



PROCEEDINGS

of

Seminar on Organ Donation and Transplantation - A Policy Perspective

during

12th National Annual Transplant Coordinators' Conference

November 30 & December 1, 2019

Indian Institute of Management Ahmedabad, India



Donate Organs... Save Lives...



Inauguration by Director - IIMA & Chairperson - CMHS



Delegates at the Conference



Mr. Sudhir Dewan speaks



Ms. Trilly Mathew



Ms. Vrinda Pusalkar



Ms. Lalitha Raghuram speaks



PPP Model - Expert Deliberations



Dr. Jayanti Ravi addressing the audience



Ms. Ann Alex



Dr. Sunil Shroff speaks



Mr. PWC Davidar



Dr. Suresh Sankar



Dr. Rakesh Gupta



Mr. Sundeep Kumar



Dr. Kishore Phadke



Dr. Sujata Rajapurkar receiving certificate



NATCO Committee Members

SUPPORTED BY

TATA TRUSTS

SBI FOUNDATION
Service Beyond Banking

SBI DFHI Limited
Come... Bond with us

Principal Sponsor



Powered by



Associate Sponsor



Crowdfunding Sponsor





Dr. Shroff, Mr. Davidar, Dr. Gupta and Dr. Singal in a discussion



Panelists - NGO Roundtable



Mr. Mahendra Kumar Rekhi receiving his certificate



Ms. Pallavi Kumar felicitated



Certificate awarded to Dr. Muneet Sahi



Dr. Piyasha Nath receiving certificate



Dr. G L Singal issuing certificate to Dr. Amit Joshi



Dr. Shroff felicitating Prof. Errol D'Souza



Delegates at the 12th National Annual Transplant Coordinators' Conference at IIM Ahmedabad



Ms. Pallavi Kumar felicitating Ms. Jaya Jairam



Mr. Srikanth Shankar awarded by Milaap



Best Scientific Paper Award - Dr. Geetika Vashishth

PROCEEDINGS

of

***Seminar on Organ Donation and Transplantation –
A Policy Perspective***

during

12th Annual Transplant Coordinators' Conference

in association with

***Centre for Management of Health Services (CMHS) –
IIM - Ahmedabad***

Conference Theme: Let us Collaborate

30th November and 1st December 2019

KLMD - IIM Ahmedabad

Title

Seminar on Organ Donation and Transplantation – A Policy Perspective

Edited By

Thyagarajan I, Shroff S, Kanvinde H, Navin S, Chandwani R, Nair M

Published By

MOHAN Foundation, For Network and Alliance of Transplant Coordinators and Centre for Management of Health Services (CMHS) – IIM Ahmedabad

Citation

Thyagarajan I, Shroff S, Kanvinde H, et al. editors. 12th Annual Transplant Coordinators' Conference: Seminar on Organ Donation and Transplantation – A Policy Perspective; 2019 Nov 30-Dec 1; Ahmedabad, India. Chennai: MOHAN Foundation; 2020.

ISBN: 978-9-35-396882-3

Cover Design

Mr. J. Suresh Kumar & Mr. P. Kumareshwaran
MOHAN Foundation

Available at

Network and Alliance of Transplant Coordinators

MOHAN Foundation,
3rd Floor Toshniwal Building
267 Kilpauk garden Road
Chennai 600010, India
Phone: 044 26447000
Email: txnatco@gmail.com

Foreword

It gives me great pleasure to write the foreword for the proceedings of the Seminar on “Organ Donation and Transplantation – A Policy Perspective”, during the 12th Annual Transplant Coordinators’ Conference. The conference was organized as a joint endeavour of the Network and Alliance of Transplant Coordinators (NATCO), MOHAN Foundation and Centre for Management of Health Services (CMHS), IIM Ahmedabad.

The conference focused on a relevant issue - enhancing deceased organ donation - that is very close to my heart and acknowledged the embedded and complex nature of the issue. Examining the challenge of enhancing deceased donation from a policy perspective entails exploring multiple dimensions and stakeholders engaged in the complex process - Government, public hospitals, private hospitals, doctors, staff, police, lawmakers and enforcers, civil society, patients and the general population at large. The conference, and rightly so, was focussed on the extremely crucial and critical role of the ‘transplant coordinator’, who facilitates the process of organ donation followed by multiple transplantation.

Though the two days seemed too few to discuss the diverse dimensions, I am glad that the compact design, careful selection of topics and papers, and well planned deliberations have attempted to focus on most of the challenges in the process, highlight some of the best practices and above all, pave the road ahead for different stakeholders.

I am confident that the well compiled ‘Proceedings’ will become a point of reference for possible solutions in this complex field among both well-performing and emerging states that are undertaking deceased donor organ transplantation. My best wishes to the scholars, policy makers, and various change agents working to promote this heroic cause.

Prof. Errol D’Souza
Director
IIM Ahmedabad

Message

Building Partnerships for Organ Donation

Organ shortage for patients is a huge public issue worldwide and especially so in India where the organ donation rate is amongst the lowest in the world. Enhancing deceased organ donation was the focus of the 12th Annual Transplant Coordinators' Conference - "Organ Donation and Transplantation - A Policy Perspective" the theme being 'Let us Collaborate.' The conference was organized jointly by the Network and Alliance of Transplant Coordinators (NATCO), MOHAN Foundation, and Centre for Management of Health Services (CMHS), IIM Ahmedabad.

Enhancement of organ donation, particularly deceased organ donation requires attention to not only the hard technical infrastructure, the ICU and operation theatre facilities, manpower, equipment and expertise, but also soft infrastructure- the regulatory frameworks, training, and coordination mechanisms to align diverse stakeholders towards the cause. The focus of the conference was on the latter- strengthening the role of various stakeholders in the process of organ donation- both from public and private spheres.

The diverse stakeholders from public and private spheres include Government departments such as police, public health, and legal; hospitals both public and private; NGOs and civil society; media; donor families; and citizens. The diversity of stakeholders involved in the complex process of deceased donation accentuate the complex nature of the phenomenon. While public private partnership (PPPs) have been advocated for dealing with complex issues, the very different goals, governance and processes of public, private and the NGO spheres make the 'partnership' difficult to achieve.

The focus of the conference was on deliberating on processes and personnel involved in initiating and nurturing the partnership. The conference that brought representation from all the relevant stakeholders provided a fertile ground for discussing the challenges of each stakeholder and also propose a way forward. The deliberations, compiled in the 'Proceedings' puts together the viewpoints of stakeholders, best practices and challenges, which can pave the way towards developing fruitful partnerships for enhancing deceased organ donation.

Prof. Rajesh Chandwani
Chairperson
Centre for Management of Health Services (CMHS)
IIM Ahmedabad

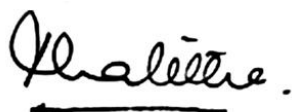
Acknowledgement

It gives us great pleasure to bring out the proceedings of the Seminar on Organ Donation and Transplantation – A Policy Perspective during the 12th Annual Transplant Coordinators’ Conference in association with Centre for Management of Health Services (CMHS) – IIM - Ahmedabad.

We acknowledge the inputs of the scientific committee members and IIM for developing the deliberations during the sessions. We thank the speakers and the chairpersons for sharing their thoughts and experiences during the meeting.

NATCO and MOHAN Foundation would like to acknowledge the support of the following organisations in making the event a success - IIM Ahmedabad, ZTCC Pune, Apollo Hospitals - Ahmedabad, Kokilaben Dhirubhai Ambani Hospital, CIMS Hospital, The Times of India, Amar Gandhi Foundation, Milaap, SBI Foundation, SBI DHFI Limited, Edelweiss Tokio and Tata Trusts.

We thank Siva Shankar T S (MOHAN Foundation) and Mini Nair (IIM-A) for the arrangements during the conference. We also thank the MOHAN Foundation team comprising Jaya Jairam, Ann Alex, Sujatha Suriyamoorthi and Dr. Muneet Kaur Sahi for preparation of this proceedings.



Mrs. Lalitha Raghuram
President
NATCO



Dr. Sunil Shroff
Managing Trustee
MOHAN Foundation

7 January 2020

Contents

30th November, Day 1 Proceedings

Welcome Address – Mrs. Lalitha Raghuram	1
--	----------

Session 1: Invited Rapid Fire Talks

<i>Topic 1: Impact of Myths on Organ Donation and Transplantation in Movies & Television Serials on the Public in India – Ms. Ann Alex</i>	1
<i>Topic 2: Organ Donation and Islam – Perspectives from South India – Ms. Ishwarya Thyagarajan</i>	3
<i>Topic 3: New Learnings Post-Transplant Coordinators' Training – Ms. Trilly Rachel Mathew</i>	3
<i>Topic 4: Transition from an Armed Forces Hospital(Government) to a Corporate Hospital - are the Pain Points the Same? – Lt. Col. Sandhya Nair</i>	5
<i>Topic 5: Ethical Dilemmas in Coordination in Corporate Hospitals – Ms. Vrinda Pusalkar</i>	6
<i>Topic 6: Life before Ashes – Impact of an Innovative Campaign – Ms. Jaya Jairam</i>	8

Session 2: Developing a Common Template for PPP Model for Organ Donation in India

<i>Introduction to Public-Private Partnership (PPP): Discussion – Dr. Sunil Shroff</i>	9
<i>Group 1 – Recommendations for the hospitals</i>	10
<i>Group 2 – How can NGOs and corporate organisations contribute?</i>	12
<i>Group 3 – How can the state governments facilitate organ donation?</i>	13
<i>Concluding Remarks:</i>	
<i>Mr. PWC Davidar</i>	14
<i>Dr. Jayanti Ravi</i>	16

Session 3: Making Transplants Affordable

A. Costs of Transplants

<i>Topic 1: Liver Transplant Costing – Dr. Sonal Asthana</i>	16
<i>Topic 2: Heart Transplant Costing – Dr. Jose Chacko Periappuram</i>	18
<i>Topic 3: Challenges of Post-operative Expenses in Renal Transplant – Dr. Mrs. Sujata Rajapurkar</i>	20

B. Crowdfunding – Checks and Balances

<i>Topic 1: Sources of Funding for Transplant Patients in India – Ms. Jaya Jairam</i> ----	22
--	-----------

<i>Topic 2: Milaap Model and Challenges – Mr. Mayukh Choudhury</i>	23
<i>Topic 3: Experience with Crowdfunding – Mr. Anil Srivatsa</i>	24
Session 4: Organ Donation – Challenges and Success in Organ Donation in Gujarat – Mr. Nilesh Mandlewala	25
Session 5: What makes a Leader? – Dr. Rakesh Gupta	26
Session 6: Free Paper Presentations	
<i>Topic 1: Brain Stem Death and Attitudes towards Organ Donation – Lt. Col. (Retd.) Sandhya Nair</i>	29
<i>Topic 2: In-Depth analysis of the Socio-Demographic factors associated with the organ donor pledges received from pan India – Dr. Geetika Vashisth</i>	30
<i>Topic 3: Recipient Coordination - Passionate work by Compassionate People – Ms. KKD Surekha</i>	31
<i>Topic 4: Medico Legal Issues related to Deceased Donation – Dr. Shabina Sheikh</i>	32
<i>Topic 5: Attitude of the Small and Mid-sized Hospitals to be registered as Non Transplant Organ Retrieval Centre (NTORC) and to Study the Roadblocks – Dr. Jimmy Gupta</i>	33
<i>Topic 6: Impact of Direct Public Education – Dr. Bhanu Chandra S</i>	34
<i>Topic 7: Transplant Coordinator's Perspective towards Non-Monetary and Monetary Assistance to Organ Donors' Families – Ms. Mayuri Barge</i>	35
<i>Topic 8: In-depth Analysis of Queries received on ORGAN India's Helpline to Identify Gaps in Information Dissemination, particularly at the Hospital Level – Dr. Devansh Vaish</i>	36
<i>Topic 9: Public Education in Chandigarh and Punjab – Ms. Neha Sharma</i>	37
Session 7: Checks and Balances to Protect Hospital Staff in Coordinating Living Transplants – Dr. Piyasha Nath	38
Session 8: Medico Legal Formalities and Organ Donation – The Role of Police	
<i>Introduction – Dr. Hemal Kanvinde</i>	39
Case Study Presentations by Transplant Coordinators	
<i>1 Northern Region – Ms. Rajinder Kaur</i>	41
<i>2 Southern Region – Dr. Bhanuchandra S</i>	42
<i>3 Central Region – Dr. Amit Joshi</i>	43
<i>Concluding Remarks: Dr. G.L. Singal</i>	44
Inaugural Ceremony	44

1st December, Day 2 Proceedings

Session 1: Roundtable: NGO Presentation – Developing a Common Template for Organ Donation Awareness -----	46
Session 2: Transplantation of Human Organs Act – 25 Years On – Dr. Sunil Shroff -----	49
Session 3: Foreign Donors in India – Ms. Pallavi Kumar -----	51
Session 4: Swamy Narayan Memorial Oration: Transplantation in India – Grounds for Optimism – Dr. Sonal Asthana -----	53
Session 5: Swamy Narayan Best Transplant Coordinator Award Presentations	56
Session 6: Organ Donor Clause in Driving Licence – Our Journey – Ms. Bhavna Jagwani -----	57
Session 7: Quality of Life of Donors and Recipients – a Nephrologist’s Perspective – Dr. Vivek Kute -----	59
Session 8: Panel Discussion - How can we Energize Indian Transplant Games?	60
Session 9: Hand Transplantation, Face Transplant and other Composite Tissue Transplants – Is there a Future for it in India? – Dr. K Boopathi -----	62
Session 10: Chronic Kidney Disease of Unknown Origin: Is it on the rise in India, and what do we know about it? – Dr. Manoj Gumber -----	64
Session 11: Sharing Experiences as a Transplant Recipient	
<i>Speaker 1: Mr. Sudhir Dewan -----</i>	67
<i>Speaker 2: Prof. Vijaya Sherry Chand -----</i>	68
Valedictory	70
NATCO Committee	71
List of Faculty	72
NATCO Membership Form	75

Proceedings

Day 1 – 30th November 2019

Welcome Address: Mrs. Lalitha Raghuram – President, Network and Alliance of Transplant Coordinators (NATCO)

Mrs. Lalitha Raghuram welcomed the faculty, speakers and members of NATCO to the 12th annual conference at IIM Ahmedabad.

She thanked IIM for giving NATCO an opportunity to conduct the conference in their campus and mentioned that the trigger for the conference was a brief conversation with Dr. Rajesh Chandwani – Chairperson, CMHS, IIM Ahmedabad.

‘Let’s Collaborate’ was the theme of this edition of the conference that mainly focused on policy perspectives and Public-Private Partnerships (PPP). A talk commemorating the 25 years of transplant law by Dr. Sunil Shroff and discussions around making transplants affordable for the economically weak were also highlights of the conference.

Also featured were paper and poster presentations, Swamy Narayan Memorial Oration and Best Transplant Coordinator Awards.

Session 1: Invited Rapid Fire Talks

Chairpersons: Dr. Sonal Asthana and Mrs. Sujatha Suriyamoorthi

Topic 1: Impact of Myths on Organ Donation and Transplantation in Movies & Television Serials on the Public in India – Ms. Ann Alex

Background: The speaker shared an experience involving her colleague who had put up an awareness stall, where one of the visitors was a woman who showed great interest in organ donation and pledging her organs. However, when her contact details were requested for the purpose of registering as donor, she was hesitant to share them only because she thought the information might be misused and she/or her family would be harmed. This shows how people still believe that their information can be misused. Consciously or subconsciously, individuals do believe what is portrayed on Television, media or web series. A short video clipping from the web series *Breathe* was played for the audience as an example to understand negative portrayal of organ donation.

Breathe talks about how a father, in order to save his child suffering from organ failure, goes on to murder registered organ donors on the registry to find a donor for his child at the earliest.

Through this study, Ms. Ann Alex's **objective was to explore the impact of depiction of myths in mass media on the public**. A poll was run on social media platforms to understand if people who pledge their organs think that their information will be used to inflict any harm on them.

Findings: A total of 211 responses were received, of which 205 were valid responses. 115 male and 90 female; 75 associated with the field of organ donation and transplantation and 130 from other fields.

Results: 21.5% of the total respondents were of the opinion that it is a fact that information will be misused and so did 8% of those who were associated with the field of organ donation and transplantation, which is surprising. This gave insights that organ donation could be misconceived through media.

Discussion: In the discussion that followed some solutions and recommendations came forward. Examples included –

- Running awareness campaigns on social media platforms to clarify misconceptions
- Play movies based on the subject ahead of release to a board of experts before issuing censor certificate
- Promote the role of cinema in dissemination of correct information
- Conduct further studies in this area

Conclusion: Ms. Ann Alex ended on a positive note that **movies do give us inspiring stories and are also a powerful tool for education**; the Malayalam language movie *Virus* is one such example of the role cinema could play in spreading social good.

Questions/Comments:

1. Dr. Sonal Asthana: Is there any data that shows us that media is a reason for the decline in the number of donations/transplants in India?

There is not much research done to show that media could be one of the reasons for the public not coming forward and donating in India.

2. Mr. Sudhir Dewan: It depends on the education level of the audience. Therefore, not everybody would be influenced by such misconceptions portrayed by media.

3. Ms. Sujatha Suriyamoorthi: Was there any follow-up done after the poll to make sure that these myths were clarified?

Posts were put up on social media platforms clarifying the myths with facts.

Topic 2: Organ Donation and Islam – Perspectives from South India – Ms. Ishwarya Thyagarajan

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: 167 respondents from the Muslim community in Chennai city and a few districts of Kerala 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: There were almost equal numbers of female and male respondents, in the age group of 18-89 years and mostly graduates who were part of the survey. While the awareness levels around what organ donation is and brain death were encouraging, only very few participants knew about the transplant law. Over 50% (87/167) respondents were of the opinion that Islam does not permit organ donation; however, 60% (99/167) were willing to consider it if their religious leaders support the cause. ***Respondents were supportive of the cause because it had the potential to save lives. Factors like desecration of the body after death and other religious beliefs prevent them from signing up as organ donors.***

Discussion: Owing to the small sample size, the responses are not representative of the community at large. However, among the Muslims, religion strongly influences decisions made in relation to donating or receiving organs in the community. Religious leaders and religious texts have considerable influence in this decision. The results also indicated 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 in the Muslim community. Providing access to religious counsel would help in decision making for the potential deceased organ donor families.

Topic 3: New Learnings Post-Transplant Coordinators’ Training – Ms. Trilly Rachel Mathew

With the help of a case study, the speaker explained how the transplant coordinators’ training helped her professionally.

Case Study: The case study involved a patient of foreign nationality suffering from kidney failure, arriving for a transplant, accompanied by his son-in-law as the potential donor. The patient’s wife

had undergone a spinal surgery and his 18-year-old daughter was pregnant, rendering them unsuitable as donors. The patient did not want his married sisters or his brothers with whom he was not on cordial terms to be donors. Hence, his only option was his son-in-law donating.

The following documents were submitted and checked by the transplant coordinator:

- Marriage certificate of the donor
- Birth certificate of the recipient's daughter and donor's wife
- UPT report of the donor's wife
- Affidavits from siblings stating their unwillingness
- NOC from the donor's wife and parents
- Medical reports of the recipient's wife
- ID proofs of the recipient and the donor
- NOC from the High Commission of Bangladesh

Though all the required documents were made available, the transplant coordinator had to verify the genuineness of the information provided. For example, the pregnancy confirmation report appeared unprofessional and incomplete, leading to suspicions such as: was the patient's daughter truly pregnant; was her marriage to the potential donor, just a 'kidney marriage'; was the donor's family aware of the fact that he had come forward to donate and what was his motivation to donate.

Discussion: A transplant coordinator dons multiple hats during every case they get involved in: interviewer, counselor, observer and assessor, verifier and decision maker.

Therefore, they have to check all of the documents and look for warning signs, before making a decision on the validity of the case and relationships:

- Understand the medical history of the patient
- Know the families of the donor and the recipient
- Understand thoroughly the relationship between the patient and the donor
- Understand the reason behind the donation
- Understand the facial expression and the body language during the counseling
- Observe behavior; assess emotional attachment; observe concern
- Thorough verification of documents
- Match the information provided during the interview along with the documents
- Make decisions based on outcome evaluations
- Arrive at a conclusion based on findings and decide to go ahead or abandon the case

A pizza base would be an apt metaphor for a transplant coordinator with continued trainings, handling complicated cases act as toppings that would add value to their work. The coordinator should not accept the information provided even by the embassy as reliable. They should investigate on their own in order to avoid controversies in the future. Crosschecking and matching the information gathered from interview transcripts and the documents submitted by the patient could be a foolproof mechanism.

Questions/Comments:

Q: Would not the embassy's clearance be enough to go ahead with such a transplant - if it is established that the patient and donor are related? It seems possible for Indians who travel overseas for a transplant accompanied by an unrelated donor and this is overlooked.

A: If the law of a particular country allows such unrelated transplants, it should be fine. However, in India, it does not and commercial dealings are not possible either.

She recommended that during the training of coordinators, the time allocated for sessions related to living donations have to be increased.

Topic 4: Transition from an Armed Forces Hospital(Government) to a Corporate Hospital - are the Pain Points the Same? – Lt. Col. Sandhya Nair

The speaker's presentation was based on personal experiences and there was not much data available on this topic to validate what was discussed.

Discussion: The ignorance factor is common for both the Government and Corporate Hospital sectors, and the highly educated could be the most ignorant. For a transplant coordinator, acceptance in the private sector is hard to come by and has to be gained after a resistance phase, whereas in the government setup it is more automatic. The private sector does not always have a standard operating procedure in place and protocols are different for every individual hospital. On the other hand, SOPs are available and followed in the armed forces that have a regimen of discipline built into the training culture.

Administrative decision makers in the private sector are generally from non-medical backgrounds and pose a major hurdle. In the armed forces hospitals, medicos who are familiar with the basics of organ donation are the decision makers. For example, when the speaker submitted a proposal for conducting awareness programmes to the authority in the private sector she was asked where would the organs of those pledging in such events, be stored, displaying the ignorance of the administrator concerned.

Funds, if sanctioned, are disbursed immediately in private sector and if refused will have to be sourced externally. In the government sector, the only challenge is the delay in the allocated funds being sanctioned and disbursed. Organising awareness events are viewed as an additional burden and met with disinterest in the private sector; the question is always 'what is in it for us'.

Conclusion: The speaker said that the idiom, 'grass is always greener on the other side' may not be applicable in this context; rather the grass is greener where you water it. Despite the multi-faceted challenges, her passion and support from her team are driving her pursuit to promote organ donation.

Topic 5: Ethical Dilemmas in Coordination in Corporate Hospitals – Ms. Vrinda Pusalkar

There are three major requirements to make a transplant happen in any hospital:

- Recipient
- Donor (in a living donation transplant) / Donor family (in a deceased donor transplant)
- Finances – surgery and post-surgery

Each of these requirements has its own set of challenges.

Recipients:

- Severe impairment with respect to health
- Negative impact on mental health
- Restriction on activities performed
- Compromised family and social life
- Difficulties in professional life

Donors:

- Living donors – Decision should be voluntary and not coerced; informed decision rather than impulsive, irrational decision
- Deceased donors – Ideally the decision should be through consensus among the family and not by an individual

Finances:

- Pre-surgery expenses
- Surgery expenses
- Post-surgery expenses

A transplant coordinator acts as cement that binds together this 'life triangle' that is a part of every end-stage organ failure patient's life.

Frequently encountered ethical dilemmas:

Gender discrimination:

- 70-75% of living donors are females, donating to mostly male members
- 13% male donors donating to female recipients (father to daughter; brother to sister)
- Women are denied transplant because of their gender

Discrimination by relationship:

- Wives, mothers and widowed sisters are taken for granted as eligible donors
- While 17% of wives are donors, only 2% of husbands donate

Donor dilemmas:

- Donor remains the center of attraction only until the surgery, after which all the focus is on the recipient
- The donor may develop the feeling of being neglected
- Donor's health after a transplant is often neglected as the recipient receives all the care from the family
- The health of marginal donors (those with hypertension) could be at stake after the surgery
- In case of a young donor, the risk of diabetes or hypertension would be unpredictable as it is high in India and this could endanger their health if it develops in them.
- When recipients develop complications or the organ gets rejected or the recipient dies – the donor may get into depression and may even feel guilty

Post-transplant recipients:

- Recipients may face emotional blackmail from donors, even though related
- Economically weaker patients find it difficult to manage finances after the surgery, risking rejection of the organ and efforts of the donation is wasted.

In addition to the above, the transplant coordinators come across a multitude of dilemmas when coordinating both living and deceased donations. A few examples are -

Living donations:

- Is it ethical to permit an alcoholic liver cirrhosis patient, who has a high possibility of relapse, to undergo alive liver transplant?
- Should a non-compliant patient be given a chance at a second living donor transplant, jeopardizing life of the donor?
- When a patient's family sells their only source of security (like house or a piece of land) for treatment, how will the other family members find security?
- Should recipients with intellectual disability be deprived of transplant?
- Are we biased sometimes and view everything with suspicion?
- Selling or buying of an organ is a punishable offence and illegal. However, we encounter patients or their families where there is financial exchange and transactions within the family itself. For example, we encountered a grandfather who was a potential kidney donor for his grandson, but demanded money from granddaughter -in- law's family to save their son-in-law.
- At times a patient has to forego his/her rights on property as mother/father is his/her potential donor

Deceased donations:

- If a family demands for waiver of the treatment charges of a person whose organs were donated after his death, should it be allowed and if so, is this not inducement?
- If there is no consensus among the family members but the next of kin gives the consent should one go ahead with organ donation or not?

- If the family insists upon knowing details of prospective recipients or request for directed donations, should it be allowed?
- The process of multi-organ donation is time consuming, which could be traumatizing for the donor family

Conclusion: Every case has to be approached with an unbiased, open mind. ***Potential living donors have to be provided with all information to help their decision-making. Recipients on the other hand, must be informed about the pros and cons. A deceased donor's family should be taken into confidence and given enough time to arrive at a decision collectively.*** Emotional involvement should be avoided at all costs in any case.

Questions/Comments:

Q: Every single patient who undergoes a transplant for Hepatitis B has the chance of recurrence of the virus. Why are we not viewing them the same way as we view alcoholics, both being medical conditions where organ failure is imminent?

Topic 6: Life before Ashes – Impact of an Innovative Campaign – Ms. Jaya Jairam

Life Before Ashes is a unique, hard-hitting campaign that gained immense popularity on social media platforms. The traveling art exhibit had models of heart, kidneys, eyeball and liver made of human ashes and mud from burial grounds and crematorium. ***The exhibit conveys the message that the organs that had the potential to save many lives, have been buried or burnt and wasted.*** It kindled curiosity and even shocked a few visitors who got to know that human ashes and mud were used to design the exhibit.

A message titled '**Karma**' urging viewers to think about organ donation and posters explaining the concept of the exhibit along with the toll-free helpline number were displayed along with the exhibit everywhere it was showcased. The exhibit has been displayed almost in every part of the country including Delhi, Nagpur, Pune, Bangalore, Jaipur, Hyderabad, Chennai and Kochi at hospitals and public places. The campaign won multiple awards and accolades: Abby Awards 2018, OAC Awards 2018, Big Bang Awards 2018, IAA Olive Crown Awards and Kyoorius Creative Awards 2019 to name a few.

Social Street, a creative agency came up with the idea and collaborated with MOHAN Foundation to develop the exhibit. A video depicting the making of the models, the display of the exhibit and media coverage was played at the end of the presentation.

Comments: Ms. Priyanka Borah of Zubleee Foundation requested that the exhibit also be showcased in the North Eastern states to spread awareness.

Session 2: Developing a Common Template for PPP Model for Organ Donation in India

Chairpersons: Mr. PWC Davidar, Dr. Rajesh Chandwani, Dr. Suresh Sankar

The objective of the seminar was to look at the best practices in the field of organ donation and transplantation and design a Common Template for PPP Model for Organ Donation in India.

With Tamil Nadu emerging as a classic example of a successful PPP model in organ donation, IIM Ahmedabad, MOHAN Foundation and NATCO (Network & Alliance of Transplant Coordinators), invited experts from government, NGOs, industry leaders, media and hospitals to examine the important ingredients of PPP model, and produce a white paper on this important issue. Best practices that are workable in India and that work in the government, successful PPP models in other spheres and challenges/obstacles that need to be overcome were some of the focus areas.

A panel of experts, in three different groups, deliberated on how an effective PPP model could be devised to improve the organ donation rates in India. The challenges and potential solutions discussed were presented to a larger audience.

Introduction to Public-Private Partnership (PPP): Discussion – Dr. Sunil Shroff

In the past, especially in developing countries like India, PPP models have been a success, especially when it comes to health. The Polio eradication programme by Rotary, Smile Train project to treat cleft lip and palate, Bill & Melinda Gates Foundation's work in the area of communicable diseases were good examples.

Blood donation and eye donation have come a long way with around 11 million voluntary blood donors every year, 300 pledged for eye donation every day and 30,000 eye donations made possible by the efforts of many NGOs. However, with respect to organ donation, the country has not made similar progress as expected, and this has to be revisited to understand how the programme could gain momentum so that the long wait list of patients could be provided hope.

Two-thirds of the 4% GDP contribution towards health comes from the private sector and the remaining one-third is from the government. While the budget for defence last year was set at 4.5 lakh crores, health was allocated only 65,000 crores, evidently showing the disparity. Presently, 13 of the 36 states and union territories do deceased donation in India, out of which only 5-6 states do it regularly. The deceased donation rate in India was 0.8 per million population.

MOHAN Foundation has been able to successfully partner with many private players like Tata Trusts, SBI Foundation, Times of India, NDTV, and Edelweiss Tokio. These partnerships have helped in conducting training programmes for transplant coordinators and grief counselors, running a 24*7 toll-free helpline to provide information about organ donation and facilitate donations. It has run print and visual media campaigns that encourage people to pledge and many

more initiatives are added every year. Similarly, the Oxford Organ Retrieval Workshops run in association with the NGO lead by Dr. Sonal Asthana have effectively trained many surgeons to perform transplants. Partnerships like these could be sustainable and highly impactful.

The Foundation has also collaborated with the governments of states of Tamil Nadu, Kerala, Rajasthan, Telangana and Manipur – few already successful and some evolving. In Tamil Nadu, the Foundation has been able to place Transplant Coordinators in most government hospitals and the deceased donor consent rate of over 65% has been promising.

NGOs like Donate Life, Organ India, Zuble Foundation and many others too have played a key role in keeping the programme afloat and creating awareness. The culmination of all these efforts reflects on the organ donation rate of the country.

The problem with the programme is the low donation rate for a country with 1.3 billion population. The problem is not in the public domain, but in the hospital domain. Majority of the hospitals fail to identify or certify brain death. An effective public-private partnership is what would help in taking forward the programme. However, the following aspects challenge the PPP model:

- Lack of systems in hospitals
- Lack of support staff
- Lack of resources for the programme
- Lack of stability at the top
- Lack of support system in Non-Transplant Organ Retrieval Centres (NTORCs)
- Lack of trust

Group 1 – Recommendations for the hospitals

Experts:

- Dr. Suresh Sankar
- Dr. Kishore Phadke
- Dr. Atul Mulay
- Dr. Dhiren Shah
- Ms. Pallavi Kumar

Points of Discussion:

a. How to encourage organ transplants in a hospital? How to train/ create awareness on brain death identification and declaration? What are the training needs, who could identify them and how will the training be administered?

- i) Having a Zonal Organ Donation Coordinator who will cover an entire zone with several hospitals would be a good strategy to keep hospitals engaged. They could be engaging at an overall level with various hospitals as opposed to a Transplant Coordinator who has access to only one hospital and is involved within that hospital. The Zonal coordinator

would look at the training needs, other challenges being faced by hospitals, monitor the programme and do brain death audits. Dr. Mulay shared that Maharashtra follows the same and to some extent it is a successful model.

- ii) In order to make the ICU / and neuro-critical care doctors important stakeholders in the programme, their involvement has to be ensured right from the very beginning including in the preparation of guidelines and having them on the advisory board for the state organ donation and transplant programmes. ZTCC Pune has active processes in place for involving the intensivists and neurologists as a part of the NGO working framework as shared by Dr. Mulay. The programme has a very dynamic relationship between private hospitals and the non-profit body.
- iii) Government participation is critical for increasing the number of donations. Partnerships with credible organisations could boost donation. For example, Dr. Phadke shared how the Karnataka government is collaborating with NIMHANS in Karnataka where a MOHAN Foundation counselor has been placed.

b. How to monitor/audit the quality of a licensed Transplant Hospital with a view to improve donations and look at the key elements?

All the experts concluded that there is a need to align with the National Accreditation Board for Hospitals & Healthcare Providers (NABH). NABH has many structural elements with respect to objectives and standards. Therefore, when a transplant hospital comes for accreditation or renewal, this element with regard to transplant outcomes has to be brought in.

Dr. Dhiren Shah mentioned that the Joint Commission International (JCI) already has a process when they come for accreditation/renewal. NABH is built on an international model, from the other interactions. He also mentioned that NABH is always open to new inputs from other industries and therefore there is scope to push.

The experts agreed that there is a need to look into the actual experience of the family during the donation process. It was suggested that a study needs to be done by an independent body (for example a leading NGO like MOHAN Foundation) to study this aspect to improve donation consents. Follow-up beyond just the survival of patient and an end-to-end approach of counseling-to-cremation should be adopted.

c. How to strengthen paper work in Non-Transplant Organ Retrieval Centres (NTORCs) or hospitals where brain death declaration is being done?

The issue of a hospital-based brain death committee is a heavy load on small hospitals and the suggestion to have a common government brain death committee to oversee would be practical. Evidently, the challenges for small hospitals, after donations, with regard to the cost and outcome of the donation create a lot of hindrance preventing them from getting into the space of NTORCs.

A hub and spoke model where an NTORC is paired with a workable partner could be explored to aid NTORCs and avoid delay in transplantation and wastage of organs. If such pairings happen effectively, especially between private-private/public-public, a smaller hospital would feel strengthened and supported to participate in the programme. An experienced staff member from the state coordination committee should be physically coordinating the process from a NTORC.

Group 2 – How can NGOs and corporate organisations contribute?

Experts:

- Dr. Rajesh Chandwani
- Mr. Amal Sivaji
- Mr. Mahendra Kumar Rekhi
- Mr. Aman Bhaiya
- Mr. Sundeep Kumar
- Dr. Somnath Chattopadhyay
- Mrs. Lalitha Raghuram
- Dr. Muneet Kaur Sahi

Points of Discussion:

a. How could the private sector hospitals participate in the care of the less affordable patients? Can the trust deficit between government and private be bridged through such initiatives?

- i. To focus on a few states where it is envisaged that immediate successes can be achieved so that these states become role models for other states to follow. To identify one hospital in each state where PPP could be implemented.
- ii. To begin with, 30 hospitals could be chosen for this model.
- iii. Method of selection of hospitals can be done by developing a matrix approved by the government for easy implementation.
- iv. Twinning partnerships with large volume hospitals to initiate smaller centres to begin deceased donations could be initiated. For example, the IKDRC a public hospital in Gujarat that does a large volume of kidney transplants could act as a resource to start partnership with private hospitals.

b. Could NGOs act as a bridge between the public and private sector? What are the areas to focus on and specialize in? Is there a role for them beyond awareness creation?

- i. NGOs should follow a structure prescribed by the government, but their activities should not be restricted because their flexibility comes from their connection with the community that the government does not have.
- ii. The main role of an NGO should be to interface with the community and the various other stakeholders because of the credibility and knowledge of the local grass root level, whatever they bring in to it.
- iii. Grief counselling should only be done by NGO partners

- iv. Partnership between NGOs and Government depends on the niche activities of each group. While the focus in government system is on service delivery to a large mass of people, efficiency is the key in the private sector, and connection with the community is at the core of NGO operations.
- v. NGOs acting as organ procurement organisations could be an area to be explored in the future
- vi. Learning and sharing between NGOs, between industries, and NGOs from other similar health projects should be encouraged

3. Funding organisations such as SBI Foundation work with different NGOs and bring to the table their expertise. How can we leverage those networks and explore possibilities?

An example of MOHAN Foundation's association with SBI Foundation was highlighted and this collaboration, through a toll-free helpline has managed not only to counsel patients about organ donation but has also saved lives through coordinating actual donations.

4. How can industry help in augmenting organ donations?

To receive funds from the government, the focus has to be on "outcome based models" and coalition approach because coalition has a substantial say in the national policy

5. Dearth of resources

Most public hospitals lack both infrastructure and work force to promote deceased organ donation. Nonetheless, in some states, public hospitals are doing exemplary work in the field of transplantation. This is because of certain champions within the government/hospitals who support the programme and are passionate about the cause.

6. Utilizing funds

Every state will have contextual needs to promote the cause, right from public awareness, creating donation pathways in hospitals, to framing the right enabling government rules. As the large CSR grants cover multiple locations, the knowledge so gathered can be tapped to augment deceased donation.

Group 3 – How can the state governments facilitate organ donation?

Experts:

- Dr. Rakesh Gupta
- Mr. PWC Davidar
- Dr. G. L. Singal
- Dr. Sunil Shroff

Points of Discussion:

a. Adopting a three-fold approach that would ensure the success of the programme in a state like Haryana that is starting off with the programme

- i. Social and Behavior Change Communication (SBCC) campaign
- ii. Setting up of a transplant center

- iii. Robust reviewing and monitoring system
 - How do we monitor, appoint, and capacity build transplant coordinators for the hospitals across the state which would be from Government and Private medical sector?
 - How do we ensure brain stem death certification is done?
 - How do we retrieve eyes from deceased?
- iv. All of the above would be executed, for example, in Haryana through:
 - Chief Minister's Good Governance Associates - The associates could support their district collectors with data collection and involve youngsters in the ideation. They could learn from within and outside the state, drive the organ donation programme and have a chance to send feedback for improvisations.
 - District Magistrate taking the lead and including the police
 - Civil Society
 - Government, Private and other Public players

The programme, if run meticulously, would be able to save around 10,000 lives a year in Haryana and other states.

Concluding Remarks

Mr. PWC Davidar

A template/white paper should shortly be developed to help states that are just starting and those that have already started and hit a roadblock, to understand what went wrong and how to improve. The following should be considered when developing the template:

- **Knowledge of the legal aspects and perception of what is legal**
Having the right Government Orders (GOs) in place can help and provide a boost to the programme. GOs help in interpreting the rules and law better and good orders can facilitate and increase comfort level in organ donation.
- **Key stakeholders: Hospital-, Government- and Region-centric**
 - Donors and their families
 - Caregivers of potential donors at the hospitals
 - Transplant Coordinators
 - Brain Death Declaration Team
 - Police
 - Regulating and Allocating organisations like - TRANSTAN
 - Logistics team to transport the organs
 - Transplant Team
 - NGOs

Programmes of states that have the backing of Chief Minister or Health Minister or Secretary are mostly successful and function without hurdles. The new states that are just starting could be spared the learning curve the other established states went through with great struggle. The transplant committees for various organs have to work in tandem to avoid controversies. This is also applicable to the Advisory Committee and the Coordinating Committee.

- **Donor Availability**

The registration process, allocation and convergence are key aspects. Convergence in this sense would mean an already existing, established health service, with protocols in place, taking on the registration and allocation aspects of organ donation. For example, the 108 emergency ambulance service, available round the clock, could come together with the state body to ensure a seamless process. Upcoming states should adopt this right from the start.

- **IT** - a very big player and an enabler

- **Create Template** –a template has to be created for every new state that wishes to start the programme and also one for brain death declaration

- All ICUs doing brain death declarations must become routine
- All tertiary medical college hospitals should have transplant programmes

- **Transparency**

Maintaining transparency at all times and all levels is highly crucial. Lack of it could kill the programme.

- **Ranking**

A template for ranking has to be built and every aspect should be scored. The ranking system should be at the hospital and state levels to keep tabs on progress. For example, if a hospital/organisation has an advisory committee that meets regularly, there should be a score given for it. Once the scores are consolidated and ranking is assigned, it would act as a good consultation point and take the hospital or state to the next level.

- **Recognizing/Rewarding donor families**

Most donors are from economically weaker backgrounds and there is always the question of the monetary rewards being given in these cases. However, it would be much better if there were systems in place to recognize and rehabilitate donor families.

- **Donors should be rewarded and not the states**

Rewarding states may set off an unhealthy rivalry in a programme that has humanity at its core.

The role of media has to be included in the template in the context of revealing identities of donors and recipients. Upcoming states could borrow ideas from government orders of other established states to make things easier to function. A body constituted by representatives of various states

could finalize a template to make it more acceptable and get a buy-in from different states. While a centralized programme may not be the solution as every state would have its own challenges, free flow of best practices and learnings should be allowed and encouraged. Making costing transparent is an aspect that needs to be deliberated on further.

Dr. Jayanti Ravi

For effective policymaking, successful examples must be studied carefully and adopted to align with the context of different states. In the Gujarat context, both the Health Minister and Hon. Chief Minister have supported the cause and the earlier impasse has been overcome and donations are being done successfully. While awards are great motivators, the selection matrix has to be a robust one.

Learnings from campaigns like the Pulse Polio, where both the government and civil society came together to make it a success, could be applied appropriately to other initiatives. Another appropriate example would be the implementation design of the 'Swachh Bharat' mission, which met with success pan India. All stakeholders must contribute their knowledge and time to create an ecosystem that promotes the cause.

The Indian society inherently is a compassionate one, having ethos of caring at its core, which could be tapped effectively. Some states may need handholding to gain momentum.

Champion NGOs like Donate Life and MOHAN Foundation could play pivotal roles in enhancing donation rates in the country.

Session 3: Making Transplants Affordable

A. Costs of Transplants

Chairpersons - Dr. Dhiren Shah and Dr. Amit Joshi

Topic 1: Liver Transplant Costing – Dr. Sonal Asthana

Dr. Asthana began his lecture by mentioning that the topic is close to his heart and it is something that he has been working on since the last four years. Why does costing matter, what are the drivers of cost and why it is different from place to place were some of the questions his talk aimed to answer.

Discussing costing is highly important because there is a lot of heterogeneity and disparity in the economics of healthcare, based on which the country could be categorized into the following, metaphorically:

- India 1 – the group having the per-capita income of Mexico, around 100 million people
- India 2 – the group having the per-capita income of the Philippines, another 100 million
- India 3 – the group having the per-capita income of Sub-Saharan Africa, around one billion people

With so much variation within the country, some mechanism has to be designed to account for healthcare expenditures, particularly when the majority pays out of their pocket for healthcare. The public health spending accounts for only 1% of the GDP, while the private sector contributes about 3%. A patient pays most of the health expenses and the out-of-pocket expenditure is around 78%.

The issue came to light when corporate hospitals were approached for support with paediatric transplants and there was no standard structure available with any hospital. Hence, Dr. Asthana began working on an intensive costing exercise in his own hospital and realized that almost 40% of the cost went towards non-recoverables like equipment and blood products; procuring these products cannot be done free and the government does it using the taxpayers' money.

The costing structure in the government hospitals that run liver transplant programmes, in itself, is highly varied. There is no clarity on how much public and private sectors charge for a liver transplant. While in a government setting, it is thought to be Rs. 4-7 lakh, it has also been quoted that the private sector might charge around Rs. 30-80 lakh for a liver transplant.

Following a costing exercise taken up in 2016 during an ISOT-MOHAN Foundation workshop, it became known that almost 50% of the cost incurred was during the first 24 hours of the surgery for blood products, investigations and equipment. Based on this it becomes evident that the costing will vary between institutions. In the government setting, where everything but the consumables are free, it may cost around Rs. 7-8 lakhs, Rs. 12-14 lakhs in a not-for profit hospital and anywhere between Rs. 17 and 20 lakhs in a corporate hospital.

What drives the cost?

- Consumables
- Professional costs – paying the doctors and nurses
- Infrastructure and hospital costs
- Profit – particularly in the corporate sector
- Variability – the most important factor as transplants are always unpredictable; in some cases, a single transplant's cost may equal the cost of nine others. Some insurance factor is billed into account for such deviations

India offers transplants at the lowest cost possible when compared to other countries; it is about 10% of what a liver transplant costs in the USA. This is because of the low labor costs in India – only 20-25% is spent towards labor, whereas it is 54.1% in other nations.

Numerous innovations across the country have also helped in maintaining the cost low. A few examples:

- ABO-incompatible LT using cascade plasmapheresis technique (Soin)
- No immune globulin in transplantation for hepatitis B (Wadhawan) – helps save around Rs. 10 lakhs and is internationally accepted
- Spilt LT expertise gained from LDLT used in DDLT as well (Rela, ILC) – maximum utilization of retrieved organs to use in multiple patients
- Auxiliary domino transplant (Rela)

The problem in India however is that people cannot afford even the lowest of costs. A study from PGI Chandigarh shows that residents of the richest city of the country have had to sell property, borrow and liquidate entire savings to pay for a kidney transplant. The question therefore is how much does a patient have to pay?

Dr. Asthana showed a funding model for paediatric transplants, where the patient has to pay only Rs. 2.5 lakh of 15 lakhs for a transplant, while the rest of it could be raised through CSR and crowd funding. In the last 4 years, 73 transplants were performed at a cost of around Rs. 8 crores based on this model. Owing to its success this model has been made public to all those hospitals that perform paediatric transplants and 140 transplants have either successfully been completed or in the pipeline, across the country. Models like this, when made public, also help build trust in the system.

The focus should be on:

- Knowing the unit cost – for money to come, numbers must be known
- Stratifying cases according to risk and complexity
- Having insurance for cost overruns
- Possibility of scaling up the efforts

Dr. Dhiren Shah commented that the initial cost to start a liver transplant programme in the private sector would amount to approximately Rs. 2.5 crore and the private sector would focus on recovering this initial investment and will therefore be part of the surgery packages.

Topic 2: Heart Transplant Costing – Dr. Jose Chacko Periappuram

Dr. Jose Periappuram, who joined the conference over Skype, began his lecture by mentioning that there are many variables in costing in various hospitals across the country and it is important to arrive at a consensus in terms of costing for heart transplant. He presented national and state-wise organ donation rates, stating that efforts have to be made to expand the donor pool; since 2013, the donation rates have increased three-fold in 2017 and is a promising trend.

Dr. Jose proceeded to brief the audience on the deceased donation procedure following brain death and presented a picture of the kidney transplantation scenario in the country where almost 90% of patients on the waiting list die without getting an organ. On the other hand, India is presently a forerunner in living donor liver transplants and the focus should be to improve the deceased donation numbers.

An article in The Times of India's Karnataka edition shows that while no heart transplants are performed in the government hospitals of the state, non-profit private hospitals charge Rs. 10-15 lakhs and the corporate ones, Rs. 22-30 lakhs.

Breaking down the cost of heart transplant in Kerala:

- Donor organ related expenses (paying the donor hospital for organ maintenance): ~ Rs 50,000
- Pre-operative work up related (investigations, scans, heart study, registry upload): ~Rs 50,500
- Surgery related (Induction immunosuppressant, RATG/Basiliximab, immediate post-op and CPB expenses, immunosuppression and other drugs, extended ICU stay, ECMO/Dialysis – if required): ~Rs 7,36,500 (may go up by ~4 lakh at the end of surgery)
- Post-operative care (Rent/medicines/levels/food/physiotherapy for ~20 days): ~Rs 2,00,000
- Transportation of organ (road/air/chartered; only if applicable): ~Rs 10,000/ 25,000/ 10,00,000
- **Total cost (without ECMO and transportation): ~Rs 10,00,000 (Ten Lakhs)**

In addition to the above, a heart recipient would have to spend Rs 30,000 to 50,000 on post-op for six months; and around Rs 10,000 to 15,000 per month for immunosuppressant, drug levels and biopsies if required.

The private system could be categorized into two:

- a. Non-profit oriented hospitals where transplantation is performed for a cost
- b. Corporate hospitals where the cost of transplantation and follow-up is high for the average Indian patient. The infrastructure and quality of care will be superior to what is offered by a government hospital.

Choices made by patients with respect to type of rooms and other amenities, condition of the patient – in ICU or on ventilator or MCS leading to extended stay and other co-morbidities like diabetes and dialysis required also would be factors that affect costing. These cannot be part of a predetermined package.

The government should come up with various packages like 'renal transplant package' or 'heart transplant package,' where the cost is borne by the government where possible. These could at the very least act as ceilings that hospitals could follow for elective cases. Subsidising cost of medicines and providing grants for patients are also ways to lower the expenses borne.

Transplants could be made affordable through the combined efforts of government and private institutions, bearing in mind the high costs the hospitals have to incur to run the programme.

Governments of Tamil Nadu, Telangana and Karnataka states offering grants to transplant patients should be adopted by other states and the central government has to push the states to do it. Institutions should also be careful and avoid serious errors that could cost them heavily.

Dr. Jose made an observation similar to that of Dr. Asthana's, on how the labour costs are very low for the effort that is being put in for every single transplant.

Comments:

Dr. Dhiren Shah raised a question on how the costing would be affected if complexities were encountered during the surgery. Dr. Jose replied that patients should always be warned that the package cost is very basic and there is a high probability of it being exceeded due to complications. Close to more than 50% of the patients always run into complications and therefore the basic package remains applicable only in less than half of the patients.

Dr. Asthana commented that in deceased donor liver transplants, only around 10-15% of patients might exceed the package cost. However, these few might end up incurring Rs. 50-60 lakhs each and this asymmetry is very unpredictable. On the other hand, the overruns might be less in living donor liver transplants as patients are better selected and surgeries are semi-elective. Patients involved in the deceased donor liver transplants are much sicker and therefore complications are common.

Dr. Phadke mentioned the Suvarna Arogya Seva Trust scheme where the Karnataka government offers 10 lakhs for heart, 12 lakhs for liver and 2 lakh rupees for kidney transplants respectively with a year's immunosuppressant drugs free to the below poverty line (BPL) patients. This scheme is applicable also to private hospitals that perform the surgeries at this cost, however the private sector has not responded to it yet. Dr. Asthana responded that every state has allocated funds as per their own will, leaving the actual cost of the transplant unclear. The numbers are not evidence based and there are no SOPs laid out that help in disbursing the allocated funds; only one heart transplant out of the 400 performed so far in Karnataka has made use of this government-funding scheme. Lack of communication between stakeholders is one of the reasons this has not worked.

Topic 3: Challenges of Post-operative Expenses in Renal Transplant – Dr. Mrs. Sujata Rajapurkar

Dr. Sujata Rajapurkar's lecture was on challenges faced by kidney transplant patients after the surgery. The main expenses could be categorized under the following heads:

- Routine Immunosuppression
- Follow-up visits for routine check-up and for emergencies
- Travel – hospitals receive patients from neighbouring states
- Investigations
- Treatment of common co-morbidities e.g., diabetes, hypertension and other complications
- Hospitalisation if required
- Medicines: other than immunosuppression and for complications

Monitoring graft function, different screenings – for cancer and infections also add up to the expenses.

Breakdown of post-transplant expenses:

- Monitoring graft function for a month (immediately post-transplant) - ~Rs 16,280
- Maintenance Immunosuppression for a month - ~ Rs 9,320
- CMV(Cytomegalovirus) Prophylaxis for 100 days - ~Rs 7,000
- Cost of Induction (depends on patient's weight) - ~ Rs 1,80,000
- CMV monitoring post-transplant for 100 days - ~ Rs 18,000 / Rs 30,000 (low risk/ high risk)
- BKV (BK Virus): Surveillance – urine and blood monitoring (8 times) - ~ Rs 96,000
- DSA (Donor Specific Antibody) monitoring
 - 2yr – DSA +ve: Rs 2,10,000
 - 2yr – Desensitized: Rs 2,45,000
 - Low risk DSA –ve: Rs 1,05,000
 - Highly sensitized: Rs 1,40,000
- Malignancy screening [HBV (Hepatitis B Virus)/ HCV (Hepatitis C Virus)/ EBV (Epstein-Barr Virus)] for 2 years - ~Rs 6,000

The patients meet these expenses mainly by way of personal funds, reimbursements, insurance, taking loans and receiving donations. Dr. Sujata Rajapurkar herself has been raising funds, some of which have been set aside to aid antirejection therapy, monitoring of renal function, detection of complications and emergencies. A very transparent process is followed where donors know how and where their donations are utilized. She has managed to raise around 21 crores from March 1980 to 2019 to help paediatric patients, dialysis patients, surgery, post-transplant costs and medicines for patients suffering from kidney and urogenital tract diseases. In the financial year 2018-19, around 1,170 patients were able to benefit from her efforts.

The following are recommendations to lower expenses post-transplant:

- Improving adherence to lower chances of infection and rejection
- Regular follow-up to ensure early detection of infection or rejection if any
- Following prescribed diet, exercise, and precautions

Questions:

Dr. Kishore Phadke: Can pre-emptive transplants be used as a strategy to lower the costs?

Dr. Sujata Rajapurkar: Of 100 transplants performed in a year, 10-15 of them are pre-emptive, requiring only one or two dialysis sessions before the surgery. Preemptive transplants definitely reduce the cost and chances of infective and rejection complications.

B. Crowdfunding – Checks and Balances

Moderator – Mr. Sundeep Kumar

Introduction

Mr. Sundeep Kumar kicked off the discussion by commenting that after having understood why transplants are expensive, it is time to know how to pay for these. Almost 41% of funds that are raised through crowdfunding are for medical expenses, he quoted a survey from as early as 2015, making it evident that these expenses are a major concern all over the world and not just India. ***An April 2018 study in India revealed that about 40% of crowdfunding campaigns were to source funds for kidney transplants, 33% for liver, 12% for lung, 11% for heart and rest for other organs.***

Credibility of such campaigns run on social media platforms is a concern for the public and the panelists attempted to address this. There is also the debate of social equity attached to this model – are those most in need, are the ones who are able to benefit from it? Are the poor tech-savvy enough to be able to go online and raise funds? Emotional quotient attached to the cases play an important part in fundraising, which is evident from the fact that it is easier to fund paediatric transplants.

Topic 1: Sources of Funding for Transplant Patients in India – Ms. Jaya Jairam

Quality of healthcare offered in India is at par with what is offered in many other countries and is much more affordable; it is around one-tenth of the cost in countries like the United States. Nonetheless, the out-of-pocket expenditure (66%) is much higher than the government spend (31%) which is not the case in other countries (58% is govt. spend). Similarly, while the rest of the world spends around 10% of their GDP on healthcare on an average, India contributes less than 5%.

The income-based demographic classification in India as of 2017 shows that the middle-class constitutes 50% of the country's population, followed by 48% of lower class and 2%, the affluent. Class-wise sources of funding:

- Affluent class: self-funded
- Lower class: Govt. hospitals, govt. Schemes, PM and CM relief funds, charities, National and State government schemes
- Middle class: caught in the middle with fewer options and have to work with a combination of the below to meet the expenses
 - Self-financing (family and friends)
 - Health Insurance Cover: Individual/Group Insurance/Part payment by Self
 - Trusts committed to helping Transplant patients e.g., Transplants – Help the Poor Foundation and Pravin Agarwal Foundation
 - Bigger Trusts e.g., Tata Trusts

- Smaller Trusts
- Crowd funding

A public-private collaboration would be an answer to this issue – the resources of the private sector could compensate for the inadequacies in the public sector.

Comments:

Mr. Sundeep Kumar commented that Jaya's talk made it clear that the middle class is squeezed in the scheme of things and crowdfunding could be the way out.

Topic 2: Milaap Model and Challenges – Mr. Mayukh Choudhury

Mr. Mayukh Choudhury's talk began with him emphasizing two basic rules or principles every crowdfunding model has to be based on:

- Donor is everything: the backbone of the model is donor trust and maintaining the right amount of credibility with the donor trust is most important.
- Crowdfunding alone is not the solution; it is only one of the solutions

Crowdfunding is not exactly a new phenomenon. The 66-68% of the out-of-pocket healthcare expenses amounts to almost 78 billion dollars every year, of which 50 billion is personal savings; the second major part comes from formal and informal lending, and the third most significant piece is contributions from friends and family. Irrespective of the existence of a formal crowdfunding setup, people helping each other in times of medical emergencies have been quite common and around 3-5 billion dollars is in play in such arrangements. A crowdfunding model merely helps in making this process more accessible, transparent and engaging with the help of technology.

A crowdfunding platform like Milaap considers the below as the overarching principles:

- **Discoverability:** helping potential donors identify/discover causes they would want to support
- **Transparency and accountability:** a patient's identity and his ailment have to be genuine to appeal to the donors. In cases where funds raised for one particular patient become unusable for reasons like the patient's early demise, reusing the money requires clearance from the donors.
- **Engagement with the donor:** not taking the donor for granted and providing them with regular updates. This mechanism would encourage the donors to contribute repeatedly and pass on the message in their circles.

Topic 3: Experience with Crowdfunding – Mr. Anil Srivatsa

Credibility is at the heart of crowdfunding and only when the donors know that their money is judiciously used, will they contribute. Accessibility to the crowdfunding platforms is not universal; those who are not tech savvy cannot utilize this option and hence are dependent on local charity organisations.

The credibility of transplant coordinators lies in validating their patients' condition when attempting to raise funds for them. Crowdfunding is a very grass-root level activity, particularly for the lower middle-class group. Collecting and maintaining the details of all local charitable groups will be effective in helping patients at all times. A donor's contribution comes from his/her heart and not just their brains or wallets.

Conclusion: Mr. Sundeep Kumar mentioned that the debate about technology being a boon or bane would remain a never-ending one. The reason why crowdfunding has garnered attention in recent times is because technology has widened the distance between a donor and a beneficiary, adding an element of anonymity to the picture giving rise to the credibility issue.

Discussion

Mr. Sundeep Kumar: How to ensure that the money raised is genuinely and effectively used?

Mr. Mayukh Choudhury: While technology has indeed widened the gap, it has also helped both donors and beneficiaries to reach out to larger circles. Maintaining the sanctity of the interaction as this reach widens is the challenge. Anonymity is actually something that people when seeking help prefer, and a crowdfunding platform helps with this. In that sense, technology does help in spreading the message. Maintaining the sanctity of such interactions is the onus of a crowdfunding platform like Milaap.

- Verification process:
- Establishing the identity of a patient – KYC verification
- Verifying the health condition – crosschecking with doctors and hospitals
- Ensuring money goes to the right cause by
 - Depositing money directly to the hospital
 - Thoroughly verifying all bills in-house
 - Continuously designing checks and balance mechanisms

However, crowdfunding platforms cannot verify the effectiveness or correctness of treatments offered for various health conditions for which money is being raised. They therefore put their trust into the healthcare service providers.

Mr. Anil Srivatsa: Having standard package rates for surgeries across the country with marginal variations will also help in making crowdfunding easy and effective. It also helps if the donors are aware of these rates so that they make an informed decision.

Dr. Sonal Asthana: Crowdfunding alone will not help; using a hybrid model where CSR partners also contribute, is more practical. Hospitals should set standard rates and advise crowdfunding platforms appropriately whenever they agree to take on a new campaign.

Dr. Atul Mulay: Is donor identity/information verified?

Dr. Kishore Phadke: The government is not in favor of the crowdfunding model. They want to either fund a transplant entirely or not get involved at all.

Mr. Mayukh Choudhury: The key is how easy it is for a donor to make the donation. Donations are usually only smaller figures and as there is payment mode that involves direct cash deposit, no stringent mechanisms are in place. Donations of larger amounts are followed up with requests for more donor details. Milaap has managed to raise around 155 crores in 5 years for treating liver ailments alone. The standard processing fees in 5% of the money raised and 15% when Milaap does the promotions on behalf of people unable to do so. The 5% is waived for the most deserving cases at times.

Session 4: Organ Donation – Challenges and Success in Organ Donation in Gujarat

Chairpersons: Dr. Sunil Shroff and Mrs. Lalitha Raghuram

Speaker: Mr. Nilesh Mandlewala

Mr. Nilesh Mandlewala introduced the Donate Life organisation and the work it does to promote organ donation. He recounted that 15 years ago, in the early days, it was difficult since there was no awareness about either brain death or organ donation and they encountered many rude and violent family members ignorant of the cause.

Another challenge that continues is the lack of infrastructure and recognition of hospitals as retrieval centers. Surat does not have a transplant center yet and Donate Life is working towards getting all hospitals to be registered as retrieval centers. There are also challenges in donor maintenance as trained intensivists are rarely available and there is a dearth of ventilators and other equipment to do brain death tests.

A lot needs to be done to create awareness about organ donation. Myths are in abundance in the minds of people regarding last rites of their loved ones, sanctity of the body and religious views on such donations. Giving and compassion are inherently part of the Indian culture and these attributes have to be focused upon when reaching out to the community.

Mr. Nilesh Mandlewala highlighted that, despite these challenges, his organisation has been counseling families and been instrumental in saving more than 700 lives through cornea and organ donation. This success is due to the full cooperation of the brain death declaration panel doctors, particularly the neurosurgeons and neurologists. All hospitals display posters explaining the importance of organ donation; all donor families are brand ambassadors for the cause; Surat Police complete their inquest in time during MLC cases; also provide green corridor when required; and post-mortems are performed at all times in Govt. hospitals whether it is day or night.

Additionally, Surat Airport Authority provides their support with priority landing and takeoff facility and Surat Municipal Corporation provides transportation of dead body without any charges anywhere in the country from Surat. Positive support from print and electronic media are factors that have contributed to improve the rates of donation in Surat. The entire effort is tied together by a set of volunteers who carry out the entire process of organ donation.

Donate Life also tends to the needs of donor families like education and felicitation functions are organized to increase awareness and motivate citizens of Gujarat to support the cause. They also visit the residence of organ donor families to offer condolences and appreciate them for making the selfless decision to consent for organ donation.

He ended his talk with a short film of a felicitation programme of donor families by the Hon'ble President of India.

Questions/Comments

If there was no authority available until recently, how was organ allocation done?

Nilesh Mandlewala: All organs are offered to the government / SOTTO then they do the allocation as per their procedure.

In case there is no recipient available in the state, then an offer is made to ROTTO Mumbai and they proceed further for allocation as per the procedure.

Sujata Ashtekar: There are many doubts around this; we do the organ allocation for all organs in the region. Only after receiving a written note from all state authorities, organs are allotted to patients of foreign origin.

Session 5: What makes a Leader?

Chairpersons: Dr. Rajesh Chandwani

Speaker: Dr. Rakesh Gupta

Dr. Gupta's personal experience as a donor family member, who agreed to donate his mother's eyes and having experienced the great feeling of knowing that it helped two others see is what motivates him to support the cause.

The state of Haryana has been able to launch the large-scale programmes listed below through which we can understand the levers for successful large-scale transformations.

- Beti Bachao Beti Padhao
- Saksham Haryana
- Antyodaya Saral
- Chief Minister's Good Governance Associates

Beti Bachao Beti Padhao (B3P) - The three main objectives of the programme:

- to prevent gender biased sex selective elimination
- survival and protection of girl child and
- to ensure education and empowerment of girl child

Some strategies that were used:

- Crack down on illegal ultrasounds centers
- SOPs issued by DGP Haryana for investigation and prosecution under MTP/ PNDT Acts
- Regular monitoring of programme from CM's office through VC & divisional reviews
- Crack down on sale of Sex Selection Drugs (SSD) under PNDT
- Inter-state and within state decoy operations
- Effective enforcement of MTP Act

Dr. Rakesh Gupta mentioned that sex rate ratio which was 871 girls against 1000 boys has increased to 920 since the launch of B3P and Haryana has been able to save 21000 girl children. These efforts have been featured in the Wall Street Journal and The Times of India and received several awards.

Antyodaya Saral: an online platform for citizen service delivery where all the citizens can get their queries answered. In the last year the platform received close to 4,00,000 applications for the 490+ schemes in the system and around 6,00,000 SMS were sent acknowledging the application receipt. They receive 70,000 helpline calls every month. Every citizen feedback is also recorded and the average citizen feedback score for Antyodaya Saral is 4.3/5. Haryana is the first state in the country to achieve this level of scheme / service delivery

Saksham Haryana: The important objective of this project is improving children's grade level competency. In the period 2014-2019, Saksham Haryana was in its first phase of systemic transformation and now the second phase Saksham 2.0 is underway. 86% of students are grade-level competent and of the 119 total blocks, 107 are Saksham blocks. NITI Aayog has recognized the efforts of Government of Haryana in bringing systematic education transformation in the state.

Chief Minister's Good Governance Associates (CMGGA) – the mandate:

Flagship schemes: CMGGAs can help improve on-ground implementation and monitoring of the flagship schemes of the state

Innovative ideas: CMGGAs can suggest new and innovative interventions across domains to further good governance in the state

Authentic feedback: CMGGAs can act as an independent channel for providing unbiased and direct feedback from the ground to the CM and his team

Graduates from diverse backgrounds, are given the opportunity to work with various ministers and the district collector's office. The present batch is working on the following work-streams, namely: property tax, higher education, women safety, e-office and Swachh Survekshan.

The levers for achievement in any large-scale programme:

- Shared vision
- Systemic approach
- Use of technology & data
- Gamification
- Taking people along
- Robust review and monitoring

Similarly, Haryana has committed to saving lives through organ transplantation and donation by adopting a systemic approach and the levers.

1. Organ donation & transplantation SBCC campaign
2. Setting up transplantation & retrieval facilities
3. Robust review & monitoring

Technology and data will be used in organ donation and transplantation activities like brain death testing, organ retrieval and allocation. Gamification could be used to drive competition amongst hospitals by tracking 'number of lives saved. 'Recognizing hospitals, transplant coordinators and best performing districts on a monthly basis will also yield results. A robust review mechanism at both, state as well as district level will drive the implementation of cadaver donations.

The CMGGAs would assist district administration and facilitate organ transplantation and donation within the same framework as other programmes:

Setting up DC reviews: CMGGAs will help improve on-ground implementation and monitoring of organ donation and transplantation

Ideating and driving organ donation: CMGGAs can suggest new and innovative interventions to solve organ donation and transplantation

Authentic feedback: CMGGAs can act as an independent channel for providing unbiased and direct feedback from the ground to the CM and his team

Session 6: Free Paper Presentations

Judges: Dr. Kishore Phadke, Ms. Priyanka Borah and Dr. Muneet Kaur Sahi

Topic 1: Brain Stem Death and Attitudes towards Organ Donation – Lt. Col. (Retd.) Sandhya Nair

Research on the data pertaining to successful organ donation cases as well as reasons for unwillingness to donate was conducted during the period 2009 to 2018.

Findings: Out of 219 brain dead cases, in the said period, in the said hospital based in the North of India, 62% were male and 38% were female. Head injury was the major reason causing brain death. 77% of the brain dead cases identified were suitable for donation and the rest were unsuitable mainly because of sepsis and malignancies.

Discussion: In the cases that were suitable for organ donation, 57% of the families were willing to donate. Top five causes of unwillingness to donate were:

- Decisional conflicts within the family
- Unable to comprehend the concept of brain death in spite of repeated counseling
- Fear of criticism by society
- Fear of mutilation of loved one's body
- Dissatisfied with healthcare meted out prior to approaching for organ donation

Other reasons included religious beliefs, hoping for a miracle, news of kidney scams, etc.

Organ donation in only 79% of the cases that had willing families was successful. Cardiac arrest was the main reason why organ donation could not be proceeded to, despite a willing family. An average of 3 solid organs per donor was donated in the successful cases.

Correlation between age and sex with respect to organ donation were analyzed and it was found that family was more likely to give consent if:

- patient's age was more than 45 years
- patient is female

Another important aspect concerning the decision maker in the family was:

- Almost no donations took place when mothers were counseled
- Most success was seen when sons were counseled for donating the parent's organs

It was highlighted during the Q&A session that religion was not one of the major reasons for unwillingness in families.

Topic 2: In-Depth analysis of the Socio-Demographic factors associated with the organ donor pledges received from pan India – Dr. Geetika Vashisth

Around 23000+ online pledges of past 4.5 years (Jan'15 to Jun'19) were analyzed in order to arrive at approaches that could make organ donation awareness more effective.

Analysis showed an encouraging picture of steady year-over-year increase in pledges, possibly due to increased emphasis on social media campaigns and collaborative efforts throughout India.

Findings:

61% of the pledges were from males and 39% from females, which shows that a stark gender difference does exist though the gap is reducing showing that both men and women are responding to the call to action. Highest number of pledges (nearly 67%) came from the youth in the age group of 18 to 35 years. Maximum pledges were received from Maharashtra followed by Delhi, Tamil Nadu and Karnataka. Cumulatively, southern states (33.7%) are doing much better than any other region of India. Most individuals (86%) pledged to donate all their organs and tissues.

Use of internet /Google search engine (36%) and popularity of social media platforms such as Facebook and Instagram (9%) in the past few years have led to increased sensitisation of public. In addition, information passed on by word of mouth (19%) by friends/relatives proved to be one of the significant factors to motivate individuals to take the pledge.

Certain limiting factors to this study such as language of data collection being only English, lack of access to internet /online platform would not have enabled interested persons to take the online pledge. Since organ donation pledge does not hold any legal validity, people might have chosen not to do it even if they agreed with the concept and just informed their next of kin. As the pledge form is not comprehensive, it misses some important socio-demographic factors such as level of education, marital status, profession, income etc.

Questions/Comments

1. How many actual organ donations took place due to their initiatives? The speaker replied that they do not have mechanism of tracking the same and that their initiative is restricted to creating awareness around organ donation, sharing information and enabling pledges.
2. How was pan India population targeted even though they are based in Delhi NCR only? The speaker replied that they reached out to pan India population through the online platforms like Facebook, Instagram, YouTube, and the offline campaigns done in collaboration with other regional NGOs, whereby a call to action is given, directing the pledges to their online platform.
3. Going forward which is the population that they would like to target? The speaker responded that they would be focusing on reaching out to the elderly people and women so that more can come forward and decide for themselves. Many who are middle aged

and above have doubts about whether they can donate their organs due to their lifestyle related diseases like diabetes, hypertension etc.

4. Since the past six months or so, MOHAN Foundation has been seeing a new trend of requests from pledgees wishing to opt out. The speaker was asked if ORGAN India was receiving similar requests. The speaker confirmed receiving such requests and shared the reasons cited as being unsure as to where and how the organs would be utilized and whether the organs will be given to the poor and needy instead of being given to the rich. The matter was highlighted that a gradual mistrust was coming into the system possibly due to misleading news and information and it was important to win these people back through awareness initiatives. The role of private hospitals and patient's experience while seeking treatment plays an important role in building and reinforcing the trust.

Topic 3: Recipient Coordination - Passionate work by Compassionate People – Ms. KKD Surekha

This presentation highlighted how crucial the role of coordination is, in enabling a patient suffering from end-stage organ failure to get a life-saving organ transplant.

A transplant coordinator's role includes counseling the recipient, their families, donor families and coordinating with a whole host of people, departments and entities such as consultants, labs, state authority, autopsy department, logistics, police, press, diagnostics, medical records, blood bank, pharmacy, OTs, ICU, surgeons, dietician, insurance, donor hospital, nursing staff, etc.

The coordinators are aware of the importance of their role and keep pushing themselves in difficult situations as they bear in mind the huge gap between the need for organs and its availability.

The process was explained as follows:

Three ways for a recipient to receive an organ – (a) living donation from near relatives (b) from other than near relatives (c) deceased donation.

A transplant coordinator helps the recipient with the registration procedure, explains to the recipient's family the costs involved, pre- and post-operative support required and the investigations required to be carried out. While live donation transplant is carried out in accordance with THOA guidelines, the deceased donation transplant is carried out once the organs are allocated by the state authority like the Jeevandan (in Andhra Pradesh), SOTTO or NOTTO, as the case may be. The requisite reports, consents, declarations and medical legal reports are obtained in case of deceased donation. Simultaneously, the coordinator readies the recipient for a transplant, by coordinating for various tests, clearance from consultants, supporting with insurance and billing. The entire process from retrieval of organs, to transplanting them into the recipient is a race against time and takes typically 48 hours.

The speaker went on to share a unique experience whereby a patient was transplanted kidneys thrice – first from his mother, second from his brother and the third from a deceased donor, and is now doing well.

Questions/Comments

1. If a child was in need of a kidney transplant and both the parents as well as the grandparents were compatible and willing to donate one of their kidneys, what would the choice be? It was discussed that in such situations, one of the grandparents might be a better choice at that time, so that going forth, if the child was in need of another transplant, years down the line, one of the parents would still be able to donate, thereby giving their child the gift of life for the second time.
2. What is the minimum age for a child to undergo a kidney transplant? It was discussed that the weight of the child (minimum 10kg is considered adequate) is the required criterion for considering a kidney transplant; not the age of the child.

Topic 4: Medico Legal Issues related to Deceased Donation – Dr. Shabina Sheikh

In Medico Legal Cases (MLC), invariably involving road traffic accidents, death is a sudden event and there is less time for the family to accept the situation, while the number of family members to be counseled can be large. This is a very challenging situation for the transplant coordinators as they break the news of brain death and thereafter counsel the family for organ donation. The various procedures involved and the timing involved has to be transparently informed to the family.

Once the family gives their consent, in such MLCs, the police department is involved for granting their “No Objection” to the process of organ donation and retrieval. Furthermore, once the retrieval process is complete, the body is to be sent to a civil hospital for post-mortem and only after completion of post-mortem, the body is handed over to the family.

In the speaker’s past experience, there have been instances of families withdrawing their consent to organ donation when they approached the police for obtaining No Objection to organ donation and fearing further delays due to body being sent to civil hospital for post-mortem. ***Lack of awareness among the police about concepts of brain death, organ donation process and their role in it, has led to them not accepting brain death certificate and insisting on death certificate, thereby creating mistrust in the minds of the already grieving family members and causing further harassment to them.*** In this case, around 5 hours were wasted further in convincing the police about the concepts and by that time, the family withdrew their consent out of anger and frustration.

Additionally, even though THOA act requires a forensic expert to be present at the time of retrieval in order to avoid re-exploration of the body which causes further delay, thereby harassing the donor families, it is not practically happening in most of the states in India.

Questions/Comments

1. What can be done to solve this issue? More awareness initiative to be conducted by the transplant coordinators at police stations in the vicinity of their hospitals.

Topic 5: Attitude of the Small and Mid-sized Hospitals to be registered as Non Transplant Organ Retrieval Centre (NTORC) and to Study the Roadblocks – Dr. Jimmy Gupta

The speaker spoke about the need to motivate the small and mid-sized hospitals, having ICU beds, infrastructure such as ventilators, ABG machines and Operation Theatre to be registered as NTORCs. Many of them have advanced facilities like laminar OTs and perform neurosurgeries, but are not too keen on registering themselves as an NTORC.

As part of our NTORC facilitation initiative, a database of potential NTORC hospitals having ICU beds was made, the owners or management were approached, the pre-requisites and the procedures were explained, the hospitals were assisted in documentation, multiple awareness initiatives were conducted amongst the paramedic and ICU staff, they were helped in preparation for inspection by the DHS for the licence, one of their ICU nurses was encouraged to be trained in basic transplant coordination and our services of grief counseling were offered.

Out of the 37 hospitals that were approached in the Navi Mumbai region, 29 were not interested or mentioned that they redirect trauma cases to the nearest tertiary care hospitals and only 8 (21%) were interested. Of the 8 interested ones, 2 hospitals obtained their NTORC licence, 2 are pending for inspection, 2 are yet to form their brain death declaration committee and 2 are in the process of putting the documents together for licence application. Eventually after a lot of efforts, tissue donations were initiated at a few of these hospitals.

The speaker concluded with recommendation that transplant coordinators from private hospitals can take a lead in motivating more NTORCs in the vicinity of their hospitals. More emphasis to be on engaging with the ICU doctors and grief counseling in these hospitals so that they can also keep contributing to the organ donation pool in each city.

Questions/Comments

Motivating smaller hospitals to become an NTORC was not easy, due to multiple reasons such as unpreparedness to carry out grief counseling and organ retrieval activities, fear of public mistrust and wrong perception that the hospital is into wrongdoing such as removal of organs. Organ donations through NTORCs, few and far between, have happened due to families coming forth and volunteering to donate the organs of their loved ones. In case of braindead patients in non-NTORC hospitals, whenever the families have been counseled for organ donation and have been informed that the patient would have to be shifted to another hospital that has the licence, the families have refused. In Kerala, there were problems with NTORCs due to improper paperwork in the hospitals. In order for NTORCs to start meaningful contributions to organ donations, well-trained transplant coordinators must handhold the hospital so that the procedures

are not too cumbersome for the latter that are not geared to handle the flurry of activities in organ donation and retrieval.

Topic 6: Impact of Direct Public Education – Dr. Bhanu Chandra S

Benefits of direct public education for spreading organ donation awareness (face-to-face interaction during awareness talks with or without PowerPoint presentation/ stalls), over indirect modes of education (through telephone, social media, flyers, etc.) were presented by the speaker. He felt that the direct route enabled for all doubts, myths and misunderstandings to be clarified to the audience, without delay. The audience leaves the room with a clear mind and less confusion. Especially because brain death is a complex concept including many legalities around it, e.g. organ allocation criteria etc., being physically present while imparting knowledge gives more authenticity to the topic.

He thereafter cited examples of how even influential persons like an MLA, District Collector, a famous film director, apart from the common public and even entire families, got motivated by his awareness talks and his detailed one-on-one explanations and ended up taking the organ donation pledge on the spot.

His final recommendation was to create separate templates of organ donation awareness for the primary, secondary and tertiary levels.

The primary level can cover concepts of blood donation, eye donation, whole-body donation, organ donation and list of organs that can be donated while living and after death. This template can be used while addressing primary school children and even the less educated sections of society.

Secondary level template may cover the concept of organ donation, types of death, types of donors, brain death process, THOA, registration on waiting list and donor and recipient stories. This may be used for high school students and above, employees of corporates, other NGOs and bodies in general.

Tertiary level topics may include international information and statistics on organ donation, brain death declaration tests, organ allocation criteria, amendments in the THOA act, bodies such as NOTTO, ROTTO, SOTTO and their functions. This would be directed at educating doctors, nurses and other medicos, management level hospital employees, government officials from health sector and such others who are interested to know in depth.

Topic 7: Transplant Coordinator's Perspective towards Non-Monetary and Monetary Assistance to Organ Donors' Families – Ms. Mayuri Barge

The objective of the paper was to study transplant coordinator's perspective towards organ donation incentive, and to identify strategies to promote sociological impetus for organ donation. As part of the study, an online questionnaire was developed and circulated amongst 30 transplant coordinators from Pune. The respondent's typical demographic profile was – age group of 25 to 55 years, experience of up to 9 years, 61% females, allied health sciences as the educational background, and have handled a range of 5 to 40 brain dead cases.

As per the survey result, 47% of the respondents felt that no compensation of any kind should be given to the donor families, while 43% of them said yes to compensation in some form and 10% were undecided.

With respect to monetary benefits, the respondents were divided about reimbursement of donor's medical expenses, tax rebate to the donor family and assistance being offered for funeral expenses. Regarding non-monetary benefits, majority felt that a certificate of appreciation should be given to the donor family. The respondents were however divided about offering health insurance benefits, giving preference in waiting list (to donor families) in case of organ failure (in future) and regarding providing educational benefits to children in the donor family

In regard to negative impact of monetary or non-monetary assistance, 57% felt that this would tarnish the image of medical professionals. Majority felt that it might lead to some form of exploitation of the poor, might adversely affect the altruism in organ donation and would end up bringing down public trust in the programme.

76% of them also felt that some form of assistance had the potential to have positive impact on increasing organ donation rates and could promote the cause.

On strategies for increasing organ donation rates:

- Majority felt the need for awareness programme at national level, inclusion in high school and college syllabus and organ donor recognition
- 47% felt that rather than assistance to donor family, deepening awareness would be more effective, while 30% felt both were equally important
- Majority of 76% felt that presumed consent law would be more effective than giving assistance to donor family

In conclusion, it was suggested that any form of monetary or non-monetary assistance to donor families, if given, must be regulated. Deeper studies on legal and ethical merits of assistance to donor families need to be carried out by the government. Government interventions are needed to implement strategies for promoting organ donation. Possibly, presumed consent law could be looked at.

Topic 8: In-depth Analysis of Queries received on ORGAN India's Helpline to Identify Gaps in Information Dissemination, particularly at the Hospital Level – Dr. Devansh Vaish

Analysis: The research analyses the queries received on ORGAN India's Helpline, in order to improve the effectiveness of information dissemination through the helpline.

The reason why people call on the helpline, type of queries, call volume and its correlation with campaigns were analyzed. The pan-India calls received over an 18-month period (Jan'18 to Jun'19) were analyzed both quantitatively and qualitatively.

Spikes were noticed in the call traffic whenever there were awareness campaigns, especially in November, since 27th Nov is the National Organ Donation day and therefore sees a big push in campaigns.

Findings: Most of the calls were related to organ donation, a few on whole-body donation and rest were general queries related to what is brain death, ABO incompatible transplants, hand transplant, swap transplant, can a cancer or HIV+ person donate and requests for awareness talks. Most of the organ donation related queries were regarding kidneys and liver, and a few regarding heart. The callers were primarily looking for help with getting donors or were looking to buy organs or sell kidneys. A few asked for information on the waiting list, cost of transplant, government schemes etc.

Some enquired about eye donation and wanted to pledge their corneas, while some wanted to donate corneas of a family member who had just passed away. They coordinated 11 such corneal donations during the said period.

A few called enquired about the process of registering on the waiting list. Many calls were received from people who wanted to commit suicide and wished to donate their organs as their last act.

Conclusion/Limitations: It is seen that awareness levels about organ donation are quite low in terms of knowledge of brain death and the process, waiting list, legal and illegal aspects of organ donation. Patients and their families end up calling the helpline because either their queries remain unanswered by the hospital doctors / transplant coordinators /counselors or they did not understand or are simply unaware of the option of waiting list and the process. Quite a few are ill informed about their options like ABO incompatible transplants, swap transplants, etc. and are redirected to the transplant coordinators after counseling.

Some of the limitations include, the helpline not being 24x7 and calls received at night were being lost. Unavailability of updated database of transplant hospitals, poses challenges in guiding patients from across the country, in the right direction. Language barrier is a very big limitation since their helpline counselors can only answer in English or Hindi.

Questions/Comments

- Should people calling to sell or buy kidneys be reported to police?

- Could calls received in languages other than Hindi or English be redirected to other NGOs who have the wherewithal to answer those calls?
- A sinister organisation called “NKF” that has been scamming victims who wanted to sell their kidney, by providing them with a living donor card and in return promising them large sums of money for the sale of kidney was a point of discussion.

Topic 9: Public Education in Chandigarh and Punjab – Ms. Neha Sharma

An update of the activities and achievements in public education in Chandigarh and Punjab was presented. Achievements included expansion of awareness activities with NCC and NSS to various cities of Punjab, Haryana & U.P., being called in as a permanent resource person in all district and state level programmes of Red Cross in Haryana, as well as at Red Cross First Aid Course in these states.

Neha undertook 160 awareness initiatives during Nov’18 to Oct’19, thereby reaching out to 18688 persons, at an average of 13.5 awareness initiatives per month. The year-on-year increase in awareness programmes conducted, has directly resulted in a corresponding increase in number of actual donations. Awareness initiatives were also undertaken in the state of Jammu & Kashmir, by way of two programmes at IIT Jammu and an awareness talk for APS, Damana (Jammu), through Skype. Awareness was also conducted at multi religious places like Brahma Kumaris and in churches.

Awareness programmes are being conducted in collaboration with various government departments like Education Department, NSS, NCC, Red Cross – Punjab & Haryana, Social Welfare Department, State Council of Education Research & Training, as well as in corporate hospitals.

Comments: When the speaker was asked to share a difficult question that she faced during her awareness talks, she mentioned that she was once asked by a student as to what if one were to take the pledge but later one’s parents were unwilling to accept that decision? The student was explained that discussing the concept of organ donation and one’s decision to pledge organs, with one’s family members was of utmost importance. The issue of school principals sometimes not agreeing to awareness initiatives in schools citing reasons that the topic may be unsuitable for school students or giving excuses to avoid the initiative, was brought out and the speaker was asked if she faced any similar challenges. The advice given was that instead of approaching the principal, one must approach the head of the organisation so that the school must comply with directives issued to it.

Session 7: Checks and Balances to Protect Hospital Staff in Coordinating Living Transplants

Chairpersons: Dr. Sunil Shroff and Mrs. Sujata Ashtekar

Speaker: Dr. Piyasha Nath

Introduction – Dr. Sunil Shroff

An issue in 2016 led to appointing a Supreme Court judge to form the Mudgal committee in Apollo Hospital, Delhi. The Mudgal committee was appointed to put systems in place to avoid discrepancies in unrelated donations. In many situations, there is falsification of documents; donors are different from what is presented and so on during live donations.

Dr. Piyasha Nath

Organ transplant is not an incidental surgery; it involves a whole gamut of dimensions such as psychological, social, financial aspects and so on. Hence, it cannot be treated like a simple elective surgery. The organ transplant programme, if constituted by an educated team that is enthusiastic and passionate to drive the programme, then half the battle is won. A lot of emphasis is given to the leaders that guide the programme. Leaders must not only lead but also walk the talk and should be readily available always. This programme requires a lot of support from the seniors in the hospital without which running the programme would become an impossible task. Adhering to clinical guidelines, donors are required to go through a screening and undergo multiple tests. An independent donor advocate associates with the donor right from the initial stages. Donors are assured that they have the liberty to opt out of donating even when they are wheeled into surgery.

The transplant team comprises physicians, surgeons, anesthetists, nurses who are well versed in educating patients about complications such as rejection and infection, then the transplant coordinator, the social workers who in many instances overlap in doing the role of the advocate. He/she has a role to play in their counseling, with regard to their finances and with vocational orientation. The transplant approval ethics committee plays a very important role. The committee includes a very senior IAS officer, a legal advisor, clinical psychologists, medical social worker, two surgeons and one physician who are independent and not related with the team, and one person representing the management. Once the hospital is convinced that the documents received from the donor and recipient are authentic, only then do they go ahead. Many times the committee has asked patients for additional documents, and many other times patients have been rejected because their documents do not match with the law of the land.

Apollo Hospitals, Ahmedabad mainly does living kidney and liver transplants. There are various other hospitals that do living lung transplants as well. Medical screening of the donor is very

important. If the hospital has the slightest doubt about a patient, it is clarified before being put forth to the ethics committee. Legal documents for international patients are also very important. Three levels of scrutiny are done before being brought to the authorization committee and for international patients it is further passed onto the government authorization committee. Once a green signal is received, the hospital goes ahead with the case. The informed consent is audio visually recorded where the physician, the surgeon, the anesthetists and the transplant coordinator coordinate the whole process. The social and psychological aspects are taken care of by the hospital's clinical psychologist and medical social worker. Certain other aspects such as state of origin, nationality, age, relationship between donor and recipient need to be looked into; authenticating the relationship for international patients is a little harder. Gender is an important aspect, as many times there is a possibility that a female donor is pressurized into the donation and in situations like these, the advocate comes into action.

Comments

With deceased donation, the lung utilization is very low and hence the demand for lungs can easily be met through deceased donors. In 2018, around 170 lung transplants were performed, but there were 900 donors, showing that there are more lungs available. Therefore, there is an opportunity to fulfill the required need because of the unutilized lungs. The lungs retrieved from donation after circulatory death (DCD) are better than those retrieved after brain death. The number of lung transplants has gone up in the world because the quality of lungs is better in DCD. In brain death, ventilation causes a lot of damage to the lungs. Invention of good preservation fluids to preserve lungs has caused a change in the approach towards DCD. On looking at the success rates of lung transplants after DCD, liver transplants were also being done after DCD and today heart transplants are also being done after DCD in Australia. Donation after circulatory death could be the future. 33% of donations in the UK are coming from DCDs where road traffic accidents have drastically gone down. Most of the donors overseas are elderly people also known as Expanded Criteria Donor (ECD) prompting a shift towards DCD. In India, Post Graduate Institute of Medical Education & Research (PGIMER) in Chandigarh has already started doing DCD.

Session 8: Medico Legal Formalities and Organ Donation – The Role of Police

Chairpersons: Dr. G.L. Singal and Ms. Arati Gokhale

Introduction – Dr. Hemal Kanvinde

Dr. Hemal Kanvinde gave an introduction with the sections from the Transplantation of Human Organs Act (1994) and Amendment (2011) that discuss the procedure for donation of organ or tissue in medico-legal cases (MLC). Following that, she presented responses from transplant

coordinators to a questionnaire on 'State-wise comparison in MLC procedures'. These responses were from different states of the country such as Tamil Nadu, Kerala, Telangana, Maharashtra, Madhya Pradesh, Rajasthan, Chandigarh and Delhi.

In India, most of the deceased organ donations involve road-traffic accident victims, thus becoming medico-legal cases and necessitate police inquest followed by post-mortem examination.

Salient points from the questionnaire responses:

1. Who conducts the inquest?

The investigating officer (IO) from the local jurisdiction where the FIR (First Information Report) was filed will be conducting the inquest in the following places - Madhya Pradesh, Telangana, Kerala, Punjab, Rajasthan and Mumbai (Maharashtra). Whereas in places like Tamil Nadu, Delhi and Pune (Maharashtra), the IO from the nearest police station (police outpost or designated police station of the hospital) starts the procedure until the IO from the local jurisdiction reaches to avoid any delay.

2. Why is there a delay in completing the medico-legal formalities?

Nearly about 70% of the delay happens when the police do not have knowledge on brain death and organ donation. Considerable time has to be spent to make them understand the concepts and their role in facilitating the donation process. It was also mentioned, even after explaining 50% of the IOs do not come on time, causing delay in expediting the post-mortem procedures.

3. Does the IO trust the transplant coordinator(s)?

Except the respondent from Mumbai, the rest said 'yes' and this comes following considerable effort and time spent in making them understand the concepts and realize the emergency. The respondents from Madhya Pradesh, Kerala and Pune (Maharashtra) stated that the inquest is conducted before the organ retrieval, whereas in places like Hyderabad, Chandigarh, Delhi, Jaipur, Mumbai and across Tamil Nadu, IO initiates the inquest prior to retrieval and completes it only after the organ are retrieved.

4. Where is the post-mortem done?

Respondents from Telangana, Madhya Pradesh and Rajasthan shared that the post-mortem will be conducted in the same operation theatre (OT) after the organ retrieval. Whereas, in places such as Punjab, Kerala, Maharashtra, Tamil Nadu and Delhi, the body will be moved to mortuary for post-mortem after retrieving organs / tissues.

The respondents from Kerala, Tamil Nadu, Madhya Pradesh, Chandigarh, Delhi and Pune (Maharashtra) shared that the cranial cavity will be examined (opening the skull) during the post-mortem. In Telangana and Rajasthan, the post-mortem procedure after deceased organ donation does not include examining the cranial cavity.

5. Who issues the No Objection Certificate for organ retrieval?

In Kerala, Madhya Pradesh, Rajasthan, Maharashtra and Chandigarh, the respondents said that the approval (No objection) from the Investigating Officer for organ donation is a mandated part of the organ donation procedure. Whereas, in states like Tamil Nadu and Telangana, the IO is requested to come at the earliest, only to expedite the inquest and post-mortem procedures. The IO does not have role in authorizing, whereas the Medical Officer performing post-mortem has to authorize organ retrieval without which the organs should not be removed for transplantation.

6. Suggestions to improve the liaising with police personnel

Sensitizing them with adequate knowledge on brain death, legal aspects, donation process and their role would help in smooth and speedy process. Involving the higher police officials (top-down approach) would help in getting adequate support from all levels. Streamlining the procedures and making it uniform would help overcome existing issues in the medico-legal cases and avoid delay in handing over the bodies to families after organ donation.

Dr. Hemal Kanvinde briefed the initiatives taken by MOHAN Foundation such as creating IEC materials on '**Organ donation and role of police**' and distributing to the police stations, conducting sensitisation programmes at various police training colleges.

Case Study Presentations by Transplant Coordinators

1 Northern Region – Ms. Rajinder Kaur

Case Study 1

A 28-year-old male, following a road traffic accident, was certified brain dead. Since he was a regular blood donor, the family did not take much time to consent for organ donation when approached. Later the police was informed to come to the hospital to expedite the MLC procedures. The IO concerned, was unaware of the organ donation process as well his role. He said that unless the deceased had expressed his willingness to donate his organs after his demise, organ donation could not place. He also stated that approval from Deputy Commissioner is mandatory for organ donation. Meanwhile, he approached the family and forced them to withdraw the consent since without family consent nothing could be done.

Since he was completely unsupportive, the transplant coordinator sought help from Superintendent of Police (SP). The SP was also unaware of the procedure. However, persistent dialogues with the SP helped him understand the concepts and procedure. He then instructed the

IO to necessitate the formalities. The family was requested to reconsider their decision and finally the donation went through.

Case Study 2

A 16-year-old was admitted to the Trauma ICU after a road traffic accident. After two sets of apnoea test, the family was counseled for organ donation. Since the family was already aware of organ donation, they immediately expressed their willingness to donate the deceased's organs. The IO was informed and on request, he issued a 'No objection' to continue the process. Later he happened to share that with his senior official who had no knowledge about organ donation and misguided him. The IO contacted the transplant coordinator and instructed her to tear the 'No Objection' certificate issued by him. As the transplant coordinator refused to do so, he arrived at the hospital to take back the papers from the transplant coordinator.

As the IO couldn't meet her, he met the family members and threatened them saying that they will be jailed as they were involved in something illegal. Eventually the family withdrew the consent and transplant coordinator was not aware of the reason behind the withdrawal of consent. After much persuasion, the family members disclosed that they were threatened by the IO for consenting to organ donation. The transplant coordinator then informed the hospital administration, to seek help from the SP. After he got involved, the IO agreed to facilitate the donation process.

2 Southern Region – Dr. Bhanuchandra S

Case Study 1

A 28-year-old woman, married for four years, was certified brain dead due to hypoxic brain damage following a suicide attempt (hanging). While counseling for organ donation, the family consented for organ donation. The state authority for organ allocation, police and forensic medicine were informed about the potential donor. The police did not show any resistance in facilitating the process, however since the FIR was not filed by that time, they advised the family members to come to the concerned station to file the FIR.

After the FIR was filed, IO informed the transplant coordinator that since it was less than seven years of marriage and the death was unnatural, an inquiry by a Revenue Divisional Officer (RDO) or Mandal Revenue Officer (MRO) was required. The MRO was then called and explained the entire procedure and requested to come with the IO to conduct the legal formalities. While he agreed over the phone, he did not act on the matter in spite of repeated phone calls from the transplant coordinator. Meanwhile the parents of the victim registered a police complaint against the husband stating that it was a dowry murder.

The issue was then escalated to the State Authority (Jeevandan) to intervene, who then informed the higher official from the Police Department. The police higher official understood the complexity of the issue and immediately contacted the MRO and instructed him to carry out the legal formalities. After saying 'yes' to the higher official, the MRO did not turn up and refused to attend any of the calls.

The possible donation process had to be kept on hold for the whole night for the legal formalities to be completed. Finally, the next day morning, the MRO answered the call and agreed to come to the hospital. After a couple of hours, the MRO arrived and then the formalities were completed involving the officials from Revenue Department, Police Department and Forensic Medicine. The organs were then retrieved and post-mortem was performed in the evening hours. There was also difficulty in handing over the body post-donation – the transplant coordinator was unsure if the body should be handed over to the parents or the husband of the deceased.

3 Central Region – Dr. Amit Joshi

Case Study 1

A patient was admitted to Bombay Hospital, Indore after a road traffic accident (RTA). The accident happened in a place in the neighbouring state (Rajasthan) which was about 200 km away from the hospital. The patient was initially admitted to a nearby centre where it was not registered as an MLC and later he was referred to the Bombay Hospital for advanced treatment. When he was admitted to the Bombay Hospital, it was registered as an MLC as since it was a RTA. After three days of intensive care treatment, the patient was declared brain dead and the family expressed willingness for organ donation.

Since the case was not registered as an MLC in the primary centre where the patient was initially admitted, no record was available from the state of Rajasthan. However, while admitting him to the Bombay Hospital in Indore, the case was registered as an MLC leading to many legal questions like:

1. Why was the case not registered as an MLC during admission at the primary centre in Rajasthan, when it was a known case of RTA?
2. Who would conduct the inquest – IO from the local police station in Indore or from the jurisdiction where the accident happened?
3. How to transfer the authority between states to complete the legal formalities?

The higher police official from Madhya Pradesh was reached out for help, who then contacted the higher police officials at Rajasthan. The permission was then obtained from the IO of the police station from the jurisdiction where the accident happened in Rajasthan. Because of all this, the donation process was delayed for more than 12 hours and the family was made to wait until all these issues were settled and cleared.

Case study 2

A 28-year-old homemaker, who committed suicide about 120 km away from Indore, was admitted to the Bombay Hospital, Indore with life support system. The IO from the concerned police station arrived as the patient was moved into the operation theater. He requested the OT in-charge to take a few photographs of the potential donor and to check identification marks. After completion of all the procedures, the body was kept in the ambulance to be taken to the hometown. The IO then instructed the OT assistant to reopen the deceased, to confirm the identification marks in the presence of family members.

The higher officials were informed and requested for help. Following a long round of discussion, the body was handed over to the relatives with a considerable delay. The funeral rituals could happen only the next day, as it was late in the evening and the body had to be taken to the hometown, which was about 120 km away from the hospital.

Concluding Remarks: Dr. G.L. Singal

Though the law was made available, it had not reached stakeholders like the police. It has to be the collective responsibility of everyone working in this programme to take initiatives to reach out to all the stakeholders to overcome hurdles on the ground level.

It will also be a worthy exercise to create uniform guidelines from the central level for the entire country. These guidelines could be made available for all the stakeholders such as police and forensic experts so that such issues are not repeated in the future and the organ donation will be carried out in the best interest of the public.

Inaugural Ceremony

Dignitaries:

Dr. Errol D'Souza, Director, Indian Institute of Management Ahmedabad (IIM-A)
Mr. PWC Davidar, IAS, Government of India (retired)
Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation
Dr. Rajesh Chandwani, Chairperson CMHS, IIM Ahmedabad
Dr. Vishavdeep Goyal, Chief Operations Officer, Apollo Hospitals, Ahmedabad
Mr. Ajith Babu, Milaap

Mrs. Lalitha Raghuram, President, NATCO welcomed the gathering. She mentioned the collaboration between NATCO and IIM-A - how it began and the subsequent efforts in conducting the conference to prepare a white paper on public private partnership (PPP). Following her address, the dignitaries lit the ceremonial lamp to officially inaugurate the conference.

Dr. Sunil Shroff in his address said that it was a privilege to collaborate with a prestigious institute like IIM-A. Organ donation possibly has the most difficult ecosystem in health care. It has been 25 years since the Transplantation of Human Organs Act was passed and the programme has gone through a lot of turmoil. The law has devised some stringent measures to prevent commercial dealings, recognized brain stem death and thus recognized multi-organ donation from deceased organ donors. Though the law was passed in 1994, there were many struggles in the initial years and from 2008, the programme kick-started in various states in the country. However, the programme has been seeing a plateau in recent years with there being not much increase in the deceased organ donation rates. On the other hand, the living donation programme in India

has seen a steady increase. The gap between the need and the availability of the organs for transplantation is too wide and growing rapidly. Having a strong deceased organ donation programme would help in reducing the waiting list as well as requiring lesser number of living organ donors. Countries like India, where road traffic accidents are a leading cause of death, have potentially a huge opportunity to have a viable deceased donation programme. However, as a country, we lack policies and guidelines on many aspects and institutions like IIM-A, could collaborate with stakeholders at various levels to develop policies that can be implemented.

Dr. Errol D'Souza, the director of IIM-A spoke next and shared that the collaboration had helped him with an opportunity to have a deeper understanding of the programme. The countries that have 'opt-out' system seem to have higher organ donation rates than the countries with 'opt-in' system. He mentioned that framing the problem is very important, as that will in turn help to frame the policies to overcome the problems. There is also the constant debate of 'should organ donation be compensated' requiring deliberation. Though the immediate response is 'no' as it is an altruistic action, would compensation help in increasing donations should be considered. The need for the organ donation has grown over the years and hence having a policy to improve the system would help overcome issues to some extent at least.

Dr. Hemal Karvinde presented the Secretary's Report of NATCO. NATCO was registered as a society on 14th November 2018. It has received memberships across the country and as on date there are 118 members. The website (www.natco.org.in) was launched in June 2019. A request was made to the members to conduct more activities and share the reports of the same.

Mr. PWC Davidar recollected the journey of the deceased donation programme in Tamil Nadu. Since 2008, many initiatives were taken at various levels to initiate the deceased donation programme in the country. It is now the second phase, where everyone involved in the programme needs to contribute consistently to take the programme to the next level. To reach that level, the roadblocks in the current system have to be studied persistently and policies / protocols to overcome those roadblocks have to be developed. This would help reach the third phase over a period when deceased donation would be considered routine in the health care system.

The transplant coordinators play a pivotal role in the entire programme. They should be recognized for doing the most complex job - coordinating with multiple stakeholders, counseling the families for organ donation during a very difficult time. Their contribution to the donation and transplantation programme is immense.

The ceremony ended with felicitation of all the supporters – IIM Ahmedabad, ZTCC Pune, Jeevasarthakathe, Karnataka, Apollo Hospitals, Ahmedabad, MILAAP and SBI Foundation. Edelweiss Tokio and Tata Trusts were thanked for their support as well.

Day 2 – 1stDecember 2019

Session 1: Roundtable: NGO Presentation – Developing a Common Template for Organ Donation Awareness

Moderators: Mr. Badal Rag and Ms. Pallavi Kumar

Panelists:

Dr. Geetika Vashisth, ORGAN India

Ms. Priyanka Borah, Zuble Foundation

Ms. Bhavna Chhabaria, Shatayu

Dr. Avnish Seth, FORT

Mr. Nilesh Mandlewala, Donate Life

Mrs. Lalitha Raghuram, MOHAN Foundation

Dr. Anita Sangwan, MF Jaipur Citizen Forum

Mr. Anil Srivatsa, Gift of Life Adventure

Dr. Geetika Vashisth from ORGAN India spoke about their first initiative, **“Collaborative Conclave”**- a platform for all NGOs working in the field of organ donation to come together and connect with each other, the Government body NOTTO, and other stakeholders in the field. It is an annual event where NGOs share their challenges and discuss their work and future strategies. Apart from this, she also spoke about other initiatives like their annual poster making competition for school students which is a public private partnership event, designing of IEC material like Hindi posters with positive messages on organ donation being displayed in prominent Government hospitals in Delhi, a community radio show being aired in Dharamshala in Hindi (till date 32 shows have been aired, giving information on organ and tissue donation) and successfully running a toll free helpline for queries related to organ donation and transplantation.

Ms. Priyanka Borah from Zuble Foundation shared that their Foundation is the first organisation that was established in Assam in North Eastern region of India working towards the cause of organ donation. They also cover other states that come under the North East. She spoke about their main initiative, **“One for the Donors”** as a tribute to all the donor families of India, organized chapter wise. It is a road show where artists perform and spread the message of organ donation. She also spoke about cyclothon, rural paintings on wall depicting messages on organ donation in different locations in the state and organothon - run for the cause of organ donation.

Ms. Bhavna Chhabaria from Shatayu spoke about organ donation initiatives taken by her organisation in the city of Ahmedabad. She spoke about a unique campaign where a poster **“Free Ticket to Heaven”** created a lot of buzz in a religious gathering that had more than 50,000 people visiting the organ donation stall. They had designed stalls in the form of gift boxes to give the message that organ donation is a gift of life and placed organ models to make people aware of what all organs can be donated. Other initiatives undertaken by Shatayu like, **Super Hero**, India's first comic book on organ donation, hoardings with a unique idea of using Bollywood movie names

and converting them to organ donation messages, bike rallies and designing and distribution of hats with organ donation messages amongst college students, were also showcased.

Dr. Avnish Seth from FORT spoke on putting out obituaries in the newspaper with the permission of the donor families in the local language, creation of first dry run in North India to introduce the concept of green corridor to Delhi and Haryana police, which was covered live on FM Radio, and the Fortis-NDTV- '**More to Give campaign**'. This campaign covered pledging from soldiers, film stars and sports personalities. '**Wall of Tribute**'- a wall was put in seven different Fortis Hospitals across different locations in India – to honor organ donor families for their supreme act of sacrifice.

Mr. Nilesh Mandlewala from Donate Life mentioned that almost 50 percent of the total cadaveric organ donations that happen in Gujarat are through their efforts. Till date through the efforts of Donate Life, around 714 people across the country and the globe have been able to get a new lease of life and vision.

He shared some of the initiatives taken by Donate Life for creating awareness about cadaver organ donations.

- **Awareness programme at a crematorium:** The first organ donation awareness session in a crematorium, which was attended by more than 500 people.
- **Organ Donation from Civil Hospital:** Organ donation for the first time was done at a Civil Hospital in Gujarat in the Surat New Civil Hospital through the efforts of Donate Life under the mentorship of the then Commissioner of Police, Surat City Shri. Satish Kumar Sharma IPS.
- **Organ donation pledge by staff of Income Tax Department:** The then Hon'ble Chief Commissioner of Income Tax, Mr. Ajai Das Mehrotra IRS along with 100 Income Tax Officers pledged for organ donation at Surat.
- **Donate Life Kite Festival with organ donors' family members:** Kite festival is celebrated with the family members of organ donors, where people from various sections of society participate and fly kites bearing the message of organ donation printed on them. Thousands of such kites are distributed in the city to spread the message.
- **Social Media:** We create awareness through social media platforms such as YouTube, Facebook and Website.
- **Felicitation Programme:** Felicitation of family members of organ donors is held every year in the presence of various dignitaries of State Govt. or Govt. of India.

Dr. Anita Sangwan from MFJCF spoke about the awareness talks on organ donation conducted in 1500 villages and 900 panchayats of Rajasthan in the native language. Other unique initiatives to honour the donors included naming a road and instituting an award in the memory of the donor. '**Lighting up of different Monuments in Green**' in the state of Rajasthan, (the cause is conventionally represented by a green ribbon), was initiated to highlight the cause of organ donation.

Mr. Anil Srivatsa from Gift of Life Adventure shared his personal experience of being a live kidney donor, having donated a kidney to his brother. He promotes living organ donation because

he feels that the deceased donation alone cannot meet our country's needs. To create awareness on organ donation, he undertook a car road journey where he covered 41 countries in 300 days and accessed more than 45,000 people.

Mrs. Lalitha Raghuram from MOHAN Foundation shared the unique initiatives undertaken by The Foundation to create awareness on organ donation.

- **'Metro Retro'** – a musical event organised in a metro station in Chennai on the occasion of the 50th anniversary of the first heart transplant in the world that was attended by 800 people and 150 people pledged their organs.
- **'Rangoli Competition'** in the parking area of another metro station that was attended by 80 people. From a 6-year-old to a 71-year-old participated in the event.
- **Poster designing competition in metro station for children** – organized during the Joy of Giving Week
- **'Lighting up of Qutub Minar in Green'**
- **'Life Before Ashes'** – a unique art installation that showcased organs made from human ashes mixed with mud, with an underlying message that what has become ashes could have been another human's heart or kidney.
- **"Dil Deke Dekho"** FM 91.1 Radio City campaign and **#NoMoreWaiting** campaign with Edelweiss Tokio Life Insurance to raise awareness on organ donation

Discussion

Mr. Badal Rag

- A common vision for organ donation, striving towards a common template for organ donation, which would lead to a multiplier effect, a common tagline, colour code, colour flash, this in turn would have an exponential effect.
- To conduct formal research that would examine the limiting factors associated with organ donation, both positive (wanting to give back to society) and negative emotions (fear). TOI would be happy to collaborate with NGOs to do this research, so that organ donation can move on to the next level of evolution.
- To involve the government and to push for inclusion of lessons on organ donation in school curriculum.

Ms. Pallavi Kumar

- To create common template for awareness sessions– content and time duration
- Video on brain death – sharing of knowledge and content and to acknowledge the contributor
- Sharing of donor stories in the session

Ms. Priyanka Borah

- Content of organ donation talk – information on the Transplant law
- Information on both living and deceased donation

Mr. Anil Srivatsa

- Stressed on the need to have family conversation to discuss organ donation

Dr. Anita Sangwan

- Time of the session – 30 minutes including discussion

Ms. Bhavna Chhabaria

- Information on coordination of deceased donation process, whom to contact and how to take the process forward if there is an actual brain-dead donor in a hospital. NGOs could coordinate the process.

Mr. Nilesh Mandlewala

- To explain clearly the difference between solid organ donation versus tissue donation after circulatory death

Dr. Avnish Seth

- Catchy uniform tag line, same colour code
-

Session 2: Transplantation of Human Organs Act – 25 Years On

Chairpersons: Ms. Arati Gokhale and Mr. Nilesh Mandlewala

Speaker: Dr. Sunil Shroff

Dr. Sunil Shroff recounted the genesis of the Act –

He showed a picture from 1988 where there was a discussion on NDTV on Deceased Organ Donation between Mr. Prannoy Roy and Dr. Samiran Nundy

In 1989, the then Prime Minister Mr. Rajiv Gandhi raised the issue of absence of deceased donation and transplantation in India and wanted to promote organ donation. Thus, the parliament initiated the formulation of an Act and in 1994, the Transplantation of Human Organs Act was passed. He pointed out that the Act recognised brain death as death and criminalised commercial trade of organs.

Dr. Shroff recalled his own first deceased donation case in India of a young boy who was bitten by a cobra and was declared brain dead. India has a large number of snakebite victims and most of the opportunities for donations are being lost.

Despite the passing of the law, there were reports of kidney rackets and thus the amendments to the Act were brought out in 2011 and new rules in 2014.

The important amendments were:

1. The Appropriate Authority was given the power of civil court. Later on these powers were used to arrest doctors and others in two hospitals in India under the suspicion of organ trade
2. Hospitals could have their own authorisation committee if the annual volume of transplants were more than 25 in number.

3. The Brain Death Panel of doctors now included intensivists, physicians and surgeons and not limited to neurologists and neurosurgeons
4. It was made mandatory that in every brain death case, the option for donation should be discussed with the family
5. Every hospital needs to have a transplant coordinator appointed to get a licence to perform transplant surgery
6. The driving licence can be used as an organ donor card (if the clause is present)
7. Tissue donation was included in the amended Act
8. Formation of a National (NOTTO), Regional (ROTTO) and State (SOTTO) based organisation to promote Organ Donation
9. The living donor pool was increased by allowing grandparents and grandchildren to donate
10. Swap donation clearly defined
11. Punitive actions against offenses were made stringent

The states that do not follow the Amended Act include Tamil Nadu, Karnataka, Punjab, Telangana and Andhra Pradesh.

He elaborated on the gaps in the law:

- a) Uniform definition of death is still missing. In India, brain death is certified only in case of organ donation. This needs to be simplified, since in many hospitals the dead body is not taken off the ventilator until cardiac arrest happens. Death is defined in three places in Indian law:
 - i. The Registration of Births and Deaths Act 1969
 - ii. Indian Penal Code section 46
 - iii. Transplantation of Human Organs Act 1994

There are efforts at the central and state levels to get a uniform definition of death in India

- b) Definition of next of kin – for easier counseling and consent
- c) Common procedure in post-mortem
- d) Donor card online form on NOTTO website has a number of fields and makes the procedure of pledging cumbersome. Requirement for simplification and a common format would help

He explained the situation of deceased organ donation:

- Currently 300 hospitals are transplant centres running 550 transplant units
- Of the 532 medical college hospitals, 260 have the infrastructure to do transplants.

Dr. Shroff hoped that by the year 2025, India could have a donation rate of 5 pmp with an annual donation from 7000 donors.

Discussion

Q: Would just the donor card be enough for donation to be done?

Dr. Shroff: Still no clarity on the legality of the donor card. However, there should be no problem in talking to a potential donor's family if the person was carrying a donor card. The current law makes the conversation now mandatory in the ICU.

Q: Is India ready for opt-out policy to increase donor pool?

Dr. Shroff: India is not ready, since there are more than 640,000 villages and the residents there need to understand what it means, since one wrong case can ruin the programme.

Q: What has been done to address the gaps in the law that you have listed?

There is a strong group (ELICIT - End of Life Care in India Taskforce) pushing for the uniform definition of death.

Session 3: Foreign Donors in India

Chairpersons: Mr. Ahsan Ullah Ansari, Ms. Sujata Ashtekar and Dr. Amit Joshi

Speaker: Ms. Pallavi Kumar

While there have not been many foreign donors in India, the influx of tourists has been steadily increasing. ***More than 10 million tourists arrive in the country every year and this number is growing by over 15%. The majority of tourists in India are mainly from 10 countries including Bangladesh, Nepal, US, UK, and Canada to name a few.*** As there are no defined protocols available on what needs to be done, it is important that guidelines be developed for all stakeholders such as hospitals, state bodies, healthcare professionals, transplant coordinators and policy makers.

In addition to increasing the donor pool, as a country that supports the organ donation cause, India should also be able to provide the opportunity to every individual and family that wishes to donate.

Three case studies involving foreign nationals documented so far were presented.

Case 1:

- 67-year-old lady from Maryland USA
- Visiting Chennai was hit by bus (October 28, 1998)
- Declared brain dead
- Was a registered organ donor – marked in driving licence
- Son gave consent for her organ retrieval
- Became the first foreign national organ donor in India in 1998
- Both kidneys, corneas and heart valves were retrieved

Case 2:

- Lady from France came with her husband to visit son
- Declared brain dead on March 15, 2014 due to brain hemorrhage
- France – opt out country; family was aware of organ donation
- Her husband and adult son were approached by a MOHAN Foundation counselor and consented to donate organs
- New Delhi's first foreign national donor
- Both kidneys and liver were retrieved

Case 3:

- 62-year-old Nepalese man had an intracerebral bleed due to a fall
- Declared brain dead on March 15, 2019
- Verbal consent, given over phone by his wife who happened to be in Nepal, was recorded
- Needed to obtain NOC from local police station + inform the Embassy of Nepal via email + permission of State Appropriate Authority of Maharashtra via email
- Mumbai's first foreign national organ donor
- Both kidneys and liver were retrieved

Learning from the cases

- Obtaining consent becomes easier in cases where the deceased had already expressed a desire to donate or came from a country where consent is presumed.
- Effective counseling encouraged consent
- Absence of guidelines and protocols created confusion and delay which cannot be afforded in deceased organ donation

Complexities often encountered in cases involving foreign nationals

- Next of kin may not be available in the country where consent is required
- Language barriers
- Need for body to be returned to country of origin
- Multiple-players and complex logistics

Recommended guidelines while encountering such cases

- Certify Brain Stem Death
- Document family's consent
 - arrange interpreter (if required)
 - presence of embassy person
 - record telephonic consent
- Inform concerned Embassy/High Commission
- Obtain No Objection from local police
- Inform appropriate Organ Donation authority
- Post-mortem formalities in medico-legal cases – ensure presence of embassy staff in absence of family member
- Assist families with funeral arrangements/transfer of body
- Letter of appreciation to family/record case history

- Ensure paperwork is in English for ease of understanding/interpretation

It is important to know when to step back in these cases. Well-paced communication style is the key.

Arranging for the body to be transferred to the home country also requires some formalities to be completed: obtaining death certificate, NOC from the police, embalming certificate and coffin certificate (to carry the body back as cargo).

These guidelines will help in:

- Providing clarity to all players
- Streamlining the process and therefore saving time
- Reducing anxiety for family members
- Giving greater confidence to try and make donations happen

While not all cases have to be classified as medico-legal cases, it is always safe to keep police in the loop for other formalities. Some complications arise in living donations that involve donors who are foreign nationals as well – for example, not understanding what OCI is.

Discussion

Two members of the audience shared their experiences of a foreign national being declared brain dead in India – while in one case, the immediate family could make it to India, in the other case, the deceased was found to be an illegal immigrant and in both cases donation did not happen.

Session 4: Swamy Narayan Memorial Oration

Title: Transplantation in India – Grounds for Optimism

Chairpersons: Mr. Raghuram Kuppuswamy and Ms. Bhavna Jagwani

Speaker: Dr. Sonal Asthana

Transplantation starts from sorrow. Transplantation starts when somebody passes away and family members are asked to make a difficult decision and it is a difficult time for anyone. On top of this poignancy, there are multiple contentious issues that have been coming up which have been frequently discussed, which makes it easy to get despondent about where transplantation is going.

We must ask ourselves in a situation like this, what is there in this programme to be optimistic about. This is a difficult time for transplantation; there is the threat of legal action when we try to do good and the fear of being misunderstood. Is the world today better than it has ever been? Looking, at news such as global warming, war and famine makes one doubt even more if the world is really better than what it was. Looking at the world from a broader perspective, over the

last two centuries, this is indeed the best time to be alive taking into account all the markers that count in terms of poverty, education, literacy, vaccination, democracy and so on. The world has never been better than what it is today. It is important to distinguish the signal from the noise and what matters is that we are better than what we were yesterday and the same holds true for transplantation.

Transplantation of organs into humans began only six decades ago, making transplantation a very young science. Liver transplant is a lot more recent; around the mid-80s is when we were able to marry science, technology and surgical technique together to achieve long-term outcomes, which is when transplantation took root. ***Only in recent times has transplantation been accepted as a standard of care, which was not the case in the earlier years.*** India's story started in 1965 when the first transplant was done in KEM Hospital and the first successful transplant in CMC Vellore in the early 70s but the programme took off only after the 80s. Transplantation of liver became accepted as a standard of care in India only post 2000.

Reasons to be optimistic:

- Improvements in organ donation rates, which means there are more people aware and there are more people donating
- Update in technological advances which are available that can keep organs alive longer and make them utilisable
- Standardisation of skill development in a country as big as India which is a difficult task
- Improvement in access

When we look at the number of transplants over the years, we can see that the numbers have actually been increasing for both deceased and living donation. In a short span of four to five years, the organ donation rate has markedly increased. Issues such as the programme plateauing and various others that are a cause of concern have been discussed but we must not forget the big picture that we are doing much better.

In the year 2011 there were around 80 donations across the country and today, in the year 2019 we are talking about 900 donations; this comparison is only over a span of eight years. It is not important where we are, it is important on how far we have come. We have better sources of data now- for a long time MOHAN Foundation was the only source of data, in the recent years the National Organ and Tissue Transplant Organisation (NOTTO) has been giving out data and now we have professional organisations taking ownership in creating a nationwide registry such as the Liver Transplantation Society of India. This is the missing link, which we use to see in the West as compared to India -professionals taking over data.

When you look at the comparison between deceased donor and living donor transplants in the country the numbers vary significantly. ***For living donor and deceased donor transplants in India, in the North, it is 94% and 6%, in the West, it is 65% and 35%, and in the South, it is 62% and 38% respectively.*** We also have survival data, which is early survival data ranging between 74% and 92% and this is comparable to the international literature.

The rise of the machines is very liberating. For the past five decades, organs were preserved in a standard way; the organs were cooled and then put on ice, which is still the gold standard of transportation. Although the number of donors is increasing the quality of organs donated are coming down. There are new approaches and devices used for all organs to change the way in which they are preserved. An examples of a machine used in liver transplants is OrganOX, which was developed in the UK. The deceased donor liver can be seen turning pink and its viability assessed before being transplanted into the recipient. Organs that were not used previously can be used because of this and organs, which had fat can be de fattened before being utilized, as these were never usable before. This system is being used in the heart and lungs as well. ***In the lungs, it has increased the number of donors available by 250%.*** Another interesting technology is 3D printing assisted treatment planning.

Thanks to MOHAN Foundation in collaboration with several other organisations, for having trained more than two-thirds of the transplant coordinators in this country. The organ retrieval workshop for surgeons, which has been running for the past five years, simulated training to retrieve organs in their hospitals. Dr. Dhiren Shah ***attended the course twice and established the first heart transplant programme in western India; Dr. A. Rathinavel established the programme in South Tamil Nadu in the government sector.*** Transplant is the involvement of teams and requires the training of teams. We should look into transplant centres helping each other. We must marry private centres with public centres to mentor and increase accessibility of transplants. Public Private Partnership has happened on an informal level. The following are examples of private centres collaborating with public centres.

- Dr. Rela Institute & Medical Centre with Government Stanley Medical College
- Medanta -The Medicity with AIIMS Delhi
- Global Hospitals, Mumbai with KEM Hospital
- Apollo Hospitals, Hyderabad with BJMC
- ILC with Bangalore Medical College
- ILC with KLE Belgaum

Raising funds for a pediatric patient helped us understand that children who need a transplant should have access to it regardless of their family's economic status. Equity is social justice; equity to healthcare is the primary determinant of whether there is social justice in the country. People should have access to quality health care. With the help of crowdfunding platforms like Milaap, the cost the family has to pay for a transplant has come down drastically. ***We can put together a thought experiment: There were 24 crore Facebook users in India a couple of years ago, the spend on Ayushman Bharat was 5000 cores in 2017-18, so if every Facebook user in the country paid Rs 210 per year they could fund healthcare in India for the entire year which is Rs 10 per month and this is an example of how 'drops can make an ocean'.***

When you put it together on how far the programme has come, we can clearly say that the world is better now than it has ever been.

Session 5: Swamy Narayan Best Transplant Coordinator Award Presentations

Judges: Mr. Raghuram Kuppuswamy, Dr. Rajesh Chandwani and Mrs. Arati Gokhale

The nominees for the award spoke and presented their case.

Speaker 1: Ms. Priti Jain

Ms. Priti Jain, from Alexis Hospital Nagpur, presented from the eight years of experience she has in transplant coordination. She works in the field of living and deceased donor transplants. She conducts various in-house sessions. She has counseled 39 deceased donor families out of which 20 families donated. She has also coordinated 95 live donations. She conducted the first deceased donor transplant in Central India and was instrumental in the first swap transplant in Nagpur, which was between a Hindu and Muslim family.

Speaker 2: Mr. Ramprasad Meena

Mr. Ramprasad works as the Chief Transplant Coordinator and In-Charge -Hemodialysis unit in SMS Hospital Jaipur. He has 27 years of experience in nursing and five years of experience as a transplant coordinator. He coordinates both living and deceased donor transplants.

Speaker 3: Ms. Rajinder Kaur

Ms. Rajinder has been working in PGIMER Chandigarh since 2012 and has been working as a transplant coordinator since 2015. She has counseled 250 families for deceased donation out of which she has successfully coordinated 159 deceased donations.

The youngest donor whose case she coordinated was a 11-month-old baby. Ms. Rajinder has coordinated 146 donations after brain death and 13 donations after circulatory death; and PGIMER is the first institute to perform donations after circulatory death in India and 33 organs have been shared. 33 green corridors were coordinated successfully. She also conducts various awareness activities and organizes transplant games.

Speaker 4: Dr. Praveenkumar Sheri

Dr. Praveenkumar works as a clinical assistant in nephrology and as a transplant coordinator in Chirayu Hospital, Kalaburagi. Upon getting the licence in the hospital, he has coordinated CMEs

and awareness programmes. Eight transplants have been coordinated - four were live donations and four were deceased donations.

Speaker 5: Lt. Col. Pioni V

Lt. Col. Pioni works as the transplant coordinator in Army Hospital (R&R). She was earlier posted in various defence hospitals including army, navy and air force as a critical care nurse administrator. She has coordinated both living and deceased donations. 16 brain stem dead patients were identified out of which 13 donations were done. 108 corneal donations have been done which is the highest donation in the Army Hospital (R&R) since 2001. In 2019, 47 live related transplants have been done so far. Two green corridors by air have also been coordinated.

Speaker 6: Mrs. Mayuri Barge

Mrs. Mayuri Barge works as Organ Transplant Coordinator and Manager in Dr. D. Y. Patil Hospital & Research Center, Pune. Earlier when working with Aditya Birla Memorial Hospital she started learning about the role of a transplant coordinator on the job. She attended a transplant coordinators' training programme in 2010. Post the training she was instrumental in convincing the management to start the deceased donor programme in the hospital. Until 2012, she had coordinated 120 live related cases, unrelated transplants, foreign national transplants and swap transplants in Aditya Birla Memorial Hospital. She has also coordinated the first successful cadaveric donation for the hospital and it was her first deceased donor coordination. In Dr. D.Y. Patil Hospital, she has conducted awareness programmes in the hospital and has coordinated living and deceased donations.

Session 6: Organ Donor Clause in Driving Licence - Our Journey

Chairperson: Mr. Sudhir Dewan

Mr. Sudhir Dewan – Opening Remarks

'Organ Donation Clause' has been included in the driving licence in Chandigarh. However, not many opt to be an organ donor as there is not much awareness. In India, most of the deceased organ donors are road traffic accident (RTA) victims. If those individuals had expressed their wish to donate their organs and discussed with their family members, a greater number of donations could have been facilitated and thus more lives could have been saved.

Speaker: Ms. Bhavna Jagwani

Making a choice about donating organs while obtaining important documents such as Driving Licence, National ID card, Insurance Card, PAN card and Pharmacy Card would help to know the individual's choice as well as help in counseling families for organ donation. A few countries such

as United States of America, United Kingdom, New Zealand, Australia, Sweden and Denmark have regulations to have organ donation clause on the driving licence. Recently India too has joined the map by making it a mandated choice while applying / renewing a driver's licence.

MOHAN Foundation has been campaigning for inclusion of organ donation clause on Indian Driving Licence since 1999. Many people are declared brain dead in road traffic accidents and there is no way for the family to know their consent. Checking the field of organ donation in their application will make it easier and has the potential to save many lives. On seeing this option, people will at least consider it, if not pledge their organs immediately.

The Ministries of Health and Family Welfare, Road Transport and Highways, and Law and Justice were approached and persuaded to consider the appeal. Multiple meetings with the personnel from Ministry of Road Transport and Highways were held to include a clause in the Rules of Motor Vehicle Act.

Finally, the state of Rajasthan issued the first driving licence with a logo of 'organ donor' in 2019.

Discussion:

Making the public aware about the new clause on the driving licence -

- Conducting sensitisation programmes for people who are coming to the Regional Transport Office (RTO) for applying / renewing driver's licence
- Using promotional materials with celebrities

Implementing the organ donor clause in driving licence - State or Central Government

- Motor Vehicle Act falls under the concurrent list that give powers to both the Central and State governments. The provision has been included in the central law; the state governments should pursue it and take appropriate action.

Donor card as one of the documents that could be saved under DigiLocker- Access to the digital document may be an easier option than the physical document. Donor card could be considered as one of the authentic documents so that the individual's choice about organ donation could be known and discussed by the family and health care team.

Session 7: Quality of Life of Donors and Recipients – a Nephrologist's Perspective

Chairpersons: Dr. Kishore Phadke and Dr. Avnish Seth

Speaker: Dr. Prof. Vivek Kute

Prof. Vivek Kute, in his talk addressed the following:

- Organ transplant in India - current status
- Safety, risk / outcome, gender disparity in living donor transplant
- Transplant recipients - risks and complications

Of all the chronic kidney disease (CKD) cases reported in India, about 61% were not on any form of renal replacement therapy (RRT), 32% on hemodialysis, 5% on peritoneal dialysis and only about 2% received/worked up for transplantation. (*Rajapurkar, M.M., John, G.T., Kirpalani, A.L. et al. What do we know about chronic kidney disease in India: first report of the Indian CKD registry. BMC Nephrol 13, 10 (2012) doi:10.1186/1471-2369-13-10*).

As per the Global Observatory on Donation and Transplantation's (GODT) report for 2018, India stands first for performing the highest number of living donor renal transplants in the world -about 85% of total renal transplants that were performed in India were from living donors. Whereas, the country has been ranked one among the 20 that performed the least number of deceased donor kidney transplants in the world(*www.transplant-observatory.org*). Since 2000, IKDRC had performed about 5800 renal transplants of which 846 were deceased donor renal transplants. (*Kute V B et al. Transpl Int. 2017 2017;30:679-88*)

The pre-transplant evaluation of a living donor aims to:

- evaluate the physical and mental fitness of the donor
- assess the capacity of the donor to decide to pursue the surgery
- evaluate the reasons for pursuing donation
- assess the ability of the donor to cope with the post donation complications (medical, psychosocial)
- assess the donor's support system

It has been estimated that the mortality rate in living kidney donation is 0.3% (1 in every 3,000 living kidney donor may die during the donation process). The 20-year risk of End Stage Renal Disease (ESRD) among the average donors vs. donors with predicted risk was reported as 34 vs. 256 cases per 10,000 donors. (*Massie, Allan B et al. "Quantifying Postdonation Risk of ESRD in Living Kidney Donors." Journal of the American Society of Nephrology: JASN vol. 28,9 (2017): 2749-2755. doi:10.1681/ASN.2016101084*)

Another study conducted in the USA showed that the 20-year risk of ESRD for living kidney donor is low but not uniform. It is influenced by multiple factors such as age, race, gender and BMI (Body

Mass Index) and increases exponentially over time. (Wainright JL, Robinson AM, Wilk AR, Klassen DK, Cherikh WS, Stewart DE. Risk of ESRD in prior living kidney donors. *Am J Transplant*. 2018; 18:1129–1139. <https://doi.org/10.1111/ajt.14678>)

The study conducted at the IKDRC to compare the quality of life of donors using the Short Form 36 (SF-36) showed that the quality of life of kidney donors was not affected by donor nephrectomy. Living kidney transplantation seems to be a suitable therapeutic option for patients with end-stage renal disease. Better psychological and technical preparation for surgery and more consistent follow-up may reduce the negative outcomes even further. (N. Kawagishi, I. Takeda, S. Miyagi, K. Sato, N. Ohuchi. Donors' Quality of Life Evaluated by Short Form-36 Analysis After Living Donor Liver Transplantation in a Single-Center Experience. *Transplantation Proceedings*. Volume 46, Issue 3. Pages 675-677)

Gender disparity continues to exist in living donor kidney transplants, especially in countries like India (80% of the donors in living donor transplants are female whereas 80% of recipients are male). Not only biological but also psychological and socioeconomic issues contribute to disparity in the outcome, as well as an inequitable access to transplantation for women and girls. (Anette et al., *Equally Interchangeable? How Sex and Gender Affect Transplantation*. *Transplantation*:2019; 103 (6): 1094-1110)

Different parameters contribute to the longevity of the transplanted graft such as HLA matching, donor specific antibody (DSA), blood group, gender and age. The risks and complications for the transplant recipients include short-term (infections, acute rejection), long-term (cardiovascular disease) and drug induced diseases (malignancy). In spite of improved early graft survival, the long-term outcomes remain a challenge in kidney transplantation. In India, the commonest causes of death among the transplant recipients are cardiovascular disease (43.5%), infection (26.3%) and malignancy (10.7%).

Living kidney donation is reasonably safe; however, there is no robust data available from India to support the claim. Policy and plan of action should be developed to eliminate gender disparity and thus achieve gender equality in donation and transplantation. More efforts have to be taken to expand deceased organ donation programme, hence more lives could be saved.

Session 8: Panel Discussion - How can we Energize Indian Transplant Games?

Moderator: Dr. Sunil Shroff

Dr. Sunil Shroff started the panel discussion about the evolution of Transplant Games in India by recollecting Dr. RVS Yadav of Chandigarh. He was a kidney transplant surgeon with a lot of foresight, who had a federation through which transplant games were organised every two years. After his unfortunate demise, it was discontinued. Dr. Baldev Singh Aulakh had taken over from

Dr. Yadav. Dr. Bharat Shah continues the transplant games now in Mumbai every year in the month of November. MOHAN Foundation too organized the Transplant Games in Chennai in 2003 and had around 300 participants from different parts of the country, including international participants from Sri Lanka, Bangladesh and Nepal. However, it is not easy conducting Transplant Games because the requirement for each recipient is different with respect to food, accommodation and travel.

Jet Airways was approached to sponsor the food arrangements because it was felt that it was the safest option. Accommodation too is a challenge because the space has to be clean and hygienic so that the recipients do not run into any health issues. With more transplants happening, there is a need to highlight that recipients are healthy and the quality of life of recipients is good.

All India transplant games' activities require to be restarted and he requested Anil, Jaya and Anita to lead the movement. He said that India needs to have representation in the international games; only 14 of them had participated last year and won seven medals, whereas the US was represented by 150 participants in Newcastle, UK. The Indian ***Transplant games should become an independent entity and a federation requires to be formed again.*** He suggested and requested all the NGOs to support and become members of the federation. It would also require by-laws to be in place. The games could be held in different locations every year ideally as a two-day event.

He also added by saying, currently around 30 NGOs can join hands and become members of the federation and promise to send five delegates to the games every year; and this way at least 75 participants would be identified and sponsored.

Ms. Jaya Jairam

During the last transplant games, a recipient was running around for sponsorship until the last minute. He did not have the chance to practice enough before the games because of the time he had spent looking for a sponsor. Therefore, a suggestion would be that the funds should be taken care of. There was also the requirement of a coach and make the whole process more systematic where the recipients are given warm-up sessions. All the NGOs coming together and taking this up is critical, and ideally the focus should be towards preparing for the world transplant games.

Dr. Shroff said that initially we may not be able to provide a coach or move to world transplant games, however getting the Indian federation in place should gradually get us there.

Ms. Bhavna Chhabaria said it is important to own this as an idea and she agreed with Dr. Shroff about how the initiative should be gradually taken forward.

Mr. Anil Srivatsa said he was glad and proud to be a part of the transplant games. He is now representing a union with a bunch of athletes. Transplant Coordinators know the best participants for such games and should nominate donors and recipients from their hospitals. Steps should be taken to go ahead and contact them or write to them and ask them to be a part of this because most of them do not know this exists. He said sponsorship can become an issue and it takes an average of 2 lakhs to participate in the world games. He said that he had initiated a committee

where the Indians could get accommodation. Dr. Shroff said that there are 10 NGOs that would be supporting this initiative including Zuble Foundation, Organ India, MOHAN Foundation, Shine India, and Shatayu.

The total cost can be from 10 to 15 lakhs to conduct the transplant games. Anil volunteered to be the Sponsorship Chairman. Dr. Shroff also mentioned that anyone who wished to join the federation needs to raise money and that is how they could join. He mentioned that this could bring in a commitment. They could also give away awards to the NGO that raised the maximum; surgeons and nephrologists can also be a part of the group.

Anil added that those who are part of the world games need not be in the national games. Just being a part of the games in itself would be a privilege.

Request from audience: Having flyers to show the recipients can be helpful to gather people and sponsorship.

In the end, to kick-start the Federation, a request was made to the NGOs to commit some funds for the federation and have a seat on the executive council. 2 lakhs from MOHAN Foundation, 1 lakh from Gift of Life Adventure, 1 lakh from Shine India, 2 lakhs from Shatayu and 1 lakh from Zuble Foundation were promised for the Federation.

Session 9: Hand Transplantation, Face Transplant and other Composite Tissue Transplants – Is there a Future for it in India?

Chairpersons: Dr. Avnish Seth

Speaker: Dr. K. Boopathi

Dr. Boopathi's lecture had three segments – introduction to hand transplants, challenges in composite transplants and future of composite tissue transplants in the country.

Nearly 2,05,000 hand injuries take place every year and in the last 50 years since the Institute for Research and Rehabilitation of the Hand and Department of Plastic Surgery was set up at Government Stanley Hospital in Chennai, around 6 lakh hand injuries have been treated. The department receives 20-30 hand injury cases on a daily basis and reimplantation procedures are routine.

Around 8.4 million people die every year, but no one is willing to donate their hands mainly because mutilation of body is not welcome.

An animated video illustrating how the hand transplant is performed was shown. Two teams each for retrieving hands from the donor and prepping the recipient are present during the entire

duration of the process. Bones, tendons, muscles and nerves are fixed and vascularisation is established.

Why hand transplants:

- Provides superior dexterity with restoring sensibility
- Intrinsic muscle function
- Proprioception (sense of movement)
- Aesthetically appeal – near match of color and size possible

Patient selection is highly crucial for a successful hand transplant. Patients between the ages of 20 and 40, bilateral amputees with Level 7 or 8 of distal amputations are preferred. Psychological and social evaluation is vital.

While face transplants are technically similar to hand transplants, India lacks the expertise and experience. Critical management of immunosuppression is required for face transplants during the postoperative period.

A video illustrating the experiences of the recent hand transplant performed at Government Stanley Hospital was played. This experience proves that hand transplant does have a future indeed; however, the following challenges need to be addressed:

- Multidisciplinary team required
- Minimisation of immunosuppression, tolerance induction
- Protocols for sensitised patients
- Improved monitoring
- Mechanisms of rejection - Acute cellular and humoral rejection
- Chronic graft deterioration
- Nerve regeneration
- Definition of acceptable ischaemic times
- Refined organ preservation
- Bridging the supply and demand gap
- Unwillingness of donor families
- Long pre-operative period with extensive evaluations

Rejection – acute or chronic is a major challenge. In some cases, tissue biopsies are required on a daily basis when rejection symptoms present themselves. Induction and triple-drug maintenance immunosuppression therapy play a key role. The highly priced drug costs contribute to poor patient compliance.

Advancements in the field of prosthetic limb designing and choosing a life-shortening treatment modality like transplant over safer rehabilitation methods have clouded the domain. Myoelectric prosthetics however, are not greatly effective, particularly for bilateral amputees. Hand transplants, while restoring functional abilities, sensation, voluntary motor control, and proprioception, also offer a sense of feeling “whole” again. Nevertheless, fear of possible rejection and complications of life-long immunosuppression persist and the procedure carries a significant financial burden to the health care system. It is becoming widely accepted despite the multitude of challenges.

Other challenges in running the programme included:

- Illiteracy
- Superstition
- Per-capita income
- Lack of Awareness
- Organ retrieval and transportation – cold ischaemic time has to be reduced as much as possible; a standard time duration has to be defined
- Infrastructure
- Financial burden – nearly 50 lakhs is spent on one hand transplant by the Govt.
- Immunosuppression
- Complications
- Rehabilitation
- Occupational

Creating awareness is the need of the hour to run the programme successfully, Dr. Boopathi mentioned in his closing remarks.

Session 10: Chronic Kidney Disease of Unknown Origin: Is it on the rise in India, and what do we know about it?

Chairpersons: Dr. Vivek Kute

Speaker: Dr. Manoj Gumber

The incidence of CKD is increasing worldwide and it has become one of the most debilitating non-communicable diseases. Diabetes and hypertension, all over the world are the main culprits of CKD. The incidence of ESRD in India is 229 per million population and more than one lakh new CKD patients need RRT annually in India.

In the first consultation with the patient, it is very important to understand the etiology of the ailment to rule out recurrence after transplant. Patient's geography, his occupation, etc. must also be known to diagnose the ailment. The common causes of CKD have to be excluded and the following must be looked at during diagnosis of CKD of unknown etiology (CKDu):

- Asymptomatic and progressive CKD
- Absent or sub-nephrotic proteinuria
- Absence of hematuria
- Absence of diabetes, chronic or severe arterial hypertension, HIV, snake bite, glomerulonephritis or other urinary tract disease
- Normal glycosylated hemoglobin (< 6.5%)
- Blood Pressure
 - <160/100 in untreated patients
 - <140/90 in patients receiving up to 2 anti hypertensives

Recently in May 2019, two more points were added to this list:

- Geographic residence in the affected areas
- Renal biopsy showing tubule-interstitial disease

Studies conducted among patients from urban and semi-urban areas showed absence of CKDu; diabetes, hypertension, obesity, overweight, stone diseases were most common risk factors in this group. On the other hand, a 2017 study from JIPMER reported 55.9% of CKDu patients.

In the early days only Mexico, Central America and Egypt reported cases of CKDu. In the recent times, it is prevalent in India and Sri Lanka as well. In India, the states of Andhra Pradesh, Odisha, Maharashtra and Goa have been identified to have CKDu prevalence. Uddanam region in AP (73% of patients), Marathwada in Maharashtra (40%), Odisha (12%) and South Goa in particular have been marked with high prevalence.

According to the CKD registry, diabetes is the leading cause of the disease and in around 16% of CKD patients the cause is CKDu. When studying the profiles of patients from Central America, Sri Lanka and India, certain common epidemiological factors became evident. Most of the patients were from an agrarian background, low socio-economic strata, and the disease presented itself in the fourth to fifth decade of life, predominantly in males.

CKDu – a summary:

- The endemic nature of CKDu was first observed in 1999
- The prevalence of the disease in the last 15 years within certain geographical locations has increased dramatically
- The percentage of CKDu is higher in developing countries than developed ones
- The disease is prevalent in regions around water reservoirs that are used for irrigation purposes and is most common among farmers

Studies carried out in North and South of India suggest the risk factors for CKDu prevalence could include: agricultural work and agrochemical exposure, water-borne agrochemicals, high silica content in drinking water, chewing of betel nuts with chemical flavoring, exposure to pesticides and genetic susceptibility; strenuous labor and heat stress could also be contributing factors.

Risk factors for CKDu may include:

- **Water consumed: Hard water containing high levels of calcium, magnesium and zinc; water from wells; water with high silica or arsenic content**
- **Cadmium: may be present in phosphate fertilizer, water, fish and lotus rhizomes**
- **Arsenic**
- **Aluminum Fluoride: utensils, water**
- **Low Selenium**
- **Smoking**
- **Cyanobacterial toxin: in water tanks and reservoirs**
- **Dehydration**
- **Ayurvedic medicines**

According to the WHO, the data related to CKDu from India is unavailable or unusable. Therefore, we must focus on gathering accurate and authentic data before attempting any action.

Managing CKDu:

- Awareness, screening, and surveillance of the affected community
- Identification of the affected population in the geographic areas and categorization into CKD stages
- Lifestyle modification: avoidance of smoking and chemically flavored betel nut chewing
- Safe drinking water supply
- Appropriate medicine, vaccination and dietary recommendations
- Adequate and accessible treatment options
- Monitoring and management of co-morbidities
- Involving nephrologists, environmentalists, geneticists, epidemiologists, and basic scientist teams for advanced research on CKDu
- Follow the WHO guidelines for CKDu

To retard the progression of CKDu:

- Prebiotics and probiotics may delay the progression of CKDu
- Prebiotic sources: breast milk, soybeans, raw oats, unrefined wheat, unrefined barley, non-digestible carbohydrates
- Probiotic sources: fermented dairy products such as yogurt, kefir, and cheese

Roadmap for CKDu:

- Step 1: Establish community-based surveillance
 - Define geography and ensure participation
 - Collect all possible data
 - Understand eGFR, blood pressure, dipstick results
- Step 2: Focus on exposures/interventions of interest
 - Identify exposures of interests and include protocols
 - Examples: heat exposure, specific chemicals, water source
- Step 3: Longitudinal follow-up studies
 - Use results from Steps 1 and 2 and other data to establish cohorts

Suspecting CKDu: some markers would be - Patients from endemic area, no diabetes, no hypertension, no oedema, no hematuria and no other known etiology, ADPKD, stone.

A participant in the audience from AIIMS Raipur mentioned that a region in Chhattisgarh state has also been identified with CKDu incidence and Dr. Gumber recommended adhering to the basic guidelines laid out by WHO.

Session 11: Sharing Experiences as a Transplant Recipient

Chairpersons: Dr. Sonal Asthana and Ms. Trilly Rachel Mathew

Speaker 1: Mr. Sudhir Dewan

He said he had been associated with MOHAN Foundation for the past decade and working as the director of the Chandigarh office. He spent this period as a liver transplant recipient as well. In 2005, around 15 years ago, he was diagnosed with liver cirrhosis. During that time, he was the General Manager in a pharmaceutical company, which required a lot of travel. He was a social drinker. The etiology was cryptogenic and he did not have any infection. Right from childhood, he had liver enlargement but no other symptoms.

He was also diagnosed with cytomegalovirus infection just before his transplant. Upon being diagnosed his condition kept deteriorating, several episodes of ascites and spontaneous bacterial peritonitis occurred. By October 2008 his condition worsened, CT scan showed a lesion of 7cm and it was a confirmed case of end-stage hepatocellular carcinoma.

During that time there were no deceased donations happening. The blood group of his wife and daughter did not match his, but the blood group of his son-in-law matched and he came forward to donate. He was convinced by his daughter's in-laws to accept the donation by their son.

Having undergone the process in search for a cadaveric liver, he pledged all his organs as his last wish before he underwent the transplant and he had given this responsibility to his daughter.

Post-transplant the figure of 20 donations came to his mind, to help at least these many people to get organs in their end stage of life. His new liver was working well and he was doing fine. Within one year of his transplant he contacted a good friend of his working in PGIMER, Chandigarh saying that he wanted to work for organ donation. His friend told him about Dr. Sunil Shroff and asked him to get in touch with him as they were doing a lot of work in this field. Dr. Shroff invited him to Chennai and this led to his association with MOHAN Foundation in 2010. The public were not even aware about this programme when he first started in Chandigarh and they have been focusing on a lot of public awareness. He has crossed the figure of 20 donations and has been instrumental in giving life to about 58 people. He was told that the liver survival outcome after 5 or 10 years is less than 50% but he was still alive and kicking and wanted to do more for the programme.

Questions/Comments:

Ms. Trilly Mathew

What was your lifestyle modification after your transplant?

Mr. Sudhir Dewan

Except for alcohol, which his doctor advised him to stop, the rest of the lifestyle is more or less the same. He walks every day, has been travelling, and eats almost everything.

Speaker 2 – Prof. Vijaya Sherry Chand

In 2006, he was diagnosed with Hepatitis C caused due to a blood transfusion he had received after a major accident about 20 years before his transplant. This very rapidly led to hepatocellular carcinoma (HCC) and all the other complications. Between being diagnosed and going through a transplant, he had to undergo treatment with interferon alpha, which caused many side effects and made him insulin dependent, but the drug did not work. After a few months he was diagnosed with HCC.

His elder sister was in charge of researching how he could get a transplant, which led him to learn a very important lesson that family network is very important. He realised that it is not just the surgeon but also the entire team that is important for a successful transplant.

He was not an ideal case of a post liver transplant recipient, since He developed Guillain–Barré syndrome (GBS) which caused many problems for him, which he was still managing. The surgeons ruled out Cytomegalovirus (CMV) as a problem and traced it to the Tacrolimus drug, which triggered the autoimmune response. Hence, he was taken off Tacrolimus and put on immunoglobulin. His time in the ICU was short but it took him about eight months to get out of bed. This led to a number of long-term consequences. Recovering from that phase, the few lessons he learnt were –

- First, the **family which is extremely important**, it is your close network that helps you stay strong through this journey,
- Second, there was difficulty in judging which doctor to choose. Everyone by default contacts multiple doctors, this is where the ability to judge becomes important, they did not have much information either on the post survival rate, how does one hospital differ from the other. At the end, it was **a matter of faith and judgment**, but once you decide there should not be any second thoughts.
- The third point would be **compliance with the drug routines**. If a drug has a 12-hour cycle, one cannot compromise on the time. He had understood that compliance was extremely important and he had made a point to follow it strictly. Compliance also includes avoiding gatherings for the first few years, being careful about food and travel, he follows this even today.
- The fourth he said is the **importance of self-educating**; it is the patient who needs to be proactive in educating oneself about the complications and so on. One needs to be prepared for difficulties, which may be common from a doctor's point of view but for the patient and his family it will seem like the end of the world.
- Finally, one has to be **prepared for emergencies** as well, such as hernia after a major surgery.

If the patient is not prepared, issues such as these become a huge problem. Over the last 11 or 12 years, it had been easy to manage these issues and it becomes easier when you have a team of trusted doctors by your side.

Comments

Dr. Sonal Asthana said this is the kind of reward that money cannot buy – patients going on to live a normal life. The importance of family had been highlighted. What is it that a medical team can do to eliminate the fears that have been spoken about such as not knowing which team to go to, having questions which could have been addressed differently, as doctors what can be done differently?

Mr. Sudhir Dewan said that the medical team would not be able to do much; it is the patients who need to do this work; when they are positive, they will recover faster. It all depends on the psychology of the patient.

Prof. Vijaya Sherry Chand responded that the absence of information sometimes comes in the way. It is better to be open about failures and successes. It does not matter if your failure record is high; one needs to overcome that. Transparency about outcomes would be the best way to address the anxiety of the patients. The absence of reliable information is where the problem lies; this was the situation many years ago.

Ms. Trilly Mathew said the key principle was compliance, without compliance a patient will not do well in a long-term plan. It is the responsibility of the transplant coordinator in ensuring that the patient is compliant. If the patient misses a follow-up session, they need to call them up and say it is time for their follow up.

Mrs. Lalitha Raghuram asked, what was the medication expenditure per month?

Mr. Sudhir Dewan said initially it was quite high but now his medication had been reduced to only 0.5 mg of Tacrolimus twice a day, which costs about Rs 30 or Rs 40 a day.

Prof. Vijaya Sherry Chand said Since Tacrolimus did not suit him he was switched to Sirolimus. That was a lot more expensive with the cost being around Rs 10,000 a month. He is also on other medication to control the long-term effects of GBS. The Sirolimus had now been cut down, so the cost had certainly been coming down.

Dr. Jimmy Gupta asked about recipient support groups in Ahmedabad.

Prof. Vijaya Sherry Chand responded there were no support groups to the best of his knowledge. In between there was an attempt made which did not continue.

Valedictory

Mrs. Lalitha Raghuram and Dr. Rajesh Chandwani shared their thoughts on the conference proceedings and mentioned that they looked forward to a fruitful collaboration.

Awards

1. **Swamy Narayan Best Transplant Coordinator Award for the year 2019**
 - **Ms. Rajinder Kaur**, Transplant Coordinator - PGIMER, Chandigarh
2. **Best Transplant Coordinators, sponsored by Abhayam Kidney Care Trust**
 - **Ms. Priti Jain** – Alexis Hospital, Nagpur
 - **Ms. G Lakshmi** – CARE Hospital, Telangana
3. **Milaap-MOHAN-NATCO Best Transplant Coordinators' Award:** recognises efforts towards fundraising for economically backward patients
 - **Mrs. Jayalaxmi Gottimukkala** – Global Hospitals, Hyderabad
 - **Mr. Srikanth Shankar** – Rela Institute & Medical Center, Chennai
 - **Ms. Pranitha Danneru** – Rainbow Children's Hospital, Hyderabad
 - **Ms. Sumitra Dhar from Dr. Rajiv's Transplant Team** – Apollo Gleneagles, Kolkata
 - **Mr. Rahul Tambe** – Sahyadri Hospital, Pune
4. **Dr. J. Amalorpavanathan Best Scientific Paper Award**
 - **Dr. Geetika Vashisth**
Paper Title: 'In-depth analysis of the socio-demographic profile of people from across India who pledged to be organ donors, and the medium of information that they interacted with leading to them pledging'
5. **Best Poster**
 - **Ms. Juhija R, Mr. Siva Shankar T S, Mr. Albin Augustin and Ms. Sunisha Shaji**
Poster Title: 'Knowledge and attitudes on organ donation among auto rickshaw drivers in Chennai'
6. **Extraordinary Efforts to Promote Organ Donation**
 - **Ms. Pallavi Kumar, Executive Director (NCR), MOHAN Foundation**
Felicitated at the event for her extraordinary achievements that include scaling the Everest Base Camp and Mt. Kilimanjaro in 2018 and 2019 respectively as a tribute to organ donors and commitment to the cause.

Dr. Sunil Shroff made the closing remarks and Mrs. Lalitha Raghuram delivered the vote of thanks.

NATCO Committee

S. No	Name	
1	Ms. Lalitha Raghuram	President
2	Ms. Arati Gokhale	Vice President
3	Dr. Hemal Kanvinde	Secretary
4	Ms. Jaya Jairam	Joint Secretary
5	Ms. Pallavi Kumar	Treasurer
6	Ms. Trilly Matthew	Executive Member
7	Ms. Priya Jebakaran	Executive Member
8	Dr. Amit Joshi	Executive Member
9	Mr. Ahsan Ullah Ansari	Executive Member
10	Ms. Sujata Ashtekar	Executive Member
11	Ms. Lakshmi G	Executive Member
12	Ms. Priyanka Borah	Executive Member
13	Lt. Col. Sandhya V Nair	Executive Member
14	Dr. Sujata Rajapurkar	Executive Member
15	Mr. Venkatesh Mohan Swamy	Executive Member

List of Faculty

S. No.	Faculty	Affiliation
1	Mr. Ahsan Ullah Ansari	Transplant Coordinator, Central Hospital, Bhopal
2	Mr. Amal Sivaji	Associate Director, Healthcare, USISPF, New Delhi
3	Mr. Aman Bhaiya	Assistant Vice President & Program Head, SBI Foundation, Mumbai
4	Dr. Amit Joshi	Officer, Special Duty & Chief Transplant Coordinator, Bombay Hospital, Indore
5	Mr. Anil Srivatsa	The Gift of Life Adventure; Founder – Radiowalla and Million Donor Project App, Bengaluru
6	Dr. Anita Hada Sangwan	Navjeevan, MF Jaipur Citizen Forum, Jaipur
7	Ms. Ann Alex	Programme Associate, MOHAN Foundation, Chennai
8	Ms. Arati Gokhale	Central Coordinator, ZTCC, Pune
9	Dr. Atul Mulay	Secretary, ZTCC, Pune
10	Dr. Avnish Seth	Director, Fortis Organ Retrieval & Transplant (FORT), New Delhi
11	Mr. Badal Rag	Associate Vice President-Brand, The Times of India, New Delhi
12	Ms. Bhavna Chhabaria	CEO, Shatayu, Ahmedabad
13	Ms. Bhavna Jagwani	Convener, MFJCF, Jaipur
14	Dr. Dhiren Shah	Cardiothoracic & Vascular Surgeon, CIMS Hospital, Ahmedabad
15	Dr. Geetika Vashisth	ORGAN India, New Delhi
16	Dr. Hemal Kanvinde	Quality Assurance Officer, MOHAN Foundation, Chennai
17	Ms. Ishwarya Thyagarajan	Research Associate, MOHAN Foundation, Chennai
18	Ms. Jaya Jairam	Project Manager, MOHAN Foundation, Mumbai
19	Dr. Jayanti Ravi, IAS	Principal Secretary Health & Family Welfare, Gujarat

20	Dr. Jose Chacko Periappuram	HOD (Cardio Thoracic Surgery), Lisie Hospital, Kochi
21	Dr. K. M. Boopathi	Institute for Research and Rehabilitation of Hand, Government Stanley Medical College & Hospital, Chennai
22	Dr. Kishore Phadke	Convener, Jeevasarthakathe, Bengaluru
23	Ms. Lalitha Raghuram	Country Director, MOHAN Foundation & President, NATCO, Hyderabad
24	Mr. Mahendra Kumar Rekhi	Managing Director & CEO, SBI Foundation, Mumbai
25	Dr. Manoj Gumber	Nephrologist, Apollo Hospitals, Ahmedabad
26	Mr. Mayukh Choudhury	CEO and Co-founder, Milaap, Bengaluru
27	Dr. Muneet Kaur Sahi	Programme Manager, MOHAN Foundation, Delhi NCR
28	Mr. Nilesh Mandlewala	Founder and President, Donate Life, Surat
29	Mr. P.W.C. Davidar, IAS	Former Principal Secretary to Government of Tamil Nadu, Chennai
30	Ms. Pallavi Kumar	Executive Director, MOHAN Foundation, Delhi NCR
31	Dr. Piyasha Nath	Deputy Medical Superintendent, Apollo Hospitals, Ahmedabad
32	Ms. Priyanka Borah	CEO, Zuble Foundation, Guwahati
33	Mr. Raghuram Kuppuswamy	MOHAN Foundation, Hyderabad
34	Dr. Rajesh Chandwani	Chairperson, CMHS, IIM, Ahmedabad
35	Ms. Rajinder Kaur	Transplant Coordinator, PGIMER, Chandigarh
36	Dr. Rakesh Gupta	IAS, Project Director, Chief Minister's Good Governance Associates Program & Nodal Officer, Beti Bachao Beti Padhao, Haryana
37	Dr. G. L. Singal	Project Coordinator, Beti Bachao Beti Padhao, Haryana
38	Lt. Col. (Retd.) Sandhya Nair	Transplant Coordinator, Batra Hospital, New Delhi
39	Dr. Somnath Chattopadhyay	HOD, Hepato-Pancreato-Biliary Surgery and Liver Transplant, Kokilaben Dhirubhai Ambani Hospital, Mumbai

40	Dr. Sonal Asthana	Clinical Lead HPB Surgery and Multi-organ Transplant, Aster CMI Hospital, Bengaluru
41	Dr. Srivari Bhanuchandra Dharani Pal	Transplant Coordinator and Program Manager, MOHAN Foundation, Hyderabad
42	Mr. Sudhir Dewan	Honorary Director, MOHAN Foundation, Chandigarh
43	Ms. Sujata Ashtekar	Consultant - ROTTO/SOTTO West, Maharashtra and Transplant Coordinator, Mumbai
44	Dr. Sujata Rajapurkar	Medical Social Worker & Transplant Coordinator, Muljibhai Patel Society for Research in Nephro-Urology, Nadiad
45	Ms. Sujatha Suriyamoorthi	Manager - Information Systems, MOHAN Foundation, Chennai
46	Mr. Sundeep Kumar	Executive Director- Corporate Affairs & Communication, Dalmia Bharat Group, New Delhi
47	Dr. Sunil Shroff	Managing Trustee, MOHAN Foundation, Chennai
48	Dr. Suresh Sankar	Nephrologist, NephroPlus, Chennai
49	Ms. Trilly Rachel Mathew	Head - Organ Transplant Program, Nayati Healthcare & Research Center, Noida
50	Prof. Vijaya Sherry Chand	Professor and Chairperson, Ravi J. Matthai Centre for Educational Innovation, IIM Ahmedabad
51	Dr. Vivek Kute	Secretary, Indian society of Organ Transplantation & Professor – Nephrology, IKDRC-ITS Ahmedabad
52	Ms. Vrinda Pusalkar	Transplant Coordinator, Jehangir Hospital, Pune



NETWORK AND ALLIANCE OF TRANSPLANT COORDINATORS, INDIA (NATCO)

Membership Form

As a life member of Network and Alliance of Transplant Coordinators, you support all our endeavours in the area of transplant coordination in India. You are entitled to participate in all the events of NATCO. Please fill the form and post it to us.

Yes, I wish to join NATCO as a member. (Fill in Capital letters)

Name: (Dr/Mr/Ms/Mrs) _____

Organization: _____

Address: _____

Pin: _____ Tel: _____ Mobile: _____

Email: _____

I remit herewith Rs. _____ by Cash/ Cheque/ Demand Draft No. _____

Dated: _____ Drawn on: _____

Date: _____ Signature: _____

Please send membership fee by Cheque/Demand Draft in the name of "NATCO" payable at Chennai.

Or NEFT Transfer -

Account Number: 520101257801055

IFSC Code: Corp0000487

Corporation Bank

Block AA, 144 III Avenue, Anna Nagar. Chennai 600040, Tamil Nadu, India

<p>Categories of membership are: ✓ (Mark the appropriate one) a) Individual member as Life member: Rs. 2,500/- b) Institutional member: Rs. 5,000/- c) Corporate member: Rs. 10,000/- (Annual member) d) Overseas member: USD 50 or its equivalent (Life Member)</p>	<p>Post your filled-in membership form along with cheque/DD to the following address:</p> <p>Mrs. Lalitha Raghuram President, NATCO #6-3-634, Flat B-1/A Second Floor Green Channel, Khairatabad, Hyderabad 500004, Telangana</p> <p>Phone – 040 66369369 Email – txnatco@gmail.com</p>
--	---



Speakers – Free Paper Presentation



Prof. Vijay Sherry Chand receiving certificate



Dr. Avnish Seth



Mr. Anil Srivatsa



Dr. Anita Hada Sangwan



Mr. Nilesh Mandiwala



Ms. Lalitha Raghuram



Ms. Bhavna Chhabaria



Ms. Rajinder Kaur receiving Best Transplant Coordinator Award



Speakers & Chairs – MLC Session



Ms. Bhavna Jagwani



Ms. Priyanka Borah



A group picture



Swamy Naryan Orator - Dr. Sonal Asthana



Dr. Manoj Gumber & Dr. Vivek Kute



Transplant Coordinators with Dr. Shroff, Dr. Chandwani, Mrs. Lalitha and Mr. Raghuram

NATCO

NETWORK AND ALLIANCE OF TRANSPLANT COORDINATORS

NATCO - Network and Alliance of Transplant Coordinators is a registered society with the vision to improve the professional careers of Transplant Coordinators and promote ethical organ donation and transplantation in India.

CONFERENCES



Hyderabad



New Delhi



Chennai



Chennai



Hyderabad



Chennai



Chandigarh



Indore



Bengaluru



Ahmedabad



H.O: 3rd Floor, Toshniwal Bldg, 267, Kilpauk Garden Road, Chennai, Tamil Nadu - 600 010

Email : txnatco@gmail.com | Web: www.natco.org.in

PH : 044 2644 7000 / +91 9849028795 | Toll Free Organ Donation Helpline
1800 103 7100