the cost of health care; with free healthcare, SIUT simplifies the patient's life with a model that has been successful and worked for the past forty years, as confirmed by the increasing number of patients and services provided.

A Board of Governors (BOG) manages the SIUT. The staff includes a director under which the paramedics and medical support staff are located. Financially, the government that owns the infrastructure provides about 50% of the budget, with the rest coming from community donations. SIUT has cost containment strategies without compromising the quality of health care, such as the use of generic medicines and basic model dialysis machines, the reuse of dialyzers, etc.



**Fig.6: Reuse filter machines.**

The growth of the SIUT is constant and continuous, it is a dynamic system where, in any case, the staff is never sufficient paragoned to the large amount of work in all the various sectors. Technology is adopted as needed, human resource development is an integral part of this model and this is made possible by a medical education department that provides training to relevant staff. Every morning, before starting to work, 45 minutes are dedicated to the discussion of a clinical case or shared special topics. There are often conferences with international speakers who are experts in renal and hepatic transplantation. There are no fixed shifts but the doctors leave the hospital at the end of the day only when they are sure they can do it. I have seen colleagues who, at the twelfth hour of the non-stop clinic, leaned their heads on the desk due to fatigue, to try to welcome the greatest number of patients; already at 7 am, hundreds of men and women, who often travelled hundreds of km on foot, even from neighbouring countries such as Afghanistan, crowd the entrance to the Outpatient Department, waiting to be visited, in a religious and respectful silence. The overhead costs are negligible, unlike other organizations. The idea is to be as self-sufficient as possible and provide the institution with the most advanced technology; SIUT has a democratic and egalitarian spirit, it allows access to all: there are no private wards, no senior doctors, including the director, have private offices; everyone is the same and, in the cafeteria, the same food is served to all doctors and paramedics, they all eat together. The SIUT is like a community that expects all its members to show compassion and humanity to colleagues, their patients, and their families. The socio-economic concerns of patients are addressed with care, to minimize the emotional, psychological, and economic stress of the patient: *who must always be at the centre of doing and thinking.*

### **The Haemodialysis at the SIUT**

The dialysis method performed is haemodialysis, mainly bicarbonate dialysis. SIUT performs an average of 1,000 dialysis sessions per day over six shifts. The institute has state-of-the-art machinery and specialized technicians who perform dialysis on patients every day. Over 400,000 patients per year underwent dialysis at SIUT. More than 5,000 new patients are registered every year, of which around 1,200 are under 18 years of age. There are 4 satellite Dialysis units in Sukkur and Karachi itself. They have a high rate of abandonment because those who come from far and cannot be transplanted go back. The cost of each dialysis session is very low compared to the West but still high in such a poor country; they try to contain costs in various ways, for example through the reuse of filters. The dialysis centre has a nutritionist for each shift, who fights the difficult war against malnutrition caused by the conditions of extreme poverty of patients. They guide every single patient on the diet both verbally and with the help of *coloured brochures*, as many are illiterate (Fig.7).



Fig. 7: Coloured brochures to help illiterate patients follow correctly a diet.

The problem of malnutrition is very serious, powdered milk is given to malnourished children and even adults on dialysis receive a cup of milk and eggs. There is also a psychological and social support team; in certain cases, very poor people can get some money for urgent needs. Often dialysis patients or those who have donated a kidney to a first-degree family member receive a job at SIUT, as an ascensionist that I've met who had donated the kidney to his mother.

### Paediatric Nephrology

The paediatric nephrology department includes: emergency unit, intensive care unit, haemodialysis unit, and an outpatient clinic. The paediatric ward has 21 beds, a combined adult and paediatric nephrology emergency unit, 20-25 patients visiting the emergency room every day; the paediatric nephrology team (2 professors, 3 assistant professors, 6 residents) runs a paediatric clinic once a week from 8 am to 5 pm and an average number of around 200 patients are seen in each clinic by the team. The intensive care unit, equipped with ventilatory support, is shared with adult nephrology patients with a capacity of 20 beds.

The haemodialysis unit operates 24 hours a day, 6 days a week, with an average number of 150 paediatric patients on maintenance haemodialysis. Common kidney diseases in the population include nephrotic syndrome, glomerular diseases, infections, hypovolemia, tubular necrosis, haemolytic uremic syndrome, CKD with congenital anomalies of the kidney and urinary tract, polycystic kidneys, tubular disorders, lupus nephritis. Many AKI are treated, the average age is 7.5 years with a prevalence of males, about 60%. The most frequent aetiologies of AKI are glomerulonephritis followed by obstructive stones [6]. The preferred modality of renal replacement therapy is haemodialysis, plasmapheresis is also available.

There is a paediatric urology unit, available 24 hours a day for emergency procedures; routine procedures include lithotripsy; routine elective surgeries include PCNL (skin nephrolithotomy), augmentation cystoplasty, reflux, cystic, ureterostomies, cystoscopy, and ureteral valve fulguration. There is a paediatric urology clinic, available twice a week, with an average of 150 patients observed in each clinic and a well-established paediatric transplant unit and on average one kidney transplant for paediatric transplant, once weekly pre-transplant surgery and daily post-transplant. All treatments including immunosuppressive and other medications, haemodialysis treatments, kidney

care, urological interventions and post-transplant immunosuppressive medications are provided free of charge for any child or adult, regardless of religion, ethnicity and socioeconomic status, every patient visiting the hospital receives free treatment.

A very critical aspect, as imaginable, is the infection in both adult and paediatric patients. All the staff fights it by doing its best but without much success due to the infectious environment and poor home hygiene.

### **The SIUT and the history of kidney transplant in Pakistan**

It is impossible to talk about the SIUT without recalling the history of transplants in Pakistan and the important role that this institution had in legislating the current law that regulates transplantation in Pakistan today. In 1979 there was the first renal transplantation from a living donor in public sector hospitals. Initially, most of the recipients were local, but the changing economic and political scenario in this part of South Asia led Pakistan to become the largest transplant tourism Centre for foreigners in private sector hospitals [3]. Until 1994, another major reason that increased traffic was the lack of dialysis and transplants in the public sector, which moved transplants to the private sector, largely based on living transplants, thus leading to the dramatic chaos of the organ trade. SIUT, after establishing itself as the leading transplant institution in the country, has campaigned severely against the sale of organs and transplant tourism, supported by WHO and various NGOs. In the beginning, India was the centre of transplant trade and tourism, with intense transplantation activity, over 4,000 transplants annually. Finally, India banned the trade and tourism of kidneys in 1994. The growth of transplant health tourism in Pakistan has been facilitated by the illegality of the practice in India and by the absence of a law prohibiting the sale of organs and transplant tourism in Pakistan. Transplantations have also been advertised throughout the world via web [7]. Thousands of rich buyers travelled to Pakistan from the Middle East, Europe, and India, so it was an incredible tourism industry; the price for a transplant was advertised between US \$ 6000–10,000.

The first deceased kidney transplantation in Pakistan was performed at SIUT in 1994 when a kidney was donated from EuroTransplantation Foundation with the courtesy of Prof. Gauke Kootstra; later in 1998 Syed Naveed Anwar, a 24-year-old university student, had a serious car accident and he was transferred in the intensive care unit of the Liaquat National Hospital in Karachi but, after a few days, he was declared “brain dead”. Naveed belonged to an educated middle-class family; despite his young age, he had been convinced of the deceased’s organ donation, expressing a desire to donate his organs in the event of premature death. His family respected his request and the two kidney transplants and his corneas took place at SIUT on November 5, 1998.

This donation was very important in the history of transplants in Pakistan and SIUT as well as that of the little American Nicholas Green was in Italy. Nicholas was killed in 1994 in Calabria, a region of Southern Italy, where there was no transplant history before, despite Italy had had a transplant law for a long time, but the generosity of his parents changed the reality of the transplant there, where I worked for five years. Both of these two donations, on two different continents, have been a watershed in awakening the hearts and minds of citizens and politicians on the issue of organ donation. In Pakistan, in 1998 there was no law on the donation of human organs but not one that prohibited it; indeed, it was possible to trace it back to the Holy Quran’s support for donation, thanks to a verse from Sural Al-Maida that reads *If someone saved a life, it would be like saving the life of all humanity* (Quran 5:32).

From various socio-economic surveys, conducted between 2005 and 2007, it emerged that 34% of people lived below the poverty line on less than \$ 1 per day; 90% were illiterate and 69% were slave labourers of the owners [7]. This modern slavery exists and is practised in several South Asian



countries; in Pakistan, there are 2.1 million slaves, where generation after generation of workers endure long hours of work to pay off the debt of their fathers or grandfathers [7]. 93% of the vendors sold kidneys to pay off their debts; however, 88% of them had no economic benefits after the sale.

It was also assessed kidney seller's health status and renal function in a 2007 study. This study showed that there was no selection based on medical evaluation of living donors, even if Pakistan is a country in which hepatitis is still endemic. The donors' GFR values averaged 70 ml/min, one third of them had GFR <60 ml/min, therefore, they were donors at high risk of developing chronic kidney disease [3, 7]. The data of these investigations, together with strong pressure from the WHO, the transplant society of Pakistan and NGOs, pressed the Pakistani government, in November 2007, to promulgate "the order of transplantation of human organs and tissues", so it was decided with a government order to prohibit the transplantation of organs for commercial purposes by locals and foreigners; instead, donations were allowed only from living donors, first degree relatives and legally registered. Donation by a non-first degree relative is also allowed after the approval of an evaluation committee. The same ordinance also allowed cadaveric donation for those who had given consent in life or with the consent of a family member after the death. This 2007 ordinance became part of the Pakistani Constitution in 2010 but in the meantime SIUT, the Pakistani nephrology association with the support of the WHO and various NGOs, has still had to fight against the organ trade lobbies that have dragged the ordinance in the judgment of the Sharia Court (an institution that supports the Supreme Court of Pakistan ensuring that all the laws of Pakistan respect Islamic laws). The lobbies wanted to prove in Sharia Court that the donation law was strict because it prohibited the transplantation of Muslims from other countries and this would have increased deaths from lack of donors; but it wasn't so, on the contrary in 2008 more than a thousand transplants of local patients were recorded, and of these about 67% were performed at the SIUT [7]. The Sharia Court, however, rejected the requests of the lobbies, declaring 'definitively' that "the sale and purchase of human organs are against Islamic law" and in 2010 the law for the transplantation of legal organs entered the constitution of Pakistan. Since 2007 transplants have been registered on the national register, which must be done within 48 hours of the transplant. Each province of Pakistan has a transplant centre referenced to a provincial monitoring authority which follows regular inspections in the Transplantation Unit. The violation of the law provides for 10 years in prison and a fine of 10,000 dollars. Prof Rizvi and the whole SIUT have worked very hard and steadily over the decades to achieve this. SIUT has created a health, economic, psychological and social support network for donors and recipients and carried out an intense activity of information and education on the population; it has created also a follow-up clinic for donors post- donation and over time.

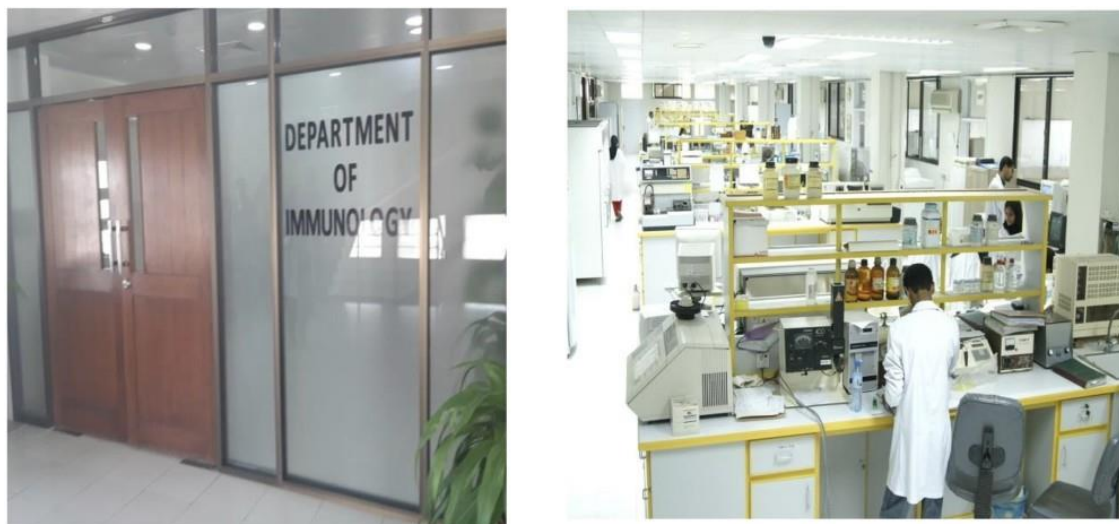


Fig. 8: SIUT laboratories.

Today the SIUT continues to work intensively the respecting of legality and to prevent private centres from attracting illegal donations, all this by welcoming an increasing number of patients, clinics, wards, operating theatres, the number of transplanted from cadaveric and living per year, with incessant work by all the staff who often have unimaginable working hours with 6511 total transplants to date.

SIUT has given in 38 years an incredible service for kidney transplantation, open to all and free, transparent and of quality. The government provides about 40% of the annual costs of transplants; doctors apply cost-cutting strategies every day, including expensive immunosuppressive therapy; in fact, most organ recipients follow a triple pharmacological regimen with Steroid, Cyclosporine and azathioprine, the dosage of drugs is also very important, with a very careful eye between the dosage of immunosuppressive and the matched haplotype; induction with ATG is done in poorly matched and sensitized patients [8]. From the data provided by SIUT, more than 300 transplants are performed every year; children have the lowest post-transplant survival; overall the rejection rate is 16%, the great survival is 98% in the first year, 90% in 5 years. Unfortunately, the infection remains the major killer, therefore, post-transplant monitoring is crucial for donors and recipients, since they are at high risk of infections. An intense battle for all clinicians in developing countries, including Pakistan, is the post-transplant tuberculous infection, present in 15% of recipients, with an incidence of 75% in the first year; the localization is predominantly pulmonary [8].

## Conclusion

The SIUT model, with exceptional values, is an incredible surprise, as it unites the medical profession with civil society, overcoming corruption and abuse. Much of the success of the SIUT can be traced back to the hard work that medical staff have been doing, for decades. It has been a very long effort; probably the most important factors are commitment, constant leadership, and the example set by Professor Rizvi, a philanthropist doctor, visionary of his time but a light of hope for millions of patients in the last forty years.

I have often wondered if this model can be exported to other developing countries but it is not easy to find the answer. The experience at SIUT impressed me deeply; it values the professionalism and humanity of our work as a nephrologist, often missing in some rich countries, where the private system manages the largest number of nephrological units and the focus is business; the role of the nephrologist is often diminished because he/she does not generate enough business, since the nephrologist works in a multi-disciplinary team, another factor abhorred by health business. The patient comes to the nephrologist, too often, when it is too late and the internal medicine doctor who followed him no longer knows what to do, or has already obtained the possible deal from that patient and then lets him/her go. At SIUT, nephrologists are extraordinary protagonists, passionate about their work, who do not spare their bodies but who weave their lives in the interest of the patient, never losing the desire for knowledge of the cultural exchange, remaining extremely humble; here nephrology regains its value, the importance that it deserves.

In Europe, since secondary school, we have always read about Pakistan as the hellish land of organ trafficking, but the SIUT model with its ethical commitment has altered this perception. The reasons that prompted me to write this editorial is that other colleagues, in Italy and Europe, should know this virtuous model and be able to create possible collaborations, sharing and cultural exchanges for globalized nephrology that can no longer do without participating in the evolution of our speciality in developing countries where there are doctors and individuals who “make the impossible possible” as wonderfully summarized by Zubeida Mustafa [1].



Fig. 9: From left to right Prof S A Anwar Naqvi, Prof S. A. H. Rizvi, Dr Tabassum Elahi

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