

Advanced Transplant Coordinators' Workshop 2019

PROCEEDINGS

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**Friday 21st June 2019, Chennai
Abu Sarovar Portico, 926, Poonamallee High Rd,
Kilpauk, Chennai, Tamil Nadu**



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Proceedings of the Advanced Transplant Coordinators' Workshop 2019

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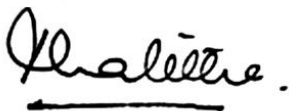
ACKNOWLEDGEMENT

It gives us great pleasure to bring out the proceedings of the Advanced Transplant Coordinators' Workshop for the year 2019. About 50 senior transplant coordinators and professionals in the field of Organ Donation and Transplantation participated in the workshop.

We thank the speakers and the chairpersons for sharing their knowledge and experiences during the meeting. Special thanks to the faculty who took time out from their work to speak to the transplant coordinators through skype. The transplant coordinators benefitted immensely with the discussions during the workshop.

NATCO would like to acknowledge the support of the following organisations in making the event a success - MOHAN Foundation, Tata Trusts, SBI Foundation, and Astellas.

We thank Mr. Siva Kumar, Mr. V. Sankar, Mr. Siva Shankar for the arrangements during the conference. We also thank the MOHAN Foundation team comprising, Ms. Sujatha Suriyamoorthi, Ms. Ishwarya Thyagarajan, Ms. Ann Alex, and Dr. Hemal Kanvinde for preparation of this proceedings.



Mrs. Lalitha Raghuram
President
NATCO



Dr. Sunil Shroff
Managing Trustee
MOHAN Foundation

AGENDA

9:30 am	INAUGURATION
10:00 am – 11:00 am	SESSION I – HAND TRANSPLANTATION Chairs – Dr. R. Krishnamurthy, Senior Consultant, SIMS Hospital, Chennai & Ms. Pallavi Kumar, MOHAN Foundation, New Delhi Experience sharing by a recipient - 15 mins Ms. Shreya Siddanagowder, Recipient from Pune Hand transplants – a pioneer speaks - 20 mins Dr. Subramania Iyer K., Head of Department, Head & Neck Surgery, Amrita School of Medicine, Kochi Requirements to establish and run a hand transplant unit in a hospital – 15mins Mr. V. G. Prasad, Transplant Coordinator, Amrita School of Medicine, Kochi
15 mins	<i>Tea Break</i>
11:15 am – 1:15 pm	SESSION II. Patient Support Group – Transplant Recipients TRIUMPH Chairs: Ms. Aneka Paul, Tata Trusts & Mrs. Lalitha Raghuram, MOHAN Foundation, Hyderabad Recipient perspective -10 mins Ms. Jaya Jairam, MOHAN Foundation, Mumbai Potential living donor perspective - 10 mins Ms. Sohini Chattopadhyay, Kolkata (via Skype) Caregiver’s perspective - 10 mins Ms. Usha Balasubramanian, Chennai Nephrologist’s perspective - 10 mins Dr. Suresh Sankar, NephroPlus, Chennai Perspective on work with haemodialysis patients - 10 mins Mr. Kamal Shah, NephroPlus, Hyderabad Panel discussion Moderator – Dr. Suresh Sankar Panelists – Mr. Kamal Shah, Dr. Balaji Kirushnan B. (Kauvery Hospital, Chennai), Ms. Jaya Jairam, Ms. Usha Balasubramanian and Ms. Sohini Chattopadhyay
60 mins	<i>Lunch Break</i>
2:15 pm –	Session III. Social Media Workshop on Twitter – Skills to take back – 45 mins

3:00 pm	<p>Chair: Mr. Adinararyana Dasika, Board Member - MOHAN USA</p> <p>Dr. Sunil Shroff, MOHAN Foundation, Chennai</p>
3:00 pm – 5:00 pm	<p>SESSION IV. Islam and Organ Donation</p> <p>Chairs: Dr. Sunil Shroff, MOHAN Foundation, Chennai</p> <p>Preliminary survey on Islamic Perspectives on Organ Donation in India Ms. Ishwarya Thyagarajan, MOHAN Foundation, Chennai; 12 mins</p> <p>Islamic perspective on Organ Donation in Middle East Dr. Riadh Fadhil, Director of Qatar Organ Donation Center – Hiba, Hamad Medical Corporation; 20 mins (via Skype)</p> <p>Improving Organ Donation in Muslim Communities in UK- Initiatives taken and progress made Mr. Amjid Ali, Partner and Project Lead, Transplantation in Islam, NHS – Blood and Transplant, UK; 20 mins (via Skype)</p> <p>Organ Donation in Islam - Introduction Mr. A. Faizur Rahman – Secretary, Islamic Forum for the Promotion of Moderate Thought, Chennai; 10 mins</p> <p>Panel/Case discussion Moderator: Dr. Sumana Navin Panelists: Mr. A. Faizur Rahman Dr. P. K. Rahiman – HoD, JBAS Centre of Islamic Studies, Madras University Dr. T. Ameen Ahmed – Professor of Department for BA – Arabic & Islamic Preston International College of Islamic Studies Mr. Senthil Kumar – Senior Transplant Coordinator, Government Stanley Medical College Hospital</p>
15 mins	<i>Tea Break</i>
5:15 pm – 5:30 pm	Valedictory/Summation

INAUGURATION

The workshop began with an invocation by Mrs. Lalitha Raghuram and lighting of a lamp by Dr. R. Krishnamurthy, Dr. K. Subramania Iyer, Mrs Lalitha Raghuram, Ms. Aneka Paul and Ms. Shreya Siddanagowder. Mrs. Lalitha Raghuram welcomed the delegates and the faculty and gave a brief account of the past workshops and how this present workshop has been designed. She requested the transplant coordinators to participate and learn from the deliberations.

Session I: Hand Transplantation

Chairpersons - Dr. R. Krishnamurthy and Ms. Pallavi Kumar

1. Experience Sharing by a Recipient

Speaker - Ms. Shreya Siddanagowder

Ms. Shreya began her session by asking the audience to look down at their respective hands and just appreciate them for a minute. A person's hands are one of their greatest assets, said Shreya. She was an 18 year old engineering student, who on 28th September 2016 met with an accident, when returning to college in a bus. Her arms were crushed and she was rushed to the hospital, and had both her arms amputated at the elbow level. Once she regained consciousness, her parents informed her that she had lost both her arms. They said that as parents telling their daughter that she lost both her arms was one of the toughest things they had to do. Shreya felt she was condemned to an existence she would never choose. After a month, she went home from the hospital, still grieving about the amputation. She had to be completely dependent on her mother, *"It reached a point where the feeling of dependency grows on you."* She began learning to use her toes and stumps. She was given prosthetic arms as an option and was told that she should be able to have 60% of her mobility back but she never reached even 6%. They started surfing the internet which led them to meeting Dr. Subramania Iyer from Amrita Institute of Medical Sciences (AIMS), Kochi. Dr. Iyer gave them a brief about the surgery, its aftermath and that she would have to take immunosuppressants for the rest of her life. Shreya got the opportunity to interact with Mr. Manu (the first hand transplant recipient in India) which gave her some hope. Ms. Shreya decided to take a break from her studies and focus on her transplantation and rehabilitation. Unlike other transplants, hand transplantation requires intensive rehabilitation.

She registered with the Kerala Network of Organ Sharing (KNOS) and got a call that same day informing her that there was a male donor. Dr. Iyer had checked with Shreya during the initial counselling sessions if she was fine with receiving male hands to which she did not object. The

transplantation was successful and Shreya became the first female in Asia to receive a bilateral upper arm transplant and the first female in the world to receive male hands. She also got to meet her donor's parents and is eternally grateful to them.



Ms. Shreya sharing her transplant story

She then spoke about life, post-transplant. The first three months were a breeze; it was after that she was diagnosed with post-transplant lymphoproliferative disease (PTLD). The doctors told her that if it came down to them having to choose between saving her life and amputating her hands, they would remove the hands. Thankfully for her, after three months she was cleared of PTLD. Shreya thanked her mother and said that if it was not for her she would not have fought PTLD; *"In a true sense she has given birth to me twice."* She also pointed out that while everyone is constantly praising her mother and that they often forget her father and the sacrifices he has made: he was living alone while they were in Kochi and he brought financial stability to the family. She went on to say that it was because of her parents that she was able to come out of the worst phase of her life and she is also grateful to have had good doctors and hospital staff.

After one year and eleven months and surviving a series of infections, Shreya said she is able to do almost everything on her own. Her hands which were a little darker post-transplant (the donor's colour) almost match her own complexion now after a year. She said that opting for hand transplantation was the best decision of her life. She ended by saying that, just like how one requires their internal organs, one needs their hands as well. Shreya requested the transplant coordinators to counsel for hand donation as well while counselling for other organs.

Q – As parents, could you share how you stayed strong and gave strength to Shreya?

A – Shreya’s mother: I told myself that I would be Shreya’s hands till she gets her hands back. I couldn’t imagine Shreya using prosthetics. So I surfed the internet and learnt about hand transplantaion. Looking at the other recipients it was encouraging to move forward in our decision. Shreya was very brave. She made one statement which I will never forget “I want to live my life even after my parents’ death. I do not want to be dependent.



Shreya’s father answering a question from the audience

Shreya’s father: Shreya was the one who was brave and said that whatever comes our way we will figure it out and move forward.

2. Hand Transplants – A Pioneer Speaks

Speaker - Dr. Subramania Iyer K

Dr. Iyer began by sharing that one of the best birthday gifts he has ever received was a letter written by Ms. Shreya.

He went on to speak about Hand Transplantation and what they have learnt so far from a medical point of view. He mentioned that prosthetics may not be the best option for patients who have lost their arms, while hand transplantation is. The hand has around 40 structures and hand transplantation takes about 15 to 16 hours with a team of 30 surgeons, 10 anaesthetists and 40 supportive staff being involved in the surgical procedure. With the help of case studies of the first few hand transplantations that were done, Dr. Iyer shared the excellent results they

were able to achieve. The Disabilities of the Arm, Shoulder and Hand (DASH) Score had given excellent results. A recipient's DASH score dropped from 91 to 13; even a drop of 20 is considered a success. Though science cannot explain this, activities of patients post-transplant could explain how beneficial hand transplantation could prove. Shreya underwent everything that could possibly go wrong for a post-transplant recipient, but was able to fight off all of it because of the family's support.

Dr. Iyer shared post-transplant stories of recipients and their donor families. Mr. Jithkumar Saji was the recipient of the first forearm transplant in the country. His donor belonged to a very poor family and his only wish was to give his parents their own home, but unfortunately passed away before doing so. This story was shared in a television channel which was viewed by someone in the US who wanted to help. A lot of people collected money and within the first year of his death anniversary a house was built for the donor's parents. During the ceremony, Mr. Jithkumar handed over the keys to the house of his donor's parents which in some sense resembled their own son handing over the keys to them. Mr. Manu, another recipient, after securing a job post-transplantation and working for a month, wanted to meet his donor's family and give them his first month's salary just like how their son would have done if he were alive.



Dr. Iyer speaking about the hand transplant programme at AIMS Kochi

Dr. Iyer said that more support is required from hospitals and NGOs; hence the AIMS protocol was designed and shared with interested hospitals. Hospitals like the Government Stanley Medical College and Hospital, Chennai; Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Puducherry; King Edward Memorial (KEM) Hospital, Mumbai; SPARSH Hospital, Bengaluru; Armed Forces Medical College, Pune; Global Hospitals, Mumbai and Gleneagles Global Health City, Chennai are some of the hospitals that are performing hand transplants in India.

Dr. Iyer spoke about the time when the confusion about the deceased donation programme began in Kerala. The perception that organ donation and transplantation is a private business should leave the minds of the public. More coordinators should be trained and for hand transplantation the Transplant Act should be amended as hands are presently classified as 'other organs'. There will be a change in people's mind-set only when more government hospitals come forward in making this programme active. Kerala requires more transplant coordinators to think about utilising all the donor arms. MOHAN Foundation has been extremely supportive in spreading the message of hand transplantation on many platforms.

The entire hand transplant programme apart from the medical aspects is being handled by Mr. Prasad, the Transplant Coordinator. Coordinators play one of the most crucial roles in promoting the deceased donation programme. There are about seven patients on the waitlist to receive a hand transplant since more than two years. Ms. Manega, a Malaysian Tamil mother of three children is one such patient. She would go to Singapore every week where she worked as a maid and come back home on the weekends to be with her family. Her husband who was schizophrenic and alcoholic doubted her intentions for going to Singapore and assuming the worst cut off her hands and legs and then killed self. Her oldest son is presently her caretaker. She wants to receive a hand transplant just to live with her children for a few more years, leading a normal life.

When Mr. Manu's donor, Mr. Binoy was brought to AIMS, they realised that those were divine hands of an artist and which should not go wasted. Mr. Prasad counselled Mr. Binoy's family to donate his organs and his hands. After Mr. Manu was able to regain the use of his hands, the first thing he had written was 'Binoy, Thank you,' thanking his donor. When the deceased donation programme in Kerala showed signs of failure, stories of Mr. Manu and Ms. Shreya have been used to promote the programme and gained the government's attention. Dr. Iyer also said that the option of retrieving the hands of a patient who has died of cardiac arrest is being explored as well. Similar to the attempts made by surgeons to reattach the arms back to the body of a person when they get cut off in accidents, retrieval and transplantation of arms from patients in hospitals following cardiac death should also be possible.

Q – Could patients with congenital deformities also get benefited?

A – One congenital hand transplant has been done so far in the world now. Since paediatric hand transplants are not being performed, by the time a person turns 18 years, he/she would have adapted to living without the hands in case of congenital hand deformities. If immunosuppressive drugs become better, then it can be thought about.

Q – What is the cost of hand transplants and Immunosuppression, and does AIMS have any funds?

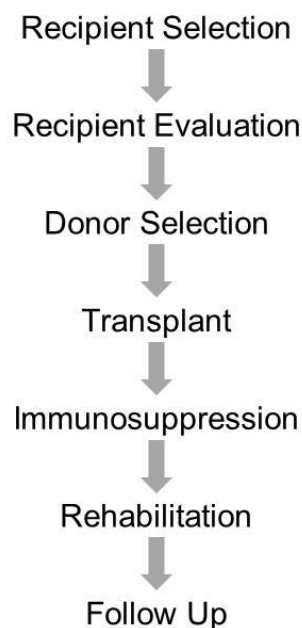
A – In AIMS it costs about Rs. 25 lakhs for everything put together. If a patient does not have the money they are generally not encouraged to consider the surgery option. An additional amount of Rs. 5 lakhs has now been added for provisions like air transport. The first transplant was done completely free of cost and the second transplant was entirely supported by the Afghan government, so there were no problems for the patients. For the third transplant, the funds were mobilised from AIMS for about Rs. 13 lakhs and the recipient paid around Rs. 7 lakhs.

3. Requirements to establish and run a hand transplant unit in a hospital

Speaker - Mr. Prasad V G

Legal Requirements and License - Establishing a plastic surgery unit, solid organ transplant unit, supportive services and having a transplant coordinator are some of the legal requirements to run a hand transplant unit. The Appropriate Authority inspects if these are met by the hospitals.

Protocol for Hand Transplantation - Mr. Prasad listed the protocol that was created and followed in AIMS, which has also been shared with other centres. Following is the protocol:



Recipient Evaluation and Listing - Recipient evaluation from a transplant coordinator's perspective begins with recipient selection; it is the initial counselling to understand the family background of the recipient. After the first transplant was performed, the team has been receiving numerous phone calls and e-mails and now many patients have been added to the waitlist, but only few transplants have been done. The selection is very important. This is followed by the basic investigation and then the imaging MRI or CT of the amputated limb. Immunology counselling is very important and in AIMS the patients are referred to the Nephrologists for immunology counselling. Psychology counselling is given importance as well; all the patients are sent to the clinical psychologist for evaluation. One of the legal requirements is to have a multi-disciplinary meeting before the listing the recipient in the state registry and to document the minutes of the meeting. Four topics to focus on in recipient counselling:

- a. Finance – as most of the patients have to bear the cost of surgery out of their pockets, finance is the first topic that is discussed with the patient's family.
- b. Motivation – unlike other organ transplants some kind of motivation is required from the recipients and their families to do aggressive physiotherapy post-transplant as they would have to stay by the hospital for a long time, hence the requirement to assess the family dynamics.
- c. Complications such as effects of immunosuppression, infections, etc. should be discussed with the family.
- d. Practical difficulties – unlike other organs for hand transplants cross matching, age matching, sex matching, colour matching is required. The availability of donor hands is also not known. A lot of the recipients come from other states and countries such as Pune and Afghanistan and have to stay near the hospital. Difficulties like these need to be discussed.



Mr. Prasad talking about setting up a hand transplant unit in a hospital

An information sheet, about 12 to 15 pages, printed in the local language and English is given to the recipients to take home and read. The counselling sessions and the consent process are video recorded as per the legal requirement. Then the recipient is listed in the state registry. Once registered, the recipient is required to stay near the hospital. To avoid any delay when a donor is identified, the recipient's blood is stored for cross matching.

Donor Counselling - When counselling families of potential brain dead donors, donation of hands is brought up last. The most common question that is raised when counselling to donate hands is the mutilation of the body and possibility of any additional delay in receiving the body if the hands are also donated. All the donor families ask for the identity of the recipient. Legally one should not reveal the identity of the recipient but for hand transplants, the recipient's condition and the details of how he/she lost his/her hands could be shared. When counselling is done, the prosthetic limbs are taken into the counselling room to help the family understand how the prosthetic limbs would be attached to the donor's body. Most of the time, the timing of the organ retrieval is decided by the transplant coordinators as they are the ones dealing with the donor family and the transplant retrieval teams, hence it is very crucial to fix the retrieval timing appropriately. When hands are donated, it is important to take photographs and complete police inquest before the retrieval in the event of a medico-legal case.

Hand Transplant Coordination - Another important point is that other organ retrieval teams may not be aware of the sequence of retrieval of organs when there is a hand donation involved. Hence it is important to arrange a meeting with other organ retrieval teams such as the heart, lung, liver, kidney, pancreas and sometimes small bowel to discuss the sequence of retrieval to avoid confusions. Having a detailed operation record especially in medico-legal cases is very important in arranging for an early autopsy. However, the most important step is handing over the donor's body to the family with the prosthetic arms, which many a time is not done by the forensic technicians and hence becomes the responsibility of the transplant coordinator to ensure that the prosthetic arms are attached to the donor's body before handing over. The transplant coordinator should take the initiative to follow up and rehabilitate both the recipient and the donor families.

Mr. Prasad's Experience

Mr. Prasad's so far has coordinated a total of five hand transplants involving two in-house donors and three donors from within 20 kms outside of AIMS. With regard to donor counselling, the counsellor should be someone who is aware of hand transplantation and its protocol. His/her presence is very important in donor counselling as well to get consent from the donor family. From his experience around 50 percent of the donor families will agree to donate hands if proper counselling is done.

Session II: Setting up a Patient Support Group – Perspectives from Stakeholders

Chairpersons - Ms. Aneka Paul (Senior Development Officer, Tata Trusts) Mrs. Lalitha Raghuram (Country Director, MOHAN Foundation)

Introduction – Ms. Aneka Paul

Patients generally encounter some barriers in identifying and joining patient support groups because of lack of awareness, time constraints and fear of confronting the negative aspects of a disease. In India there are support groups for cancer, HIV, mental health, bereavement, elderly care and sickle cell anaemia, being the most recent. In this context it is essential to discuss having a patient support group for organ donation and transplantation. Transplant Recipient's Indian Organisation Meant to Provide Hope (TRIOMPH) is one such initiative of MOHAN Foundation.

1. Transplant Journey

Speaker - Mrs. Jaya Jairam

The speaker shared with the audience her kidney transplant journey which began in 2008 with sudden unexplained weight loss. There were no standard symptoms related to a kidney failure like decreased urine output or swelling visible, and the doctors who were consulted were unable to identify the issue. She was told that her creatinine levels had elevated to about 3.5 and she should meet with a Nephrologist; she was stunned by these responses as many terms mentioned were completely unfamiliar to an engineering graduate that she was and left her confused. She remembers driving alone to meet with a Nephrologist who asked a lot of questions and wanted to know her medical history, while maintaining a poker face. She was asked about her childbirth, medications if she were taking any, serious illnesses she has suffered, etc. Another specialist was consulted based on the suggestion of her family doctor, who again had the same questions and expressions. No reassurances were given in either case. A biopsy was prescribed after electrolyte tests and a few other tests before she was finally diagnosed with chronic renal failure (CRF).

Her reaction to the diagnosis ranged from shock, 'why me?' (same as Shreya, the hand transplant recipient, after her accident) to 'why was I very disciplined and not have more fun during my school and college days and what would happen next?' She sought a second opinion from a bigger specialist at a larger hospital, had the biopsy redone at a higher cost (almost 5 times higher), hoping that it would not be CRF. Unfortunately this doctor also had the same diagnosis and informed that her kidney function was at less than 10 per cent. A new set of

medicines were also prescribed. She wanted to know how it happened – was it something she did or ate? It was explained that it had happened gradually, over a period of time and the damage is done and it is the end-stage. In Jaya's words, *"my world came crashing down"* upon hearing this.

Getting the biopsy done the second time was a very unpleasant experience that could never be forgotten said Jaya. She was admitted to the hospital in the morning around 8:30 AM and the biopsy was scheduled for 4 PM. Around 3-4 assistant doctors repeatedly tried their hands at removing tissue from her back and refusing to stop when she protested in pain, making her feel violated and she was left crying uncontrollably. She decided to go back to the earlier doctor to continue getting treated.

Nausea worsened, creatinine levels kept going up and getting through every single day became a challenge. She felt like she was losing control over things and obsessively began getting tested every day at home and knowing her potassium and sodium levels by the evening. The everyday fluctuations affected her emotionally. What to eat and what not to became one of the biggest confusions and she consulted doctors, dieticians and nutritionists who could recommend a diet that would stabilize the numbers. Despite all this, her potassium was more than 5 and creatinine over 6 and nothing could control them. She was recommended hemodialysis and the options of peritoneal dialysis and transplant were not offered. She was also unwilling to get an AV fistula for the dialysis which would be a lifelong reminder. Instead, a catheter had to be placed in her neck on an emergency basis, which was kept hidden with a dupatta while stepping out of the house in order to avoid questions by curious neighbours and relatives.

Jaya and her husband began doing their own research with the help of internet and Jaya was able to have a discussion with Mr. Kamal Shah who was undergoing peritoneal dialysis which would give more freedom and allow one to continue working. Jaya's husband was the one to suggest the option of getting a transplant and was willing to offer one of his kidneys. Jaya who was 33 years old then, immediately thought of her 5 year old daughter and her future and everything appeared bleak.

Relatives began offering suggestions to try out alternate medicines like Ayurveda, Homeopathy and visit random people for treatment. Jaya did not know what to discuss with them. Life became miserable; she did not want to get out of the bed in the mornings. With every deep breath she took, the overwhelming smell of ammonia gave her the feeling of a 'public urinal' as the amount of urea and uric acid build up was very high.

Jaya's daughter, who was five years of age that time, gave her hope by doing something as simple as leaving notes with drawings and messages encouraging her to get back in life.



Ms. Jaya Jairam sharing her kidney transplant journey

Jaya wants everyone to understand that nothing is offered on a platter to a patient and his family when looking for help; it is a journey where one will learn things as they move forward. Jaya had the following emotions and questions: why me, irritation, loss of will to work, future of the family, dilemmas related to dialysis, safety of living related donors, a range of questions related to life after transplant, and believes that a patient support group (PSG) will help patients deal with them. There will also be numerous questions related to expenses involved in buying immunosuppressants and check-ups following the surgery, insurance, infections, and side effects. It would help make life easier and less lonely, and have control over things. A PSG will help in sharing personal experiences, getting first-hand information on disease management, ways of coping and getting emotional support. There are many support groups for kidney transplant patients but hardly any for the liver and heart transplant patients. TRIOMPH (Transplant Recipient's Indian Organisation – Meant to Provide Hope) could be an umbrella for all transplant recipients to come together to support each other, educate, create awareness, activism and advocacy for legislative changes and raise funds. She then showed pictures from marathons and other events where the recipients and donors were involved in raising funds and concluded with a heart-warming picture of Jaya with her mother who donated one of her kidneys.

2. Views of a Potential Living Donor

Speaker - Ms. Sohini Chattopadhyay (over Skype)

Sohini calls herself a '*failed liver donor*' since last year, after she dropped out of donating to her father and instead her mother donated 70 per cent of her liver to him. Her father was recommended to get a liver transplant at the earliest, early last year. He was suffering from

end-stage liver disease for a few years and had refused to undergo a transplant until he slipped into a coma induced by hepatic encephalopathy for a second time.



Audience listening to Ms. Sohini Chattopadhyay (over skype)

Sohini remembers two junior Hepatologists making an observation that as an unmarried daughter she could be a potential donor for her father as her blood group was compatible as well. One of them went on to offer a compliment on Sohini's physical appearance, implying that she appeared fit enough to be a healthy donor. When asked about the nature of the surgery, Sohini was told that it would be similar to an appendicitis removal procedure and this reassured her to agree to be a donor and make an appointment with a surgeon. The surgical resident on duty informed her that there is a 0.5 per cent chance of death and the global statistics indicate 1 in every 200 donors dies. This came as a shock to Sohini who was in fact advised to get married before the surgery. It was on very same day that she had to undergo her first set of transplant workup tests to determine donor fitness. Her results showed high blood sugar levels.

Despite 0.5 per cent being a small number, it was hard for Sohini to digest that you could be one of them. Like what everybody would do, she also resorted to Google to understand the statistics better. A search of 'liver donor surgeries' returned information on donor deaths, with the one in KEM Hospital, Mumbai, being on the top. Additionally, there is no data available on India's donor mortality rates. Having heard the surgery to be as simple as an appendectomy was juxtaposed by reading about the donor deaths and Sohini was in for a shock. She was terrified by the thought of death following the surgery and could not confide in anybody as she was filled with the guilt of not stepping up for her father.

When Sohini met a transplant coordinator to submit her test results at one of the premier institutes in New Delhi, she was suggested to have a discussion with other patients. The

hospital's estimated surgery cost was one of the lowest in comparison to a few others located in metros including Chennai and Mumbai. The transplant coordinator mentioned the time and place where the patient families meet and also added that the family members of deceased patients – either recipient or donor, may not be joining the meeting. A transplant will be an emotional turmoil for anybody, particularly in the Northern part of the country where most transplants involve living donors. Hearing only from the families of patients who are doing well will be very biased and Sohini would not stand a chance to know both sides of the story.

It was at this moment that Sohini felt that a PSG would have immensely helped, despite the transplant coordinator being very helpful. She added that her experience with the TCs in all the cities she visited was good and they could be regarded as a 'confidante.' They were also very assertive and confident while advocating for their patients. Coming back to PSGs, she felt such groups could have helped her understand the surgery and post-surgery periods better. It would also have been easier to believe information regarding donor deaths if shared by the group. The fact that the hospitals in India refuse to share donor mortality data is bound to raise suspicions by itself.

She firmly believes that a PSG would benefit all patients, particularly someone like her father who was reluctant to undergo the surgery; had he met with other patients outside the hospital, the surgery could have taken place sooner. If the surgery had taken place earlier, the option of receiving the liver of a cadaveric donor would have been available, whereas her 56 year old mother had to step in at the last minute.

While speaking in her professional capacity she mentioned the article ('Sum of her parts' in The Hindu) she had written on the subject of living donations in India, sharing her experience in it as well.

3. Caregiving of a CKD Patient

Speaker - Mrs. Usha Balasubramanian

Usha was a participant in the one-month transplant coordinators' training programme held in the month of May in Chennai and is very passionate about caregivers.

As Usha began speaking, she recalled the fateful day 8 years ago when her husband was diagnosed with kidney failure. It was a huge shock for the whole family and Usha felt numb, clueless about how to react. Life after kidney failure is filled with hassles – both dialysis and transplant are not easy and both are expensive. In her 8-year journey as a caregiver, she made a lot of friends and shared a lot; life became an open book. Friends have now become family – both patients and caregivers.

The group constantly discussed their experiences and innumerable questions they had and Usha still knows a few people whose questions remain unanswered. She believes that a group like that is blessed to have TRIOPMH, a MOHAN Foundation initiative which would be a platform to share and interact in order to cope better. Expert panels consisting of doctors, dieticians and specialists would be invited by the PSG to share specific information related to transplants and both patients and caregivers can have their queries answered. Both physical and emotional challenges could be overcome through such meetings.

A transplant could help a patient break free from the dietary and lifestyle restrictions imposed by dialysis. She recalls her husband's comment, 'doctors tell that the quality of life improves markedly after a transplant, but when transplant in itself is lifesaving and awesome, quality of life becomes only secondary. Moreover, it is the end of dialysis, which is really great.'

All caregivers face the issue of financing the treatments. She quoted the example of one her friends, a 52-year-old patient who is his family's bread winner, currently on dialysis thrice a week, states that his monthly income equals his medical expenses. He has been on dialysis for 2 years now, waiting for a transplant and the recent heart issues have stopped him from going to work. His wife is the one supporting the family with the income of around Rs. 3,000 from the monthly tuitions she takes at home and their savings. His children are yet to complete their studies. Since he has almost another year to make it to the top of the transplant waiting list, the family is planning to sell their house to meet the expenses.

Medical bills can be huge enough to exhaust insurance and savings and most patients do not have insurance. TRIOPMH could provide advice on financial matters like insurance, crowd funding, etc. which would greatly help struggling patients and families. The advances in the field of transplant have allowed for extended life span and improved quality of life for those with end-stage renal disease and this in turn has increased the demand for organs for transplant.

Here she quoted MOHAN Foundation's contribution to the field by paving way for deceased organ donation in India for more than 20 years and its mission statement which she found inspiring. Being a part of the Foundation now, she hopes to make significant contributions.

One of the crucial factors that determine the success of a kidney transplant is the immunosuppressants which are taken life long after a transplant. An assistant doctor had shared with Usha that a recipient not taking immunosuppressant as prescribed is one of the most important reasons for a failed transplant. She mentioned how a young recipient lost her transplanted kidney just 3 months after the surgery because of this. Recipients should understand that the drugs help in maintain the health and functioning of the newly transplanted organ. Usha has noticed weight gain, high blood pressure, cold and cough, stomach upset and fever – the common side-effects of a transplant that force patients make frequent hospital visits and admissions.



Mrs. Usha Balasubramanian talking about her experience as a caregiver

Diet continues to play an important role even post-transplant and quoted from an article by the dietician of NephroPlus, ('Post-transplant Nutritional Care'), prescribed diet being the key to speedy and successful recovery. Monitoring urine output, gut function and taking supplements if required are crucial and applicable to any post-surgical care context.

She concluded by saying that a PSG like TRIOMPH could help patients, caregivers and their families in meeting all possible challenges and coping with them.

4. The Need for a PSG – a Nephrologist's Viewpoint

Speaker - Dr. Suresh Sankar

Dr. Suresh described the changes in health care over the years. He said that that the country has witnessed a lot of changes in terms of life expectancy, healthcare affordability, awareness about hygiene and basic health issues, etc. Likewise, the health delivery system has also changed. There has been a transition from infectious to non-infectious disease prevalence. Non-infectious diseases have multiple causal factors and not solely dependent either on family history, lifestyle or such individual factors. It becomes a challenge to articulate and convey the diagnosis and causes in its entirety during a patient's very first visit.

This has led to changes in the doctor-patient dynamics when a lot of other factors like tests, imaging, medicines, insurance, other hospital staff and administration, technology and advanced devices come into play. Every patient has to navigate through all these aspects while the doctor-patient relationship is somewhere in the middle of this maze. Furthermore, tertiary care is very complex in nature and higher the complexity, higher the cost.

Paying for healthcare is an area that India is lagging behind, in comparison to the developed countries and even some of its counterpart developing nations that fare better in out-of-pocket payments. Every single component like diagnostics, drugs and tests which are complex and high-end cost a lot eventually one has to pay out of pocket for all this. Therefore, the focus should be on how this cost could be borne by families, insurance, employers etc. Only around 20-25 per cent of people have some form of insurance.

All these components in the system are interdependent but function with the intent of serving an individual seeking care. The question would be, are they balanced? From a patient's perspective it is a huge maze and they are unable to differentiate between genuine and trusted information. They are unaware of the source of the balance as both public and private sectors have their own set of issues. It is also fair for anybody to expect excellent care at reasonable pricing and short timeframe, which could be a possibility in the future in the Indian context where the GDP contribution to healthcare is very low presently.

Explaining the doctors point of view, Dr Suresh said that the patient-doctor ratio in the country is skewed against the doctor in addition to the fact that the doctors are not formally trained in soft skills like communication during their training or thereafter. A doctor concerns himself with getting his diagnosis and treatments right, whereas patients overwhelmed with anxiety, approach the situation from an entirely different angle, making it a 'men are from Mars and women are from Venus' sort of situation. Particularly in all complex diagnoses, the anxiety is more and a lot of information that gets passed to the patients goes unregistered. Other factors like patient demography, language barriers, concerns about paying for the treatment and recovery also hamper effective communication.



Dr. Suresh Sankar talking about the need for a PSG

Dr. Sankar also commented on what the recipient and caregivers had to say about not being offered options in the transplantation context. All the systems have to be in a sequence and

have to interact in tandem, right from the first doctor visit and first test, delivering accurate information through representatives each of whom speaks a different language. For example, a lab technician and an administration officer would speak on two entirely different matters. This makes healthcare unique in comparison to other settings like banking or hotel. While the hospitals are receiving accreditations and regulations are improving, it is essential that a patient-centric approach is at the core and here is where patient support groups come into play.

5. Options of Dialysis for CKD Patients

Speaker - Mr. Kamal Shah

Kamal was diagnosed with kidney failure in 1997, following a round of vaccinations before a trip overseas. There were no other symptoms present and he was put on dialysis immediately. He underwent a transplant in 1998, with his mother donating a kidney, which lasted for only 11 days as there was a recurrence of his primary disease. Following this he began peritoneal dialysis which continued for six years, the best of times in Kamal's kidney disease journey. He came to know about peritoneal dialysis through the internet.

Kamal was caught in the tsunami of December 2004 in Mahabalipuram right after a dialysis session, miraculously escaped and drove to Chennai to get treated. Unfortunately by the time he got back to Hyderabad, he had contracted a series of infections and had to give up peritoneal dialysis (PD). He was extremely upset as the option had allowed him to work and offered a great amount of normalcy. Following this he was suggested by a doctor to consider home hemodialysis and equipped with additional knowledge from the internet, Kamal decided to opt for daily nocturnal home hemodialysis which he is presently on. He also started writing a blog about his journey which became hugely popular. Vikram who came across the blog was intent on doing something for the healthcare sector of India, suggested starting a dialysis center network. He was of the opinion that Kamal was the most apt person to lead it and NephroPlus, which is now one of India's leading dialysis networks, came into being.

Kamal recalls at the time when he was diagnosed the only support a patient could have was from another patient who was undergoing dialysis and their families from each while waiting in the waiting area. Lot of information exchange including perpetuation of misconceptions ranging from dialysis frequency to alternate medicines would take place. This informal network was the patient support system in those days.

The internet revolution changed things; Listserv – the email support group technology became widely popular. A patient could receive response to his query from people across the world.

The web-based forums were next and WhatsApp and Facebook have taken over now with numerous city-based groups and disease-based groups being sought after.

The way patients support each other has also changed over time. In 2000 when Kamal was on PD, he developed severe Restless Legs Syndrome (RLS). He found it difficult to manage the condition and began losing sleep; he had the never ending urge to shake his legs. His doctor had no clue about this when Kamal consulted him. He found a support group for PD, wrote to them and from the very first response he received, Kamal found that RLS was very common in people undergoing dialysis. His exact symptoms were listed in the reply received and he was recommended a drug which his doctor very positively told to try. Within a week's time after taking the drug, his symptoms completely disappeared.

Similarly when he was recommended home hemo by his doctor in 2006, he could not find anybody within India on the modality and the possibility of going through dialysis within one's home was scary and required reassurance. An email support group – Home Dialysis Center with patients from US, UK, Canada and Australia, came to Kamal's rescue again. First-hand experiences of people on home dialysis were good enough and convinced him to opt for home hemo. These were two instances where PSGs immensely helped Kamal.

The doctor to patient ratio in India is very low, and it would be impossible for doctors to interact extensively with numerous patients waiting to consult them. They would not have the time to discuss every aspect about a patient's health, particularly those that would not have a long-term effect on their health, affecting their morbidity and mortality. But for a patient every minor, simple aspect could be disturbing; similar to Kamal's RLS which bothered him the most.



Mr. Kamal sharing his dialysis experience and how PSGs helped him

Only a patient would be able to understand another patient and his symptoms better than anybody else. A doctor will be unable to offer any emotional support to a patient as they

wouldn't be able to comprehend the situation in its entirety. While it would not be advisable to talk to other patients about clinical matters, when it comes to emotional support, patient support would be the only option that works best.

Kamal emphasized that every patient is different and what works for one may not work for another and hence in clinical matters it is essential to approach only doctors. With the increasing popularity of social media, people are always armed with free pieces of advice to give out. Finance is another aspect where PSGs could offer support to patients. Only around 15 per cent of patients who need dialysis actually undergo dialysis and the rest could not afford or do not have access to a dialysis center. The support the government is offering has not been enough to meet the rising demands.

He then spoke about the Aashayein Kidney Foundation, a trust set up by NephroPlus that helps patients and their families secure funds for treatments, dialysis, medications and other investigations. He also had suggestions for people who are looking set up such platforms to help patients.

6. Panel Discussion – Setting up a Patient Support Group – What does TRIOMPH need?

Moderator – Dr. Suresh Sankar

Q: Suresh Sankar – What are the two areas a PSG like TRIOPMH should focus on?

A: Balaji Kirushnan: Glad that a PSG is being set up. Focus should be on having frequent meetings and improving doctor-patient communication. From his experience, he quoted an example of a patient requiring a transplant, from the rural part of the country, after having met with several doctors not knowing for a very long time that her spouse could be a potential donor. Such knowledge gaps could be addressed if doctors initially spend around 20-30 minutes counselling patients during their first visit. The PSG should have a mission and frequently meet with doctors, dieticians, transplant coordinators, dialysis technicians, NGOs etc., at least once a month with a clear agenda. Emotional, social, financial constraints could be discussed with questions being answered; misconceptions could be clarified.

A: Jaya Jairam: When deliberating about accepting her mother's kidney when it was offered, it would have helped to know another donor or recipient's perspective, particularly because Jaya was worried for her mother's safety. Today when people see her they are surprised to know she is a recipient; a PSG could give a patient confidence to make decisions.

A: Sohini Chattopadhyay: In addition to information and education, mentioned by other speakers what is also missing is empathy from the doctors' side. Sohini would expect a group like TRIOMPH to have a helpline or lifeline like setup that would answer queries of patients outside of the hospital atmosphere; it would help if answers come from someone not part of the hospital bureaucracy. She also thinks that meetings as few as 5 in a year could highly benefit a patient like her father who has just completed a year since his transplant; monthly meetings may not be very practical though.

PSGs could also double up as lobbying networks, advocating for patients encountering challenging situations like shortage of immunosuppressants or when their prices shoot up. It would not be practical to expect the doctors to step up and help during their hectic schedules. Activism, emotional support and a tele-calling service are three things a PSG could offer.

A: Kamal Shah: Information dissemination and addressing misconceptions would be the key aspects. One should consider both the online and offline components; online would be apt for FAQs and myths. In the Indian context, language is crucial as majority do not understand English and hence it is essential to pass on information in the local language. Though a fairly good amount of the population has access to online platforms like the WhatsApp, there should be an offline mechanism available for giving out information related to health matters. Volunteers should be recruited for this task of answering queries.

Q: Suresh Sankar – What are some of ideas that could be borrowed from PSGs for other diseases like cancer, HIV or Hepatitis? (HIV probably would be an outlier in this context)

A: Kamal Shah: The breast cancer awareness activities would be a good example. An awareness month could be dedicated for kidney disease or transplants and activities could be organized. Fundraising could also be attempted during such times.

A: Sohini Chattopadhyay: HIV networks, with their energy levels are always very inspiring. The socio-economic and demographic aspects are important as they can make a difference and should be considered while PSGs are being setup. Sohini gave the example of 'Chai for Cancer' a cancer support group helping to raise funds for patients suffering from two specific cancer types. The funds raised serve only one purpose – help in patients' commute to collect their monthly supply of drugs from an organisation that provides the drugs for free. Most patients of the group were from the economically weaker section of the society. Sustainability of this fundraising model maybe questionable though.

A: Jaya Jairam: Challenges for a recipient continue even after a transplant in terms of paying for their drugs. Though certain states like Tamil Nadu offer them at a subsidized price, it is extremely difficult for many other patients. There are patients who run around every month, to and fro between organisations for paltry sums in order to manage the situation.

A: Usha Balasubramanian: The financial aspect is the most important and a PSG should address concerns in that area. Dr. Sankar added that to achieve equity in access and care in a country like the India, at least 8-9 per cent of the GDP should be contributed, while it is lower than 2 per cent presently. Usha also added empathy as a focus area.

A: Balaji Kirushnan: Patients usually have money for the transplant surgery, but the burden continues to remain even after the surgery especially if other complications arise. An affluent dialysis patient of Kauvery Hospitals has helped set up 'Save a Life Today (SALT)'- a support group for dialysis patients, offering free dialysis for one patient in a day. After his unfortunate demise, his sons continue to support the initiative. The SALT group, using its funds, was even able to help another young patient on the verge of a rejection post-transplant get some basic treatment. Dr. Balaji is unsure if a PSG like TRIOPMH would be able to receive support from other cancer or HIV groups; like-minded causes will be the key.

A: Kamal Shah: In its initial stages, TRIOPMH should be taking small steps like trying to help only those patients who are unable to secure immunosuppressants after the first two years post-transplant when the risk of rejection is the highest. It would be advisable not to take on a lot like attempting to fund an entire transplant or pay for drugs in the long term.

Q: Suresh Sankar – How could the private sector (hospitals and pharmaceuticals in particular) collectively contribute?



Panel Discussion about PSG in progress

A: Jaya Jairam: There could be campaigning for health insurance cover for transplants

A: Kamal Shah: In the long run the government in India has to get involved in the matter. The hospitals and government should engage in dialogues – the hospitals should make provisions for treatments and government should bear the cost. Hospitals should adhere to norms and promise to provide quality care at reasonable prices.

A: Sohini Chattopadhyay: Hospitals, despite having the infrastructure, may not be the right candidates to offer the support that is required as they would not have the time and energy required for a PSG to function. Hospitals and surgeons look for numbers and volumes and they could bring together patients in large numbers. Crowd funding platforms are very genuine and have the potential to start chain funding; but the focus is only on the surgery part of the process. Crowd funding organisations could also think about stepping into post-surgical care sphere and supporting PSGs.

A: Usha Balasubramanian: A friend of hers was able to raise funds for his transplant through Milaap, a crowd funding platform.

Concluding Remarks: Ms. Aneka Paul: Perspectives from different stakeholders was very much essential for the context. TRIOMPH could play a moderator's role in ensuring accurate, reliable and relevant information is communicated at all times. A lot of empathy would be required while addressing both patients and caregivers. With regard to learning from other PSGs, Aneka suggested the sickle cell anaemia and mental illness groups that share the chronicity of illness and caregivers' fatigues aspects with a transplant PSG.

Session III: Using Social Media to Promote Organ Donation

Chairperson - Mr. Adinarayana Dasika

Speaker: Dr. Sunil Shroff

Dr. Sunil Shroff's session was split into three parts: Introduction to Social Media, Creation of Infographics and Videos and using Twitter.

Dr. Shroff said that there are 3.7 billion users of social media and more than 400 hours of videos are uploaded on YouTube every minute. How to position ourselves on various platforms was explained using examples like:

Twitter – 'I am eating masala dosa'

Facebook – 'I like masala dosa'

Instagram – 'Picture of me eating a masala dosa'

You tube – ‘This is how I eat masala dosa’

LinkedIn – ‘My skill is making a masala dosa’

The audience were given a similar exercise to attempt blood donation promotion on various social media platforms. Dr. Shroff suggested that the participants should use these social media platforms to promote organ donation.

He mentioned that the age of email is coming to an end and is being taken over by WhatsApp and similar apps. 93% of patients get medical information via the internet. 1200 communities in Facebook – catering to needs of patients). Health care professionals are not active on social media and this should be rectified. There are more mobile users than the population of the world. He advised that the participants should download all the apps on their mobile, since most of us travel – updating this would be easier.

He asked the transplant coordinators if social media can be helpful. Many of the participants found the media to be useful. He gave the example of the Ice Bucket Challenge as a successful awareness creating and fund raising campaign. Dr. Shroff enumerated the positive aspects of social media as: creating awareness, raising funds, crowd funding, finding solutions. But soliciting of donors has brought out the ugly side of social media. He said that the premier Indian Society of Organ Transplantation has to bring out guidelines for all transplant professionals to follow.

Dr. Shroff made an appeal to the delegates to participate in an impromptu crowd funding activity for the benefit of Patient Support Group TRIOMPH. Mrs. Bhavna was chosen as the fund collector and a bag was sent around the room for collection. The activity was able to raise around Rs. 7000/- .He cited examples of two MF employees who successfully raised funds for surgeries and cancer treatments. Organisations like Ketto and Milaap use the power of social media to raise funds for patients.

He mentioned that Facebook has a feature in the profile page that allows for setting life event to ‘Registered as an Organ Donor.’ He requested everyone to update their status to reflect organ donor registration. He urged all the delegates to use this exercise as an activity in their public interactions. He guided the delegates in creating Twitter accounts.

Then session on creation of info graphics, animations and video was handled by Ms. Amala. She started with the importance of choosing a light colour to be the base colour which matches the theme while creating graphics. She added that the text needs to be kept to the minimum and statistics can be depicted by using flat pictures and icons. Next she guided the audience through the “Animaker” web tool to make animations. She explained colouring, font designing, and character animations. Editing tools and including music were also explained.



Dr. Sunil Shroff and Ms. Amala guiding the audience on using social media effectively

Dr. Shroff began the session on Twitter using his own account as an example. He touched upon the following topics in his talk on Twitter: Twitter as a social media platform; how to create a poll; strategies to acquire more followers and likes; lists on organ donation; help to build up the community (sense of awareness); role of celebrities: involving celebrities to reach the mass population, trends going on Twitter. He said that tweets are like microblogs (180 characters), retweets make the message more powerful. Tagging friends and followers and celebrities is also possible. He explained the importance of using hashtags in Twitter, Facebook and Instagram, to improve brand recognition and image. He also explained how to create a trend in twitter using hashtags like ‘#MFOrganDonor’ or ‘#IslamandOrganDonation.’

Mr. Gowtham of Brand That Social conducted a short exercise on how to generate maximum “likes” on one’s own FB page using #MFDDonateOrgans and using a creative from MF Facebook page. At the end Dr. Shroff announced that the delegate with the most likes after posting a MF creative shall be awarded a prize.

Session IV: Islam and Organ Donation

Chairperson - Dr. Sunil Shroff

1. Preliminary survey on Islamic Perception on Organ Donation

Speaker - Ms. Ishwarya Thyagarajan

Ms. Ishwarya Thyagarajan presented the abstract of a preliminary survey conducted on Islamic perception on organ donation.

Background: Organ donation often receives opposition from Muslim ulemas (scholars) and muftis (jurists) in South Asia as the human body is considered an ‘amaanat’ (trusteeship) from God and should not be desecrated after death. This study aimed to gain basic understanding about the Islamic perspectives on organ donation.

Material / Method: 75 respondents from Chennai city and a few districts of Kerala (stratified random sampling) were interviewed using a questionnaire designed by MOHAN Foundation. The questionnaire included demographic profiling, awareness about organ donation and transplantation and religious views and attitude towards organ donation and transplantation.

Results: Owing to the minuscule nature of the sample size, the responses were skewed and did not allow for any concrete conclusions to be arrived at. However, they did indicate that religion strongly influences decisions made in relation to donating or receiving organs in the community. Religious leaders and religious texts have considerable clout in the matter. The results also suggested that while there is a strong reluctance to donate organs, receiving organs is widely accepted. A lack of general awareness regarding organ donation and transplantation was evident as well.

Conclusion: Facilitating dialogues among religious leaders would help in understanding the Islamic perspectives on organ donation and transplantation. Awareness activities should be initiated to spread those religious perspectives among the Muslim communities. Providing access to religious counsel would help in decision making for the potential deceased organ donor families.

2. Islamic perspective on organ donation in Middle East

Speaker - Prof. Riadh A.S. Fadhil, Qatar (via Skype)

Prof. Riadh A.S. Fadhil expressed that the success of a transplant programme not just depends on clinical expertise and infrastructure but also on the public participation; the public will not participate unless they develop trust in the system. While many factors influence public trust, faith opinion regarding organ donation and transplantation plays a vital role in the public decision making to participate. He stressed that medical ethics principles such as autonomy, beneficence and non-maleficence, equity help build trust which eventually will help in influencing public participation.

Prof. Fadhil introduced the audience to the culturally-diverse society of Qatar and the change in the public awareness and attitude that happened in Qatar. He said that almost 85% of Qatar’s population is expatriates and most of them (60-70%) are low income workers and mostly from Middle East and Southeast Asia. While talking about Qatari natives’ perception about organ donation and transplantation, he said historically speaking, ten years ago, the natives often

refused to receive transplants from their relatives and to be enlisted on waiting list as well. Most of them used to search for organ transplant abroad.

Most of the expatriates had come merely for occupation purpose and live alone in Qatar (about 70%). If they become potential deceased organ donors during their stay in Qatar, then their families are approached for organ donation through international telephone calls. The families' knowledge and decision about organ donation is based on their experience in their home country and that reflects on their participation in organ donation in Qatar. And if they need a live donor their relatives are abroad.

This status gradually changed to the opposite. The lack of awareness in general in the multicultural society whether for expatriates or the natives started changing gradually from 2009 when the Doha Donation Accord was launched and its multilingual organ donation promotion campaign helped raise awareness and educate people on the positive views of different religions and faiths on organ donation and on the different strategies that are adopted in Qatar which respect equity, autonomy and human dignity.

Currently majority of our patients (90%) receive organs from their ethically approved relatives or from deceased donors. Education was the main tool that made the change in the attitude and participation in the organ donation program.

Prof. Fadhil said that there were many Islamic rulings (fatwas) issued on organ donation and transplantation by various Islamic societies across the world.

- Live organ donation is permitted in Islam as this act will alleviate the pain and suffering of the fellow human being - Abdul Rahman Al Saadi (1955)
- Any type of organ donation is prohibited in Islam on the grounds that humans do not own their bodies - Sheikh Al Shaarawi 1980
- Azhar Fatwa Council, 1980 - Organ donation is permissible not only from living donor, also from a deceased person, if the deceased has consented to it while he was alive, or if his next-of-kin has consented it.

Prof. Fadhil narrated various arguments and counter-arguments on organ donation held by Islamic scholars in the past. At the beginning there were many opponents expressing their opinions against organ donation during 1950's stating the following:

- The dignity of the human being bestowed by God will be dishonoured
- Sanctity of the human body will be desecrated by the act of organ donation (Breaking the bone of the dead is as forbidden as breaking the bones of the living).
- God is the owner of our body and our organs. God granted the man to benefit from his organs. He is not entitled to donate these organs.
- Benefits versus Harms - Doubtful benefit to the recipients (rejection), death of donors.

However, with the development of transplantation sciences and techniques and better understanding of the procedures by scholars, the scenario slowly changed between 1970 and 1980, and there were increased support from government, politicians, healthcare sector and Muslim scholars and councils. There were many proponents who expressed their views in favour of organ donation stating that:

- The dignity of human body is not compromised
- The retrieval of organs is ordinary operation and not mutilation.
- God is the Owner but the human being is the trustee of the organs, and they can be used in good intention to save lives of other human being. Charity is a great pillar of Islam. He is not selling them and it is given by free will. In Islam “Deeds are rewarded by their intentions”
- Progress in the field of transplantation and outcome of procedures are much better nowadays and living donation is much safer.

The Council of the International Islamic Fiqh Academy - The Council of the International Islamic Fiqh Academy held in Amman, Jordan, October 11 – 16, 1986 after looking into issues raised in relation with life supporting equipment, expressed its resolutions and recommendations as follows:

Resolution No 17 (5-3) – Concerning Resuscitation or Life Supporting Equipment

According to Shari'a, a person is considered dead, and all Shari'a rules regarding death become effective, if he shows one of the following two signs:

1. Complete cardio-respiratory arrest and confirmation by physicians that such arrest is irreversible;
2. Cessation of all brain activity and confirmation by physicians that such cessation is irreversible and that the brain has entered the state of decomposition.

Under these circumstances he can be weaned of the intensive care equipment supporting him, even though some organs of his body, like the heart, continue to function artificially, with the help of the supporting equipment.

So currently the vast majority of scholars and Islamic councils' fatwas are in favor of Live and Deceased Organ Donation provided that the following conditions are observed:

- ✓ Donation should be from an adult on his/her free will and not forced to coercion physically or morally
- ✓ The donated organ should not be one of the solitary organs such as heart, because the person cannot live without them
- ✓ The removal of organ or part of the body e.g. the eye should not cause disfigurement of the donor

- ✓ No harm should be inflicted on living donor due to the donation process
- ✓ Donation is the only mean to save the patient, and there are no other means to do that
- ✓ Transplanted organs should not be the carriers of genes such as testicle, ovaries
- ✓ The transplant should not be through sale or trafficking but through altruistic donation. There is no objection to a reasonable reward or gift without pre-condition
- ✓ In the case of deceased donation, a will from the deceased or the permission of his family or the guardian, to donate his body after being injured in an accident and he is in the brain death status, even if the heart is still beating
- ✓ The most likely outcome of the donation is to benefit the recipient with certainty and save his life and at the same time there is no harm to the donor

Prof. Fadhil concluded his talk saying that a considerable Muslim population around the world still believes that organ donation is prohibited by their religion but it is not true. Islam is fully supportive of organ donation and transplantation. Lack of knowledge is the main cause for the low organ donation rate among Muslim communities.

3. Improving organ donation in Muslim Communities in UK- Initiatives taken and progress made

Speaker - Mr. Amjid Ali, UK (via Skype)

Mr. Amjid Ali said that in principle all the major faith groups support organ donation. However, a research conducted among the UK-BAME community (United Kingdom Black, Asian & Minority Ethnic) suggested that in some faith based communities the position of one's religion is used to inform their decision about organ donation (Randhawa, 1998; Oliver et al. 2011).

Though the Islamic perspectives on organ donation and transplantation have been extensively debated over the last 50 years and while there are many areas of consensus, Islamic scholars sometimes differ in their opinions depending on their method of reasoning. This means, certain rulings considered to be permissible under Islamic law by some Islamic scholars, may be deemed impermissible by others. Organ donation had been one of the areas which was not widely discussed among faith leaders and the diverse Muslim communities primarily due to lack of knowledge and understanding about the process of donation and the permissibility of organ donation in Islam. This had led the Islamic faith community to seek guidance from religious leaders about organ donation before involving themselves in any sort of engagements.

This insight into religion's position in decision making helped NHSBT to derive three possible strategic options for consideration:

- Do nothing and let the organ donation rate (ODR) among the BAME community continue to be less.
- Maintain status quo (existing state of affairs) and this unsettled issue will become more problematic for future generations
- Invest in community engagement which might help in increased ODR among BAME community and more lives could be saved.

Attitudinal segments of faith communities - He emphasized that studying the attitudinal segments of faith communities was essential to understand the barriers for public engagement. He further briefed about the three distinct groups and their attitude towards organ donation.

- Interested but uninformed – A segment that feels organ donation is important and like to participate. However, they do not know enough about the process and need clarification from Sharia scholars
- Interested but cautious – Segment of people who feel that organ donation is important and like to participate. However, they are worried about Sharia rulings and fear about Islamic consequences.
- Cynics – This segment feels that organ donation is a serious breach of their religious faith and feels that Islam strictly prohibits organ donation.

He also talked about the conference that was convened by the NHSBT for the BAME community in 2013. The conference intended to discuss the role of faith in organ donation and to structure a way forward to work with various faith communities. As a result, a number of strategic objectives were formulated and one of them was securing an updated religious opinion on organ donation in the UK.



Mr. Amjid Ali (via Skype) speaking about his experience with the Muslim community in UK

Community engagement plan - Mr. Amjid Ali stated that all those understandings helped NHSBT determine its efforts for effective engagement and participation. He further talked about the NHSBT's strategic community engagement plan which included the following:

- Engaging stakeholders to secure their support and to enhance communication links for more number of faith groups to be addressed.
- Review engagement plan and device communication plans to address the specific needs of various faith groups.
- Organise Muslim scholars' conference to help them understand the subject matter, brain death and organ donation therefore.
- Trainings for Imams and community based groups on medical and religious aspects of organ donation.
- Implement communication plans which are consistent and aligned.

Fatwa from Sunni perspective to clarify Islamic position on organ donation – Issued by Mufti Mohammed Zubair Butt, a leading Islamic scholar in the UK

Mr. Amjid Ali said that this community engagement plan seemed to be effective and is starting to show results in favour of organ donation. He shared his experience on how he secured Mufti Mohammed Zubair Butt's support in producing an updated fatwa on organ donation. Going with the community engagement plan, Mufti Mohammed Zubair Butt was approached for the need of Islamic community's participation and was sought for his guidance. He was then linked with clinical experts to understand and research thoroughly about the subject of brain death and organ donation. Over a period of five months, Mufti Mohammed Zubair Butt introduced a fatwa from a Sunni perspective which addresses a number of concerns that the Muslim community may have around organ donation.

Mr. Amjid Ali said that after this significant result, numerous faith groups have started showing their support for organ donation. However, this is only the start of the journey and a concerted effort is now required to inform the diverse Muslim communities about the change in law 'deemed consent' and to encourage Muslims to make an informed decision about becoming organ donors. The fragmented approach by various Islamic groups is found to be a weakness in implementing communication plans in the UK. The strong scrutiny of the Muslim community in the UK and misinterpretation by press often led to a decrease in the community's participation fearing criticism.

He concluded his talk saying that, looking at the UK's experience, 'Educate – Inspire – Reform' would be the way forward for effective community engagement.

4. Panel Discussion

Moderator – Dr. Sumana Navin

Introduction – Mr. Faizur Rahman



Mr. Faizur Rahman explaining the practice of organ donation among Muslim community

In his introduction, Mr. A. Faizur Rahman said that the practice of organ donation is low among Muslims and it is mainly because of the uncertainty in the community around the Islamic law and Islamic viewpoint on organ donation. He added that Islam is perceived merely as a religion, which it is not. Islam is all about humanitarianism; it is a set of values and should be looked beyond religion. He quoted a verse from Qur'an which says that 'Unless you give what you love the most to a person who needs, without compromising your life, you cannot even think about attaining the pinnacle of goodness'. He also said that the Holy Qur'an is often misinterpreted and therefore the basic understanding about Islam and its perspective on organ donation among the community is often incorrect.

Dr. Sumana highlighted a few scenarios for panel discussion.

1. Celebrity speak for organ donation

- *Mansoor Ali Khan Pataudi, Indian Cricketer pledged for eye donation. His family went ahead and donated his eye after he passed away.*
- *Syed Kirmani, Indian Cricketer pledged to donate his eyes but later retracted. He stated, "I pledged to donate my eyes. However, I might not be able to honour my commitment due to some religious values."*

Q: Sumana Navin – How would these celebrities’ views influence a specific faith group?

A: Abdul Rahiman: Celebrities making such statements that their religion does not support organ donation adds to the stigma that already exists. They should be more responsible and accountable as organ donation is a very sensitive social issue.

A: Faizur Rahman: The Islamic values do not support retraction of the commitments that are made. Therefore, this cannot be attributed to religious values.

A: Ameen Ahmed: It is nowhere mentioned in the Holy Qur’an that organ donation is prohibited in Islam. Taking support from religion for one’s own purpose is not acceptable. Influencers like celebrities, political leaders should be more accountable.

2. Moral dilemmas of Common Muslims

There are many Islamic countries that have a law on organ donation and some of them have established successful deceased donor programmes (www.irodat.org). However, there are some moral dilemmas that exist among the common Muslims such as:

- *Ownership of human body*
- *Sanctity of the human corpse being violated*
- *Delay in performing funeral rites*
- *Moral responsibility of the donor, if the recipient commits wrongdoing*
- *Donating organs to non-Muslims*

Q: Sumana Navin – How to address these moral dilemmas and what are the Islamic perspectives?

A: Abdul Rahiman: Response to - ‘Moral responsibility of the donor, if the recipient commits wrongdoing’ & ‘Donating organs to non-Muslims’

“No person earns any (sin) except against himself (only), and no bearer of burdens shall bear the burden of another” - Holy Qur’an (6:164).

In Islam, there is no such issue of whether one will become an accomplice of another person’s misdeeds. The Iman (Islamic faith) says that every individual is responsible for his/her own actions; every deed is governed by his/her own intentions. The benefit of the act alone is most important and that has to be perpetuating. The moral responsibility of the donor is only to have good intention. Islamic jurisprudence on social responsibility stresses that taking care of fellow human beings’ needs is the responsibility of every Muslim. The Iman is not a mere abstraction;

it has to be the ground reality of human lives. Islam allows these interpretations to be expanded to the medical science as it is considered to be one of the noblest sciences.

A: Faizur Rahman: Response to - 'Donating organs to non-Muslims'

Islam advocates doing good and showing compassion to all creations and this evidently includes non-Muslims as well.

A: Ameen Ahmed: Response for 'Donating organs to non-Muslims'

"Whosoever saves a life, it would be as if he saved the life of all mankind." - Holy Qur'an (5:32).

Islam does not differentiate between a Muslim and a non-Muslim.

Response for 'Delay in performing funeral rites'

The Islamic jurisprudence says that when a person dies, there should not be any unnecessary delay in burying the deceased. However, it shall be accepted in situations like organ donation as this act will save a few lives.



Dr. Sumana Navin moderating a Panel Discussion on Organ Donation in Islam

3. Case study discussion – Approaching Muslim families for Organ Donation

Q: Sumana Navin – As a transplant coordinator, what is your experience in approaching Muslim families?

A: Senthil Kumar: All the Muslim families that were approached for organ donation in his hospital had turned down the conversation saying that organ donation is not permitted by Islam. However, the team still continues to approach every Muslim family whose next of kin has been pronounced brain dead because organ donation is an opportunity for them to save the mankind.

4. Case study discussion – Recommendations of Islamic Fiqh Academy, India, 1989

The Islamic Fiqh Academy, India, 1989 had expressed the following two contradictory statements:

- *Organ donation is permissible from a corpse if the deceased has expressed will while alive and his inheritor has consented to it.*
- *However, it also says that if someone expressed his wish that after his death his organs may be used for transplantation purpose, it cannot be considered as Wasiyat (will) and is invalid according to Sharia and such a wish is not to be honoured.*

The topic of ‘Brain death’ has been mentioned in the 16th Fiqhi Seminar (Azamgarh, UP, 2007) but no further outcome on the same.

Q: Sumana Navin – Suggestions to involve the Islamic Fiqh Academy, India for better engagement with the Islamic faith community in India.

A: Abdul Rahiman: In general, there is not much engagement between Islamic scholars and medical fraternity in South Asian Countries and needs to be addressed. Educating Islamic scholars on subject matter and sensitising medical fraternity about Islamic views and jurisprudence will help in engaging the Muslim communities.

A: Faizur Rahman: Reforming the understanding of Islam among the religious scholars and the common Muslims is much needed. If someone had expressed his wish to donate his organs after his death, it should be considered as Wasiyat (will) according to the Islamic laws. The next-of-kin shall ascertain his wish to be an organ donor after his death is carried out. In the absence of a Wasiyat, the local religious leader shall take a decision and consent for organ donation.

A: Ameen Ahmed: Involving subject experts in Islamic academic activities has not been a routine practice in India. Engaging the ulemas in the organ donation movement would help in updating fatwas on organ donation. The transplant community should take initiatives to educate religious leaders which in turn will help in educating faith communities.

5. Fatwas and their legal bindings

Q: Sumana Navin – What is the legal binding of fatwas? How could having a fatwa in favour of organ donation help improving the organ donation among the Muslims?

A: Faizur Rahman: A fatwa is an Islamic non-binding legal pronouncement, issued by a religious expert pertaining to a specific issue. The Supreme Court of India, in 2014 ruled that fatwas issued by any mufti has no legal sanctity. It also said that it would be illegal to impose religion-based opinions on any individual and will be considered as violation of fundamental rights.

A: Abdul Rahiman: Fatwas are only the opinions of religious scholars and they do not have any legal binding. However, there are a large number of Muslims who look up to religious scholars' opinions on social issues. This is only to ensure that their actions are within the framework of their faith.

A: Amjid Ali: The social and humanitarian benefits of organ donation have to be understood by the faith.

There are fatwas that support living donation but not deceased donation. This has to be introspected because when organ donation while living is considered an act of sacrifice, donating organs after death is considered haram on the other hand.

In brain death, death is confirmed using neurological criteria while the heart is still beating; this seemed to be not aligning with the theological definition of death. Hence it remains a question among the majority that when does the soul depart from the human body in deceased organ donation.

When families are approached for organ donation, and if they are uncertain about their faith perspectives, an updated fatwa on organ donation shall help them in making decisions about organ donation in such situations.

A: Ameen Ahmed: The Holy Qur'an says that when you do not know, seek guidance from the religious scholars. No rulings of Islam will contradict the humanitarian values. Hence, having fatwas on organ donation, issued by authentic religious scholars will certainly help to engage the faith group.

6. Buying or selling the human organ

The practice of selling the kidney for profit is legal and regulated by the government in Iran. The country also has a very robust deceased organ donation programme.

Q: Sumana Navin – Is buying or selling of organs acceptable in Islam?

A: Ameen Ahmed: It is not permissible to subject human organs to sale under any circumstances.

A: Faizur Rahman: It is highly immoral as it violates human sanctity.

A: Abdul Rahiman: Sheikh Dr. Yusuf al-Qaradawi's fatwa says that transplant should not be through sale or trafficking but through pure donation. However, there is no objection to the reward or gift without condition. In this context, can the paid living donor programme be merely perceived as commercial as the state of Iran itself facilitates the process and incentivise the donor?

7. Donating organs/receiving transplants - Muslim's perspectives

The practice of selling the kidney for profit is legal and regulated by the government in Iran. The country also has a very robust deceased organ donation programme.

Mr. Vittal Shende (Transplant Coordinator, KEM Hospital, Pune): There are many Muslim patients waiting to receive a transplant and receiving an organ does not seem to be an issue. But to donate organs, they seem to have a lot of queries which are mostly about religious views and the scholars' opinions.

Dr. Bhanu Chandra (Manager - Operations, MOHAN Foundation, Hyderabad): Had approached around 14 Muslim families for organ donation and received consent from only one. The family took almost 1 and half days to give consent. Post donation, the family was comfortable to talk about their experience in the community and they even attended the donor family felicitation programme conducted by MOHAN Foundation. Among the 14, there were about 5 to 6 families that were willing to have a conversation but the rest did not even want to talk about organ donation.

Mrs. Bhavna Jagwani (Convenor, MOHAN Foundation - Jaipur Citizen Forum (MFJCF), Jaipur): Mrs. Bhavna Jagwani shared the experience of her friend who was a Muslim. Her 7-year-old son received liver transplant twice and she was so inspired by this act of organ donation. She has now involved herself in creating awareness - "If we can receive, we can also give". She mainly works with the Bohra community and conducts events such as marathons and walkathons to promote the message of organ donation.

Dr. Jimmy Gupta (Programme Coordinator Hospital Outreach, MOHAN Foundation, Mumbai): As a team, we have counselled many families but we have not been successful. In one incident, the father of a 20-year-old who was declared brain dead expressed his willingness to donate his

daughter's organs. However, he did not want to disclose the donation to anyone including his wife. We had to abandon our efforts, as this would lead to legal issues and it would also be ethically incorrect not to involve the mother in decision making.

Ms. Sujata Ashtekar (Regional Organ and Tissue Transplant Organization (ROTO), Mumbai): She said that in her experience, all the families that were approached for organ donation wanted to know their religion's view on organ donation - whether it is acceptable or not. Understanding about the different Islamic sects, their beliefs, Islamic jurisprudence, scholars' opinions become important. Educating transplant coordinators on these aspects would help.

Moderator's remark: Involving recipients and their caregivers in advocacy and getting their help to take the message may help us in going forward.

8. Muslims do not agree for organ donation – Are we thinking stereotype

Ms. Pallavi Kumar: Should we really be having these discussions in the absence of proper studies? We may also need to know whether the refusal is merely because of religious reasons, as there are a lot of largely Muslim populated countries doing well in the field of organ donation.



Ms. Sujatha sharing her experience

Ms. Sujatha Suriyamoorthi (Manager - Information Systems, MOHAN Foundation, Chennai): She quoted from her experience that the transplant coordinators' motivation level sort of goes down as they often experience refusals from Islamic families. It has also been seen that the medical fraternity is hesitant to certify brain deaths if the individual is a Muslim. This has to be

addressed to move to the next level. Unless the brain deaths are not certified, the families could not be approached; and therefore we would not know what the families' perceptions would be.

Dr. Sunil Shroff: At present we do not have any concrete data available in India. However, the South Asian community in the UK presented the similar issue and that was the reason why the NHSBT had to devise community engagement plans to assure the faith groups that organ donation is within the framework of Sharia.

Moderator's remark: In Islamic countries like Saudi, Qatar, most of the donors are expats. The natives also feel that the law on brain death and deceased organ donation is actually for the expats (quoted from Prof. Riadh A.S. Fadhil's talk).

9. Donating external organs

Syed (Medical Student): According to Islamic theories, mutilation of the corpse is forbidden. Hence is donating external organs such as hands, facial tissues acceptable?

Faizur Rahman: The muftis who give fatwas are often unaware of the medical science. If they are made conversant with medical facts, then they would be able to guide the faith community in a much better way. Therefore, reform in Islamic values and perceptions among the ulemas is very important.

Recommendations / Comments from Panelists:

Abdul Rahiman: Collating and presenting the existing fatwas on organ donation to the different sections of Muslim communities in India has to be initiated. This would help tide over the various questions raised on fatwas by the common Muslims and therefore help the larger well-being of the society.

Faizur Rahman: Organ donation is low among the Muslims; the religion Islam is as such not a reason, but the Islamic interpretations are. Interpreting the Qur'an to the modern times without violating the basic values of Islamic faith is the need of the hour.

Ameen Ahmed: Religion may not be the lone hindrance. There may be other factors which could have been experienced by non-Muslims as well. These factors should be looked at and addressed as well.

Amjid Ali: A multi-dimensional approach would help in holistic education. Disseminating knowledge about the religious faith among the medical community; educating the ulemas on the medical science; engaging the faith groups which will appeal the human interest.

Senthil Kumar: Muslims who have expressed their unwillingness have stated only religion as the reason for refusal, even if they had other personal concerns.

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VALEDICTORY

Mrs. Lalitha Raghuram thanked the faculty for taking time and sharing their knowledge and experience with the transplant coordinators. She also thanked the sponsors for their generosity towards the workshop and requested the participants to use their learning in their work.

Feedback forms were collected and certificates of participation were issued as the session concluded.



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