

**11th National
Annual Transplant Coordinators' Conference
&
Declaration of Istanbul Custodian Group (DICG)
Symposium**

Pre-Congress of 14th World Congress of Bioethics

PROCEEDINGS

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The **DECLARATION** of **ISTANBUL**
on ORGAN TRAFFICKING and TRANSPLANT TOURISM

3rd - 4th December 2018

**St. John's National Academy of Health Sciences,
Bengaluru, India**



11th Annual Transplant Coordinators' Conference
Emerging Ethical Dilemmas in Organ Donation and Transplantation
in India

&

Declaration of Istanbul Custodian Group (DICG)
Symposium
Organ Donation and Transplantation in a World of Inequality

Pre Congress - 14th World Congress of Bioethics

3rd and 4th December 2018

Bengaluru

PROCEEDINGS

Title

Proceedings of the 11th Annual Transplant Coordinators' Conference and the Declaration of Istanbul Custodian Group (DICG) Symposium

Edited By

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MOHAN Foundation

For Network and Alliance of Transplant Coordinators

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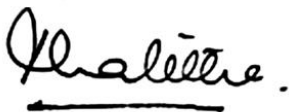
Acknowledgement

It gives us great pleasure to bring out the proceedings of the 11th Annual Transplant Coordinators' Conference and the Declaration of Istanbul Custodian Group (DICG) Symposium.

We had more than 200 delegates and faculty. We acknowledge the inputs of the scientific committee members of our society for developing the scientific sessions. We thank the speakers and the chairpersons for sharing their thoughts and experiences during the meeting. Special thanks to the overseas faculty who took time out from their work to attend the meeting.

NATCO would like to acknowledge the support of the following organisations in making the event a success - MOHAN Foundation, Declaration of Istanbul Custodian Group (DICG), Tata Trusts, SBI Foundation, Zonal Transplant Coordination Centre (ZTCC) - Pune, Jeevasarthakathe - Government of Karnataka, Amar Gandhi Foundation - Mumbai and Narmada Kidney Foundation - Mumbai. We are also grateful to the organisers of the 14th World Congress of Bioethics.

We thank Dr. Sanjay Nagral, Dr. Dominique Martin, and Dr. Sumana Navin for the scientific program. We thank Mr. Ruban Victor for the arrangements during the conference. We also thank the MOHAN Foundation team comprising Jaya Jairam, Hemal Kanvinde, Ishwarya Thyagarajan, Ann Alex, Kavitha Aneesh, Anindita Sabath, and Pavithra Ramesh for preparation of this proceedings.



Mrs. Lalitha Raghuram
President
NATCO



Dr. Sunil Shroff
Managing Trustee
MOHAN Foundation

Foreword

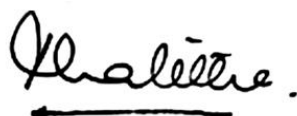
India has over 2500 trained transplant coordinators that are instrumental in coordinating over 15000 organ transplants. We are proud of the work they do with complete devotion and professionalism. The stories of transplant coordinators and the challenges they face while counseling and coordinating an organ donation or transplant often go unrecognized.

MOHAN Foundation has trained over 2000 transplant coordinators since December 2009. It has been conducting the National Annual Transplant Coordinators' Conference every year successfully. **NATCO - *Network & Alliance of Transplant Coordinators*** is a registered non-profit charitable society, and has a strong executive committee and membership base from across India.

NATCO's vision is to improve the professional career of Transplant Coordinators and promote ethical organ donation and transplantation in India. A website for NATCO along with a Facebook page is in the planning phase.

This year, we conducted the 11th National Annual Transplant Coordinators' Conference in partnership with Declaration of Istanbul Custodian Group on 3rd and 4th December 2018 at the St. John's Academy of Health Sciences, Bengaluru. We hope to continue to give the best of scientific sessions by renowned speakers to deliver latest information and improve our understanding of donations and transplantation.

The proceedings are a step forward in this direction.



Ms. Lalitha Raghuram
President, NATCO
Hyderabad

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

Overseas Faculty		
Dr. Benita Padilla	Dr. Daniel Fu-Chang Tsai	Dr. Philip Thomas
Dr. Charitha Prasanna	Dr. Elmi Muller	Prof. Gurch Randhawa
Dr. Dominique Martin	Dr. Mohammad Shakib Uz Zaman Arefin	Prof. Alexander Capron
National Faculty		
Dr. Amit Joshi	Dr. Noble Gracious	Dr. Sonal Asthana
Dr. Anil Kumar	Dr. Omprakash Nandimath	Dr. Sridhar Nagaiyan
Dr. Astrid Lobo	Dr. Peush Sahni	Dr. Sudhindran S.
Dr. Avnish Seth	Mr. Premdas Pinto	Ms. Sujata Ashtekar
Dr. Bala Ramachandran	Dr. R. K. Mani	Ms. Sujatha Suriyamoorthi
Ms. Bhavna Jagwani	Dr. Ramesh	Dr. Sumana Navin
Mr. C. E. Karunakaran	Mr. K. Raghuram	Dr. Sunil Shroff
Ms. Dhvani Mehta	Dr. Roop Gursahani	Dr. Srivari Bhanu Chandra
Ms. Jayalaxmi Gottimukkala	Dr. Samiran Nundy	Dr. B. Umadethan
Dr. Joga Rao	Dr. Sanjay Nagral	Ms. Urmila Mahajan
Dr. Julius Punnen	Dr. S. K. Mathur	Dr. Vinay Kumaran
Mr. Keshav Desiraju	Ms. Sohini Chattopadhyay	Dr. Vivekanand Jha
Dr. Kishore Phadke		Ms. Vrinda Pusalkar
Dr. Nagesh N S		
Dr. Nagesh Simha		
Ms. Neha Bali		



11th ANNUAL TRANSPLANT COORDINATORS' CONFERENCE 2018

Date: 03rd & 04th December 2018 | Venue: St. John's National Academy of Health Sciences, Bengaluru, Karnataka, India



Emerging Ethical Dilemmas in Organ Donation and Transplantation in India (Under the aegis of NATCO & MOHAN Foundation)

Day 1 Monday – 3rd Dec 2018 (Programme Schedule: 9 am – 6.30 pm)

Morning session: 9 am – 1 pm

Session	Topic
8.30 am	<i>Registration, Coffee and tea</i>
09.00 – 10.00 am	Models of successful organ donation and transplantation programmes for BPL (below poverty line) patients Chair: Dr. Nagesh N S Dr. Srivari Bhanu Chandra Ms. Sujatha Suriyamoorthi Ms. Bhavna Jagwani Ms. Sujata Ashtekar
10.00 - 10.45 am	Free Paper Presentation Chairs: Dr. Kishore Phadke & Ms. Arati Gokhale
10.45 – 11.00 am	Tea Break
11.00 - 11.30 am	Presentation by nominees of Swamy Narayan Award Chairs: Dr. Kishore Phadke & Ms. Arati Gokhale
11.30 am – 12.15 pm	Ethical issues that transplant coordinators face in live donor transplants Chairs: Dr. Sumana Navin & Dr. Anil Kumar Ms. Vrinda Pusalkar Dr. Amit Joshi Ms. Neha Bali Ms. Jayalaxmi Gottimukkala
12.15 – 01.00 pm	Swamy Narayan Memorial Lecture Chair: Mr. K. Raghuram
	A perspective on transplant issues from South Africa Dr. Elmi Muller
01.00 – 02.00 pm	LUNCH

Afternoon session: 2 pm – 6.30 pm

Session	Topic
Session1 (2 pm – 4.30 pm)	<p>i) Day of Judgement - Supreme Court Judgments that have implications on death and organ donation in India Mr. Keshav Desiraju, Chairperson, Dr. Samiran Nundy, Co-chairperson & Dr. Ramesh, Co-Chairperson</p> <p>a. Aruna Shanbaug Judgment & Donation after cardiac death: Does the Supreme Court judgment make it possible in the future, Dr. Roop Gursahani</p> <p>b. Passive euthanasia judgment: Do these judgments empower ICU consultants to withdraw treatment? Dr. R. K. Mani</p>
	<p>ii) Debate Dr. Joga Rao, Chairperson & Dr. Julius Punnen, Co-chairperson</p> <p>a. USA's position of whole brain death: Should it be followed in India? Dr. Sonal Asthana</p> <p>b. UK's position on brain-stem death: Is it adequate? Dr. Vinay Kumaran</p>
	<p>iii) Kerala High Court judgment on non-directed donation and compensation: Ethical challenges Dr. S. K Mathur, Chairperson & Mr. C. E. Karunakaran, Co-Chairperson</p> <p>a. Judgment and protocol highlights. Dr. Noble Gracious</p> <p>b. Ethical challenge. Dr. Philip Thomas</p>
	<p>iv) Brain-stem death protocols: Help or hindrance? Dr. Peush Sahni, Chairperson & Dr. Sonal Asthana, Co-chairperson</p> <p>a. Presenting the protocol. Dr. S Sudhindran</p> <p>b. Does the protocol violate privacy and should it be challenged? Dr. B. Umadethan</p>
Session 2 (4.30 pm – 5.30 pm)	<p>i) Lessons from the UK Dr. J Amalorpavanathan¹, Chairperson & Dr. Elmi Muller, Co-chairperson</p> <p>a. Is organ donation and transplantation a reality for everyone in an unequal world? Prof. Gurch Randhawa</p>
	<p>ii) Ethical considerations in Brain-stem death testing and organ donation in pregnancy a. Protocols in the UK. Dr. Sridhar Nagaiyan</p>
	<p>iii) Indian guidelines on paediatric brain death testing Dr. Sunil Shroff, Chairperson & Dr. Avnish Seth, Co-chairperson</p> <p>a. Should it include anencephaly and organ donation? Dr. Bala Ramachandran</p>
Session3 (5.30 pm – 6.30 pm)	<p>i) Look who's talking? Dr. Benita Padilla, Chairperson & Dr. Dominique Martin, Co-chairperson</p> <p>a. Social media, organ donation and transplantation: Ethical challenges and solutions. Dr. Sunil Shroff</p>
	<p>ii) Debate Dr. Astrid Lobo Gajiwala, Chairperson & Dr. Sunil Shroff, Co-chairperson</p> <p>a. National organ donation pledge registry in India: Is it an expensive exercise that is likely to go nowhere? Dr. J. Amalorpavanathan</p> <p>b. National Organ Donation pledge registry in India: Will it increase donation rate and is it a step in the right direction? Dr. Avnish Seth</p>

¹ Was unable to attend the conference



Theme - 'Organ donation and transplantation in an unequal world'

(Under the aegis of the Declaration of Istanbul Custodian Group -DICG
with support from the MOHAN Foundation at the 14th World Congress of Bioethics)

Day 2 Tuesday – 4th Dec 2018 (Programme Schedule: 9 am – 5 pm)

Time	Presenter	Topic
8.30 am	Registration	
9.00 am	Sanjay Nagral, India Dominique Martin, Australia	Welcome Introduction to the DICG and the 2018 edition of the Declaration of Istanbul
Session 1	Organ trafficking and the role of health professional Chairs: Kishore Phadke, Bengaluru and C. E. Karunakaran, Chennai	
9.20 am	Benita Padilla Sunil Shroff Charitha Prasanna Adib Rizvi	Overview of Organ Trafficking in South Asia (Case studies) Philippines India Sri Lanka Pakistan
10.00 am	Sumana Navin, India	Ethical concerns about organ selling
10.20 am	Daniel Fu-Chang Tsai, Taiwan	Health professional responsibilities and barriers to addressing trafficking
10.40 am	Tea break	
Session 2	Ethical risk management in living organ donation Chairs: Philip Thomas, Kochi & Omprakash Nandimath, Bengaluru	
11.00 am	Riadh Fadhil ² , Qatar	Role of psychosocial evaluation
11.20 am	Benita Padilla, Philippines	Practical challenges for effective implementation
11.40 am	Moderator: Sanjay Nagral Panel Members: Nagesh Simha, Bengaluru Astrid Lobo, Mumbai, Sonal Asthana, Bengaluru, Premdas Pinto, Bengaluru, Urmila Mahajan, Mumbai Sohini Chattopadhyay, Kolkata	Negotiating the local terrain in organ donation and transplantation <i>A case based multidisciplinary panel discussion on special challenges in South Asia</i>
12.30 pm	Lunch	
Session 3	Barriers to equity in donation and transplantation Chairs: S. K. Mathur, Mumbai & Noble Gracious, Trivandrum	
1.30 pm	Dominique Martin, Australia	Inequities in deceased donation: Impact of end of life healthcare costs on donation decision making
1.50 pm	Vivekananda Jha, India	Inequities in access to transplantation services: impact of costs of dialysis, surgery and post-transplant care

² Was unable to attend the conference

2.10 pm	Elmi Muller, South Africa	Inequities in organ allocation: impact of allocation protocols favoring private sector
2.30 pm	Tea break	

Session 4	Law and policy in promoting ethics and equity Chairs: Dhvani Mehta, Anil Kumar and Samiran Nundy, Delhi	
2.50 pm	J. Amalorpavanathan	HOTA & access to transplantation: impact and challenges
3.10 pm	Alexander Capron, USA	Financial incentives for donors and donor families
3.30 pm	Benita Padilla Riadh Fadhil ³ Charitha Prasanna Adib Rizvi ⁴ Elmi Muller	Legislative change: how it can make a difference (Case studies) Philippines Qatar Sri Lanka Pakistan South Africa
4.30 – 5.00 pm	Dominique Martin Sanjay Nagral	Closing Remarks

³ Was unable to attend the conference.

⁴ Was unable to attend the conference.

Meeting Highlights

The central theme for the transplant coordinators' conference was the ethical dilemmas that were emerging in the organ donation and transplantation field. It was a platform for transplant coordinators from all over the country to share their perspectives on the theme. The following were the takeaways from the conference:

- Understanding the recent judgement and state orders in India and how they impact organ donation
- Getting an overview of international perspectives in organ allocation and transplantation
- Exposure to common ethical dilemmas in the field of organ donation in India with the possibility of creating guidelines for such clinical scenarios
- The use of social media in the field of organ donation and transplantation and creating guidelines for the Indian transplant programme

The DICG Symposium witnessed discussions around inequalities in organ donation and transplantation around the world. Discussions helped establish priorities for action in the Asian region, and reflect on the possibility of formation of professional networks in the region that will contribute to action around the world to promote equity in donation and transplantation. The participants were able to get perspectives on the following topics:

- Key elements of organ trafficking and their ethical and professional implications
- Factors that influence inequities in organ donation and transplantation
- Role of ethics and law in managing risk and promoting equity in organ donation and transplantation

3rd December, Day 1 Proceedings

Day 1 – Morning Session

9:00AM-10:00AM

Topic – Models of successful organ donation and transplantation programmes for Below Poverty Line (BPL) patients

Chairperson – Dr. Nagesh N. S. (Head of Department of Surgical Gastroenterology, Bangalore Medical College and Research Institute)

Speaker 1 – Dr. Srivari Bhanu Chandra,
MOHAN Foundation, Hyderabad

The speaker started his presentation by putting forth his observations as a transplant coordinator. He discussed some of the cases he handled. According to his observations, around 60% of the organ donors in his hospital belong to the BPL section. However, it is a challenge talking to such families about organ donation because of their lack of knowledge, financial issues and the preconceived myths. He concluded by saying that there should be awareness programs in rural areas and more clarity should be given to them on social and religious myths.

Suggestions – Counselling should be strategized and key members of the family should be identified before counselling.

Speaker 2 – Ms. Sujatha Suriyamoorthi
MOHAN Foundation, Chennai

The speaker shared her experience of leading the work of transplant coordinators in public hospitals of Tamil Nadu. She discussed the factors responsible for the success of a deceased donation programme in a hospital. She narrated the history of how MOHAN Foundation started its work in Rajiv Gandhi Govt. General Hospital, Chennai. Based on her experience, the number of donations did not depend upon the literacy levels of the public but on the nature of counselling services provided by the hospitals. Challenges faced as a transplant coordinator were also discussed.

Questions

1. How do you manage the funding for transplant in a public hospital?
2. What are the challenges faced during brain death certification?
3. What is the role of the Intensivists in conversion rate for organ donation?

Speaker 3 – Ms. Bhavna Jagwani
MFJCF, Jaipur

The speaker gave a brief introduction of MOHAN Foundation-Jaipur Citizen Forum (MFJCF) and the work it does in Rajasthan. The number of awareness programmes held so far was discussed. Bhama Shah Scheme of the Govt. of Rajasthan was looked into, wherein monetary donations are sought from business houses and the collections are used to aid financially poor patients for health benefits. She also shared some of her donor stories and majority of them were from the weaker economic sections of the society.

Questions

1. As majority of the donors were from poor families, can compensation of any sort be provided to the families?
2. Can NGOs come together to support the donor families financially?

Speaker 4 – Ms. Sujata Ashtekar

ROTT, Mumbai

The speaker shared the data of donations that has happened in the last 3 years in Maharashtra. She discussed the model followed in KEM Hospital, Mumbai. Mahatma Phule Jeevan Dayi Yojana was discussed and also the number of transplants done in KEM Hospital. A comparison was drawn between the models followed in private and public hospitals in Maharashtra. She also put forth the challenges faced by ROTT in public hospitals.

Questions

1. Can government look into funding public hospitals for equipment, infrastructure etc.?

10:00AM-10:45AM

Topic – Free Paper Presentation

Chairpersons: Dr Kishore Phadke, Paediatric Nephrologist, Convenor – Jeevasarthakathe, Government of Karnataka; Mrs. Arati Gokhale Central Coordinator, Zonal Transplant Coordination Committee, Pune

Speaker 1 – Ms. Pavithra Ramesh

An intern MOHAN Foundation Chennai, the speaker presented on the topic, “Why is organ donation difficult? Can *Dharma* make it easier?”

She spoke about how *Dharma* gave structure to decision making and highlighted that the intent with which the donation is being made must be *Dharmik* and that results of *Dharma* must be positive and beneficial. She discussed what a righteous person would do with his/her organs and proved that organ donation is a righteous act as it includes benevolence, kindness and goodness.

Questions

1. Will the reincarnated body miss the organs?

Speaker 2 – Ms. Anindita Sabath

The speaker is a Transplant Coordinator working at MOHAN Foundation Delhi. She presented on the topic “Perceptions and attitudes of people towards organ donation amongst people of Odisha”

She highlighted through a survey, how the gap between people getting a transplant and waiting to receive a life-saving organ has widened in Odisha. Her study showed that lack of knowledge about organ donation and pre-conceived notions and attitudes of people were the main causes. Her survey highlighted the following causes as the main reasons for virtually nil organ donation rate in Odisha – religious beliefs, lack of altruism, empathy, and acceptance of mortality, fear of disfigurement, lack of trust in healthcare (mainly in the allocation procedure), trying to avoid donating saying that their

organs could already be defective due to bad habits, family influence, etc. She concluded by saying that the state government needs to take serious cognizance of these issues and work together with other bodies to address them.

Speaker 3 – Ms. Priscilla N

Ms. Priscilla represented Jeevandan, Andhra Pradesh, and presented a Poster that illustrated the concept of organ donation and the various myths and facts relating to organ donation lucidly. Lastly the call to action in the form of their Toll Free Helpline No. and website link was included too.

Speaker 4 – Ms. Indira

Ms. Indira, a transplant coordinator from Pinnacle Hospital, Vishakhapatnam, presented an inspiring video in Telugu, which was made by an organ donor's brother. It was an appeal to all to donate their organs.

The J. Amalorpavanathan Best Scientific Paper was awarded to Ms. Anindita Sabath.

11:00AM-11:30AM

Topic – Presentations by the nominees of Swamy Narayan Award for the Best Transplant Coordinator

Chairpersons – Dr. Kishore Phadke, Convenor – Jeevasarthakathe, Government of Karnataka;
Mrs. Arati Gokhale, Central Coordinator, Zonal Transplant Coordination Committee, Pune

Nominee 1 – Lt. Col. Sandhya Nair

A transplant coordinator in the Army Hospital Research & Referral (AHRR) Delhi, the speaker began by introducing herself. She provided the data on brain deaths certified in AHRR and coordination activities in the hospital were discussed. Coordination with the Indian Air Force and creating the nation's longest green corridor was highlighted. In 2017, AHRR had done the maximum MLC donations. The biggest awareness activity was put up this year, the Diwali Mela. She also briefed about the training programmes conducted by AHRR along with MOHAN Foundation every year.

Questions

1. What is your opinion on convincing armed forces members for organ donation?
2. What are the reasons for refusal to donate among the army personnel?
3. Is required request followed among armed forces?
4. How many organs has AHRR received from non-army hospitals?
5. How many organs has AHRR received from non-army retrieval centres?

Nominee 2 – Ms. Swarupa Sangaappa Kavalgi

The speaker works as a transplant coordinator in Ashwini Hospital, Solapur. She discussed the major tasks she handles as a transplant coordinator and the challenges she faces in the hospital. She also discussed some of the cases she handled where she counselled families for organ donation. She converted 3 out of 6 brain deaths to donations in 2018.

Nominee 3 – Mr. Yuvraj Bhoopathi

The speaker works as a transplant coordinator in Manipal Hospitals, Bengaluru. He began sharing his work experiences and narrated the initial challenges he faced in counselling when he moved to Bengaluru from Tamil Nadu. He has counselled 52 families so far, of which 37 families have consented to organ donation.

Questions

1. What should be done to take this program forward in Karnataka?

Nominee 4 – Ms. Sarika Saha

The speaker is from Yawatmal, Nagpur. She has conducted a number of awareness sessions on organ donation in rural and urban areas of Nagpur. She has organised more than 50 workshops and obtained more than 2000 pledges from public for organ and cornea donation. She has coordinated more than 20 cornea donations and 10 body donations till date.

Nominee 5 – Ms. Sharmila Padhye

The speaker works as a transplant coordinator in Sahyadri Hospital, Pune. She discussed the major tasks she handles as a transplant coordinator and the challenges she faces in the hospital. She also discussed some of the cases where she counselled families for organ donation. She discussed her key responsibilities involved in both living and deceased donations. Out of the 26 brain deaths that were certified, she was able to convince 22 families for organ donation in her hospital.

11:30AM-12:15PM

Topic – Ethical issues that transplant coordinators face in living donor transplants

Chairperson – Dr. Sumana Navin, Course Director, MOHAN Foundation, Chennai

Speaker – Dr. Amit Joshi, *Transplant Coordinator, Bombay Hospital, Indore*

Dr. Amit Joshi began by putting forth challenging questions such as, is the patient's body a commodity or does it belong to a particular family, should one person receive several organs or several persons receive one, should one person have a second transplant when the first one fails or should a different person be given a first chance at a new organ, should those who abuse their organs by drinking be given an organ or those whose organs have been damaged by some disease, should be prioritised. Donor families who have close family members or friends, waiting for an

organ, request that their organs be allocated to their relative or friend. A challenge, transplant coordinators face is explaining who gets the priority; patients and donor families expect an explanation in detail on the priority of a supra urgent list, why other are patients declined and so on. He followed the challenging questions with few ethical principles on the respect for the individual, beneficence, justice, non-maleficence.

Q – How many deceased donor organs do you get per year?

A – In Indore, we were able to get 37 brain dead patients donate. Our deceased donation rates are much better compared to other states.

Q – What is the living related donor rate compared to the deceased donation rate in Indore.

A – Living related donations are more in number than the deceased donations. Living donations are higher in case kidney transplants when compared to liver. Living donation for liver has not yet started in Madhya Pradesh. The ratio for living related compared to deceased donors would be around 3:1.

Speaker – Ms. Neha Bali, Transplant Coordinator, Medanta Hospital, Gurugram

Ms. Neha Bali began by explaining the law on organ donation and the various ways an organ failure patient can receive an organ from a living donor. The donor can be faced with emotional and psychological pressure. She stressed that as a transplant coordinator the emphasis should be on donor safety, motivation and evaluation.

She highlighted a few cases, the ethical issues in each case and the way forward. The first case had the donor withdrawing consent on the OT table just before the procedure began. The donor was then counselled and made comfortable to share the reasons for her withdrawal. She was found to be apprehensive and scared about the surgery but there was immense pressure from the family and hence she couldn't say 'no' to her husband and sons. The procedure was cancelled. Both, donor consenting and counselling was initiated and the entire procedure was videotaped. Donor-recipient consultation was conducted by two separate nephrologists, the family was re-counselled and the recipient's sister came forward to donate and the transplant was done. She pointed out that, as medical professionals we should never take the donor's consent for granted and make a conscious effort to make the donor comfortable to approach us to say 'no' if they do not wish to donate. She pointed out that donors can withdraw consent legally anytime even after the legal board clearance.

She highlighted another case where the medical clearance was done and the patient's brother was a prospective donor. On the day of the ethics committee meeting the HLA typing reports were pending. Donor constantly exhibited a hesitant behaviour and other members of the family would respond on the donor's behalf. The discrepancy in the signature was noticed when he submitted the affidavit and the self-attested ID proof. In this case it was decided to take the HLA typing of the parents as well. The results showed that it was a match for the recipient but a complete mismatch for the donor. They confessed it was a fraud case and that the donor was paid. An FIR was launched against the transplant patient.

Comment – We should look at engaging independent donor advocates, who do not belong to the hospital, to counsel donors, particularly when undecided donors are involved, in order to avoid coercion. We could recommend this and maybe take this forward in the corporate sector specifically.

Speaker – Ms. Vrinda Pusalkar, Transplant Coordinator, Jehangir Hospital, Pune

Ms. Vrinda Pusalkar began with the statistics that 95% of transplants involve living donors and only 5% are cadaveric transplants published by NOTTO, hence the role of a coordinator is very important. We are working towards promoting donation after cardiac death. When we look at living donors the law seems to violate the traditional first rule of 'do no harm'. A person becomes a patient to benefit another person who is already a patient. A lot of ethical issues such as gender discrimination arise - about 70% to 75% are female donors for both male and female recipients, whereas only 13% are male donors for a female recipient (father to daughter or brother to sister, for example). Females are denied a transplant because of their gender, discriminated by their relatives, wives are being forced to donate when their husbands develop organ failure, widowed sisters who have brothers with organ failure being forced to donate and so on. The donors are caught in many such difficult dilemmas. There are times post-transplant, when the donor is unable afford a private room, whereas recipient is in one.

It is the duty of the medical professionals to give all the facts to potential living donors and inform them about the pros and cons of donating their organs. Ms. Pusalkar ended with a case that involved a grandfather who donated to his grandson and demanded money after the donation from the granddaughter-in-law's family.

Q – The living donor numbers are actually not 95% living and 5%, but about 30% are cadaver donation, wherein the donor breakup is completely opposite, it is about 80% male and 20% female. Why?

A – Probably because there are more wives giving consent

A – Most road traffic accident victims are males

Comment – In Rajasthan almost 98% of living donors are females.

Speaker – Ms. Jayalaxmi Gottimukkala, Transplant Coordinator, Global Hospital, Hyderabad

Ms. Jayalaxmi spoke about the demand for organs far exceeding the number of organs available from deceased donors. If the number of cadaveric donations rises, the living donor rates will come down. The psychological issues are of the greatest concern in living donation; ensuring the donor is fully informed about the risks involved and is willing to donate without coercion is essential. It is important to monitor the donor's psychosocial behaviour. Very few cases involving independent and economically stable men, donating to their wives are reported. In some rare cases the donors come back to the hospital requiring a transplant, hence it is important to promote deceased organ donation.

Comment – You had mentioned that women are donors mainly because of economic situations, but it could be more than that with the social situation where the women are treated as second class citizens and are expected to be self-sacrificing, always be available to the men of the family, in terms of donating. I think the economic and social issues work together. We should probably look at why more men are not donating.

12:15PM-1:00PM

Topic – Swamy Narayan Memorial Lecture: A perspective on transplant issues from South Africa

Chairperson – Mr. K. Raghuram

Speaker – Dr. Elmi Muller, Prof. of Surgery, Groote Schuur Hospital, University of Cape Town, South Africa; Past Co-chair, the DICG; Councillor, the Transplantation Society; Past President, South African Society of Transplantation

Dr. Muller began by explaining how clinicians are focussed on their patients and try their best to treat patients given their socio-economic conditions, lack of government support and non-existence of medical insurance. Around 5-7% population of the world is affected by kidney failure and among the youth, this is mainly due to hypertension.

She described the limitations of providing for organ transplantation in a resource depleted country. She elaborated on three issues – prevalence of the conditions that require transplantations, costs and effectiveness of transplantation, and existing services within the country. Quoting from the Global Burden of Disease study, she mentioned that while in 1990 CKD was 27th on the most common causes of death it had risen to the position 18th in the year 2010.

According to Dr. Muller, out of the 50.5 million people in South Africa, 5.38 million people are affected by HIV and 84% of South Africans have no medical insurance cover and depend on the state for healthcare. CKD is gaining pace in developing countries but its early recognition can lead to less financial burden on the patients. There is a necessity to understand the need for organ transplant. As poverty is one of the major issues in S. Africa, only a few transplantations are performed. Patients and families who can afford the costs travel to other countries for transplantation.

She also spoke about the 3 categories of patients and the selection criteria for dialysis in S. Africa that does not allow HIV+ CKD patients, access to dialysis services. She shared the number of donors and transplants that had happened in the last 10 years. She recalled that earlier, until about 2007, the policy was to decline organs from a HIV+ donor. However the S. African government started tackling the HIV epidemic post 2000 and initiated programmes to tackle poverty issues first. One in five of the HIV infected patient develops HIVAN kidney disease. Since 2008 the hospitals have been doing transplants using HIV+ donor organs and have done 51 transplants till 2018.

She explained the screening systems, reporting systems, risks of transmission, drug resistance to ART, meticulous follow up of the recipients. Certain virological considerations such as donor virus being detected in the recipient plasma, HIV recurrence etc. were also discussed.

Questions

1. What is the process of counselling in S. Africa?
2. Who counsels the recipients in case of HIV donors?

Afternoon Session

2:00PM-4:30PM

Topic - Day of Judgement

Chairpersons – Mr. Keshav Desiraju, Former Secretary Ministry of Health and Family Welfare, Govt. of India;

Dr. Samiran Nundy, Academic & Writer, Ex-Dean Gangaram Institute of Postgraduate Medical Sciences, New Delhi, India;

Dr. D. Ramesh, Former Secretary, Zonal Coordination Committee of Karnataka (ZCCK), Bengaluru, India.

I. Supreme Court Judgements that have implications on death and organ donation in India

a) Aruna Shanbaug's Judgement &

b) Donation after cardiac death: Does the Supreme Court judgement make it possible in the future

Speaker – Dr. Roop Gursahani, Consultant Neurologist & Epileptologist, P.D. Hinduja National Hospital, Mumbai, India

Dr. Gursahani put forth a few questions to the audience: has anything changed since the Aruna Shanbaug case? Is the glass half empty or half full? Will India get to the point of permitting donation after cardiac death? The judgement made through Aruna Shanbaug's case was not applied at the time of her own death. No one has really applied this case anywhere in India. He quoted the subtext of the judgement "we are decriminalising medical decision making for Indians at the end of life".

The guidelines framed by the Indian Association of Palliative Care and Indian Society of Critical Care Medicine in 2014 would not have happened if not for the Aruna Shanbaug judgement in 2011. Public opinion, medical capabilities, legal framework all have to evolve together. At one point in time deaths occurred at home. Now deaths have become medicalised and normal people have lost control. In USA it has been more than four decades since the first living will was proposed in the 1960s. It is important to understand death and the ecosystems of humans dying in the world.

A lot of people will more or less have a predictable death, but predictable does not mean a good death. Around 50% people will have a long and painful fade out. A good death is not a default mode; it has to be worked at.

We should have the knowledge to know when death is near, to understand what is expected. Organ donation is a way of making sense of something that is senseless. For example, the Obamas have already written down their will as they do not know what the future holds. In another example, Michael Schumacher did not write his will, his wife spent all their savings on hospital bills. No one wants to be in the condition that Schumacher is in and some of us do not even want to think about it. But for those of us who do want to think of it, we should be given the opportunity to speak up about it. We do not know anyone who has written a living will.

The most difficult part was the constitutional guarantee of the medical economy. Turned out it would take a Supreme Court judgement to let that out. The legal effect and medical system should

make it happen. Having said this, how effective are living wills? Only a quarter of the population have made these documents.

In the case of organ donors, the transplant community and organ failure patients would prefer only young donors. It is about death, but it is also about living well in the last days of our lives. The way forward is to have the conversation about death in public and in private, improve facilities for palliative care and we need a media campaign for public awareness.

c) Passive euthanasia judgement: Do these judgements empower ICU consultants to withdraw treatment?

Speaker – Dr. R.K. Mani, Medical Director and Chairman, Critical Care Pulmonology, Batra Hospital and Medical Research Center, New Delhi, India

Dr. Mani began by agreeing that the judgements on passive euthanasia empower physicians to protect patient and societal interests. If passive euthanasia (appropriate withdrawal and withholding of life support) is allowed in other parts of the world it should be equally allowed for us. People always ask is there a law, but a lot of things need to be in place before a law is formulated. There is the right to living will and treatment withdrawal (Common cause vs. The Union of India). The constitutional rights of Indians exist which includes the Right to Privacy that translates as autonomy in healthcare choices. If it is an inviolable fundamental right, then it is sacred and an obligation of the state to protect it.

The subject has been over legalised by us. We think it is euthanasia when it isn't. This is something actively done where the physician administers a lethal injection, with an intention to kill as an act of mercy. This is of course not what we are talking about. We think all cases are like Aruna Shanbaug which is a rare situation and we think courts have to intervene to not start or stop intervention which is not true. We undoubtedly have the right to refuse medical treatment. If the doctors think it does not make sense to institute treatment they have no obligation to offer non-beneficial treatment. Anything can be misused; it is about the patient rights and physicians' ethical obligations. These are difficult decisions but that doesn't mean you have to go to court. The 1969 rules of death determination are inapplicable in today's world. People want the best technological care in the world, while at the same time they do not want you to adopt the best ethical framework, which will only increase avoidable suffering.

The Supreme Court has recommended a procedure that is hard to follow in the real world where most withdrawal/withholding decisions have to be made within a few days. Therefore, such a procedure will not be widely utilised. Majority of our patients are dying in a state which they do not deserve, a lot of suffering in the last days is avoidable, but there is also a great opportunity to provide compassionate, cost-effective palliative care. We cannot deny people their rights otherwise we are denying people their very humanity. What is the mechanism of caring? Advance care planning is the modern standard of care. By the bed side the physician is supposed to ask himself this question – would I be surprised if the patient does not live after 6 months. Accordingly, he must discuss the reasonable goals of care with the patient/family.

Do Not Resuscitate (DNR) is at one end of the spectrum and euthanasia is at the other extreme of treatment limitation. Being truthful and transparent are very important for building trust between physicians and patients/families. A shared decision making enables both parties to arrive at the best course of treatment. The United States understood End of Life treatment limitation 40 years ago and we should not take another 40 years to understand its importance. The US Supreme Court in 1976

ruled that the right to privacy includes right to refuse medical care and that this right also extends to incompetent patients exercised through their legal guardian. 70% of patients in ICUs in the US have an end of life treatment limitation.

We need to reflect, are we caring for patients with a poor prognosis differently and appropriately.

Q – Brain dead patients are being ventilated when families do not give consent for donation. Do we remove the patient from the ventilator?

A – Dr. Mani – remove the patient from the ventilator. Just for technical arguments they have been clubbed together.

Q – I am practicing, but I am concerned as it not written anywhere that we can remove the patient from the ventilator.

A – You can ask yourself, are you practicing for the donor or the patient

A – We started to take off patients from the ventilator in 1995 when working in St. John's. Nothing will happen; no one will take you to court.

Q – You can switch off the ventilator, but majority of the critical care doctors refuse to switch off. Why has ISSCM not come out with a statement?

A – Yes, physicians are reluctant and they are uncomfortable to do it in many patients. The other case is they are ready to switch off the machines when the patient's family runs out of money.

Comment – There is an issue with certifying brain death. If a law comes out with a uniform determination of death, that would make it much easier. It is too early for India to issue donation after cardiac death. In the case of Aruna Shanbaug's case if she was brain dead we would have taken her off the ventilator. The Law was framed not to facilitate transplants but to facilitate brain death.

II. Debate

Chairpersons – Dr. Joga Rao, Postdoctoral Research Scholar in Healthcare Law and Ethics, National Law School of India university, Bengaluru, India;

Dr. Julius Punnen, Senior Consultant Cardiac Surgeon, Institute of Cardiac Sciences Narayana Hrudayalaya Hospital, India

USA's position of whole brain death: Should it be followed in India?

Speaker – Dr. Sonal Asthana, HPB and Multi-organ Transplant Surgeon, Aster Integrated Liver Care (ILC) Group, Aster CMI Hospital, Bengaluru, Karnataka, India

Dr. Sonal Asthana began defining irreversible coma. The brain death standard adopted, states, loss of all functions of the brain including the brain stem. They included death with the loss of personhood. The uniform declaration of brain death in the USA occurred after brain stem death was already being practiced. The key difference is brain stem death is performed clinically. The cons of brain stem death and whole brain death the same. In India we follow the brain stem death criteria.

1. Death is a process – in the olden days they were extra cautious because patients would wake up after being certified dead.
2. Time of death – it is a social and religious contrast. It has got a lot to do with ourselves and how we define death.
- 3 Culture > Science – we think if we give people enough data they will make a rational decision. Brain stem death is a secular definition, but is affected by the

culture. I can put forth an argument that the soul is in the heart. We defined death in a way where the patient was unconscious. 4. Words matter – Be relevant to the most prevalent situations and practices, be uniform among people and situations, be adaptable to advances in technique and knowledge, be reliable in application, be acceptable to practitioners and the public.

UK's position on brain-stem death: Is it adequate?

Speaker – Dr. Vinay Kumaran, Liver Transplant and HPB Surgery Kokilaben Dhirubhai Ambani Hospital, Mumbai

Dr. Vinay Kumaran reviewed earlier case studies with the audience. Pointing out that all the patients who were said to have woken up after being declared brain stem dead, never actually met the brain stem death criteria. Earlier consent was taken as a list of organ donors or nominative representatives. In Wales it is not a hard to opt out, so the consent rate is still 72%. Many people said they would opt out. It is interesting that they do not declare a 2-month-old infant brain dead, but they accept organs for infant patients.

Comment – The Jahi McMath case is relevant to India. Jahi was a 13-year-old African American girl who suffered catastrophic brain injury following a routine tonsil surgery. She was declared brain dead on December 12, 2013. Her family rejected the brain death diagnosis alleging that the doctors were interested only in getting her organs. This is similar to what is being cited in India i.e. brain stem death is being certified only in the context of organ donation.

III. Kerala High Court judgement on non-directed donations and compensation: ethical challenges

Chairpersons – Dr. S.K. Mathur, HPB & Transplant Surgeon, President, Zonal Transplant Coordination Centre, Mumbai, Maharashtra, India;

Mr. C. E. Karunakaran, Trustee, National Network for Organ Sharing (NNOS), Chennai, Tamil Nadu, India

Judgement and protocol highlights

Speaker – Dr. Noble Gracious, Assoc. Professor, Dept. of Nephrology, Govt. Medical College, Thiruvananthapuram; Nodal Officer, Kerala Network for Organ Sharing, Thiruvananthapuram, Kerala, India

Dr. Noble Gracious spoke about the current organ donation statistics in Kerala and its state of affairs. Many people have begun advertising that they are seeking organs. The government wrote a circular to ban advertisements seeking organs and after about 30 petitions to the high court, they responded upholding the ban. There is a need for a centralised system. The court suggested that altruistic donations and non-directed donations may be the answer. We have requested the government to take steps to bring out guidelines. Unfortunately the medical community did not accept the true sense of this order. All the orders were dismissed, because the judgement could not move forward.

Points we need to focus on: is non-directed donation possible in our country, how can we protect the best interests of the donor, how we can ensure donor follow-up, will the donor be eligible for

health insurance in the future, what will be the compensation for the donor, who will cover the donor's health risks in the future.

Ethical challenges to the Judgement

Speaker – Dr. Philip Thomas, Transplant Surgeon, Renaissance Transplant Institute, Texas, USA

Dr. Philip Thomas said that the law follows ethics and needs an enforcement mechanism. The state government has to change the law and the government orders. Most judges in democracy will try to leave law making to the legislature and only interpret the law. Health is a “State” subject and the government is free to bring out legislations for the betterment of the public. The Kerala Government made a law that they cannot enforce. The law is like the Bible, the law was made for man and man was not made for the law. Indians are the most litigious people on the planet. It is possible to adhere to law and violate ethics. All progress ultimately runs the risk of breaking the law. We are in a situation where you are going to tangle with law. The difference between nurses and doctors, is that nurses do not want to go to court. If you work as a transplant coordinator you need to be ready to defend what you are doing in court. The unique situation in Kerala is that it has almost 100% literacy, they should know the law. Lack of knowledge of the law is not an excuse, but we know the law and avoid ethics.

The fear is not that I shall be taken to court, but that the judge will not be qualified to judge properly. An ‘amicus curiae’ (expert panel comprising Transplant doctors, ICU doctors, senior judges, members of Press) to aid the government and courts in India may help.

Q – Was the court aware what a slippery slope compensation can become?

A – The judge might not have gone through the WHO Guiding Principles. The Spanish delegation that came to Kerala was critical of the issue of compensation.

Q – Let altruism be allowed from the rich to the poor.

A – Altruism is always compensated – rich or poor, an altruistic donor acquires a better self-image than the average person. In the US the living donor is compensated by getting an enhanced number on the waitlist if he were to end up with organ failure.

Comment – Increasing the deceased organ donation rate does not mean that things are being done incorrectly. The only way you can find fault with somebody is if he was doing his work wrong. With regard to organ distribution, in fact a lot of the organ flow was from private to government hospitals in Kerala. Regarding brain-stem death certification, the one thing Kerala could have done was to have an independent audit of all the brain deaths by an invited panel from outside Kerala. The problem with the accusations is that it is all based on unfounded facts. If we are not careful Kerala's story is going to repeat itself in other states.

IV. Brain-Stem Death protocols: Help or Hindrance?

Chairpersons – Dr. Peush Sahni, Professor and Head, GI Surgery, All India Institute of Medical Sciences, New Delhi, India;

Dr. Sonal Asthana, HBPa and Multi-organ transplant Surgeon, Aster Integrated Liver Care (ILC) group Aster CMI Hospital, Bengaluru, Karnataka, India

Presenting the Protocol

Speaker – Dr. S. Sudhindran, Clinical Professor in Transplantation and Gastrointestinal Surgery, Amrita Institute of Medical Sciences and Research Centre, Kochi, India

Dr. Sudhindran's presentation covered all aspects of the protocols to be followed in case of brain-stem death. While covering the various steps of brain-death certification Dr. Sudhindran emphasized the concept and criticality of brain-stem and the need to study the signs of brain-stem death with caution. He further answered pertinent questions such as how to do apnoea test, when to stop the test, when to do ancillary tests and highlighted the documentation required for the tests. On a closing note, Dr. Sudhindran raised his concerns about the recent Government Orders issued in the state of Kerala that reflect concerns about the brain-stem death certification process and allow videography of the process.

Does the Protocol violate privacy and should it be challenged?

Speaker – Dr. Umadethan, Professor and Head of Forensic Medicine at Amrita School of Medicine, Amrita Institute of Medical Sciences (AIMS), Kochi, India

Dr. Umadethan challenged the protocols as presented earlier.

He made his presentation on the brain-stem death protocols. His presentation inquired into whether brain-stem death protocols are a violation of privacy. In building his case, Dr. Umadethan highlighted the difference of opinions that exist with respect to the effectiveness of apnoea test and suggested that a panel be put together to evaluate and revise protocols as discussed. While, Dr. Umadethan could be seen taking a strong stand against violation of patient's privacy, he could also be seen stressing on the need for transparency in the protocols. He further highlighted that times have changed in Kerala and that patients are increasingly viewing doctors with suspicion. He concluded with several recommendations including effectively tapping the organ pool and promoting priority distribution of organs.

Much of the debate and discussion that followed was fuelled by questions around brain-stem testing and the videography permitted for the same in the state of Kerala. There was a common consensus about videography being a violation of the patients' privacy.

4:30PM-5:30PM

Topic – Lessons from the UK

Chairpersons – Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation; Urologist and Transplant Surgeon, Madras Medical Mission Hospital, Chennai, India

Dr. Avnish Seth, Director, Fortis Organ Retrieval & Transplant (FORT) Gurugram, India

Is Organ donation and transplantation a reality for everyone in an unequal world? Lessons from UK

Speaker – Prof. Gurch Randhawa, Professor of Diversity in Public Health & Director, Institute for Health Research university of Bedfordshire England, UK

Prof. Gurch Randhawa presented on the topic of organ donation and transplantation for everyone in an unequal world. The session was built around lessons from the UK. Prof Randhawa approached the diversity in UK's populations from two different angles (i) impact it has on demand for organs and (ii) the organ donor/recipient disparity. He further presented the findings of research done in the UK which suggest different health concerns among different diasporas, transplant tourism, reduced opportunity for transplantation and poor end-of-life care. Based on the findings, Prof Randhawa identified an intercultural approach to organ donation (based on a deep understanding and respect for all cultures) as the potential way forward. While discussing the Organ Donation Task force 2008, Prof Randhawa emphasized staff training and public outreach. The key takeaway from the session was the need to promote engagement of multi-ethnic and multi-faith communities. Community-led, community funded programmes were identified as more successful in gaining public trust. Other recommendations included: (i) utilizing social media (ii) approaching colleges (iii) involving donor families and local level politicians for community-based campaigns.

The discussion that followed the lessons from UK, primarily between Dr. Nundy and Prof Randhawa was about the attitude towards donation. Observations were made about the willingness to receive as against the willingness to donate. The potential of the 'opt-out' system was discussed in light of improving willingness to donate.

Ethical considerations in brain-stem death testing and organ donation in pregnancy: Protocols in the UK

Speaker – Dr. Sridhar Nagaiyan, Senior ICU Consultant, Kauvery Hospital, Chennai and Former NHSBT Regional Director for Organ Donation, Midlands, UK

Dr. Sridhar Nagaiyan covered the topic based on protocols in the UK. Dr. Sridhar drew attention to the risk matrix on the subject of organ donation in pregnancy. He stressed that while the probability of such cases maybe rare, the consequence or impact of such cases can be huge. He further explained that the process of organ retrieval from a pregnant donor after brain death would cause the foetal heartbeat to cease and the foetus to subsequently die; thus making this a delicate situation that concerns the life of the unborn. In conclusion, Dr. Sridhar listed a few key aspects of the protocol in case of organ donation in pregnancy where the decision was made not to support a viable foetus which included: (i) that donors must only proceed as donation after circulatory death donors and (ii) that both maternal and foetal death must be established.

At the end of the session, Dr. Benita Padilla enquired about the frequency of such cases. For which, Dr. Sridhar quoted 1%-2% as an approximate percentage for such cases in a year. The discussion

ended with a Transplant Coordinator from the Apollo Group of Hospitals sharing his experience of facilitating donation for a pregnant donor after circulatory death with the consent of the family.

Indian guidelines on pediatric brain death testing: Should it include anencephaly and organ donation

Speaker – Dr. Bala Ramachandran, Head of the Department, Pediatric ICU, Kanchi Kamakoti CHILDS Trust Hospital Chennai, India

The session focused on anencephaly and organ donation. The speaker, Dr. Bala Ramachandran provided an insight into anencephaly and what it looks like. He then traced the history of donation from anencephalic babies from the year 1967 and cited cases of such donations from across the world up until 2015. Dr. Ramachandran further discussed the ethical concerns around modifying brain death criteria to include infants with anencephaly. Citing the AMA code; Canadian pediatric society's position statement (2005) and the UK's Guidelines for organ donation in anencephaly (2016), Dr. Ramachandran concluded that donation from anencephaly babies should be allowed if the parents wish it, *after* the declaration of circulatory death. He also emphasized on the need to utilize existing donor pool optimally.

Chairperson Dr. Sunil Shroff thanked Dr. Bala Ramachandran for the educative session and further appreciated the clarity with which the content was put together. Dr. Shroff then recounted a recent incident in Chennai where two sets of parents had willingly donated organs from their anencephalic babies (after their death).

5:30PM-6:30PM

Topic – Look who's talking?

Chairpersons – Dr. Benita Padilla, Past President, Philippine Society of Nephrology; Member, WHO Organ and Tissue Transplantation Task Force; Nephrologist and Member, Philippine Board of Organ Donation and Transplantation, Philippines;

Dr. Dominique Martin, Past Co-chair, the Declaration of Istanbul Custodian Group (DICG) Senior Lecturer in Health Ethics and Professionalism, School of Medicine, Faculty of Health, Deakin University, Australia

Social media, organ donation and transplantation: Ethical challenges and solutions

Speaker – Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation; Urologist and Transplant Surgeon, Madras Medical Mission Hospital, Chennai, India

Dr. Shroff spoke about the ubiquitous presence of social media and the impact that messages on social media could carry. He quoted examples of the ALS Ice bucket challenge and several other successful online campaigns that went viral. Social media was presented as a good medium to create awareness and raise funds. At the same time the perils of the medium were also elucidated through examples of online kidney rackets and websites that function as middlemen for kidney sale. Dr. Shroff further brought to light the ethical problems that transplant activities get exposed to due to social media. Such problems include breach of confidentiality and privacy. The presentation concluded with due emphasis on the need for guidelines for social media usage and policy intervention to support the same.

The discussion on the presented topic was largely around how crowd funding for medical causes work. Dr. Sonal Asthana briefed that organizations and hospitals involved in crowd funding have a mechanism in place to allocate and utilize excess funds raised and to compensate for any shortage of funds if any. Dr. Shroff subsequently stressed on the need to verify information and details of the organizations to ensure validity.

Debate

I. National Organ donation pledge registry in India: Will it increase donation rate and is it a step in the right direction?

Speaker – Dr. Avnish Seth, Director, Fortis Organ Retrieval & Transplant (FORT) Gurugram, India

Dr. Avnish Seth was the first among the two to present his arguments. He began with the principal question – ‘*So why don’t people donate?*’ and subsequently established the lack of awareness about the topic. He then argued that pledging organs would lead to increased awareness and vice-versa. Dr. Seth further listed a few reasons as to how pledging could help. He said that a pledge registry would (i) get the nation to start thinking about donation; (ii) prove to be a multiplier effect and spread the message of donation; (iii) keep organ donation in the news and (iv) make counseling for grieving families easier. Dr. Seth further discussed the opt-in and opt-out organ donor registries and provided examples from Germany and USA. He finally concluded with some recommendations on how to make pledging more effective. His recommendations included effective nudging and campaigning to make it normal to donate rather than projecting it as exceptional or heroic.

II. National Organ donation pledge registry in India: Is it an expensive exercise that is likely to go nowhere?

Speaker – Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation; Urologist and Transplant Surgeon, Madras Medical Mission Hospital, Chennai, India

Dr. Shroff’s arguments against national organ registry were primarily around the expenses the exercise would entail. His arguments were built on data and numbers that reflected that the expenditure allotted for public health would be crucial for basic healthcare facilities rather than investing in the organ registry. He further presented that servicing the national pledge registry would be a tedious exercise and would require extensive infrastructure and costs. Additional concerns raised included storage and protection of data provided by willing donors and cost of issuing donor cards. He finally questioned the end result of the elaborate donor registry and left the audience to ponder about whether the registry should be seen as an urgent and crucial healthcare expense.

4th December, Day 2 Proceedings

Day 2 – Morning Session

Theme – Organ donation and transplantation in an unequal world

Welcome and overview of the symposium

Speaker – Dr. Sanjay Nagral, Director, Dept of Surgical Gastroenterology, Jaslok Hospital & Research Centre, Mumbai, Publisher, Indian Journal of Medical Ethics, Member Board of Councillors, DICG
Dr. Nagral welcomed the audience and gave a brief introduction about the symposium and DICG (Declaration of Istanbul Custodian Group).

Speaker – Dr. Dominique Martin, Past Co- chair, the Declaration of Istanbul Custodian Group (DICG); Senior Lecturer in Health Ethics and Professionalism, School of Medicine, Faculty of Health, Deakin University, Australia

Dr. Dominique started by explaining why the Declaration of Istanbul was created and who created it. The Declaration was created to address the urgent and growing problems of organ sale, transplant tourism, and trafficking in organ donors in the context of the global shortage of organs. The Declaration and the work of the DICG are supported by The Transplantation Society and the International Society of Nephrology who funded this symposium. More than 130 organisations, including MOHAN Foundation, have formally endorsed the Declaration. She explained the definitions in the 2018 edition of this Declaration and its principles. The Declaration has been translated into Hindi by MOHAN Foundation.

9:20AM-10:40AM

Session 1: Organ trafficking and the role of health professionals

Topic: Overview of organ trafficking in South Asia (Case studies)

Chairpersons- Dr. Kishore Phadke, Paediatric Nephrologist, Convenor, Jeevasarthakathe, Bengaluru, India;

C.E. Karunakaran, Trustee, National Network for Organ Sharing (NNOS), Chennai, India

Philippines

Speaker - Dr. Benita Padilla, Past President, Philippine Society of Nephrology; Member, WHO Organ and Tissue Transplantation Task Force; Nephrologist and Member, Philippine Board of Organ Donation and Transplantation

The number of people with end stage organ failure is rising in Philippines, and is leading to an increase in the number of people seeking transplants. Some resort to black market to avail such treatments when there is unavailability of organs. There are numerous advertisements online for organ sale which should be prohibited. The written standard procedures for transplantation approved by the hospital managements do not have enough details on responsibilities and alert indicators that would effectively detect and validate crucial signals on organ trafficking. The ethics committee of the concerned hospital raised some important weaknesses of the DOH programs and systems especially regarding orientation and training of the members of ethics committee

nationwide. In Philippines, referral has been given to the inter agency council against trafficking, but there is no action from the department of justice until now. Dr. Padilla recommended that all transplants to foreigners in Philippines should be reviewed by the National Transplant Ethics Committee.

India

Speaker - Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation; Urologist and Transplant Surgeon, Madras Medical Mission Hospital, Chennai, India

India is the largest living kidney transplant country in the world but the question arises as to why does organ sale happen despite a tough law. The reason cited by Dr. Shroff was that organ failure patients use the law to find instant affection to a stranger who is willing to donate his/her organs for money and later the same person claims that he was duped and not paid enough money for the organ. The obstacles in the initial years were largely related to delayed adoption of the Transplantation of Human Organs Act (THOA) in different states. In the later years THOA's clause on unrelated living donors was widely exploited to further commercial dealings for transplant. Different scams and cases of kidney rackets were also highlighted.

Questions

1. In Philippines whose responsibility is it to establish the relationship between the donor and the recipient?
2. What is the role of embassy in case of foreign recipients?
3. In Philippines, how many transplants happen in govt. hospitals and how many in private hospitals?

Ethical concerns in organ selling

Speaker- Dr. Sumana Navin, Course Director, MOHAN Foundation, Chennai, India

The speaker started her presentation by discussing a case where a patient with end-stage organ failure had to choose between a life-saving organ transplant and legal principles. He chose to undergo a transplant using a paid donor. The case for organ sales and the case against organ sales - both sides of the argument were presented effectively, compelling the audience to think about the ramifications. She also spoke about the Iranian model of organ sale. A case scenario where there was professional tolerance of commercialism was also discussed. Some of the solutions offered to counter organ sales were prevention, deceased donor organ transplantation, fair and equitable organ allocation systems, and new therapies for organ failure (stem cells).

Question

1. What about coercive consent in living related donation?

Ans. Subtle coercion is an issue that must be addressed in living related donation. Prospective donors must be given complete information about the risks so that they can make informed decisions.

Health professionals' responsibilities and barriers to addressing trafficking (Battling transplantation tourism through policy and legal reform in Taiwan)

Speaker – Dr. Daniel Fu-Chang Tsai, Physician and Bioethicist; Director, Center for Biomedical Ethics at National Taiwan University, Taiwan

The speaker started his presentation by explaining the transplantation tourism concept, which is the practice of travelling outside one's own country to receive an organ transplantation which often involves organ trade or trafficking. This accounts for around 10% of organ transplants around the world. This process is however discouraged by many international guidelines on the grounds of possible exploitation of the poor and vulnerable. The speaker then provided data on domestic and overseas kidney transplant recipients from 1994-2014. The features of overseas transplant groups were discussed. In Taiwan, the ethics and regulations have however led to reduction of transplant tourism. Council of Europe Convention against trafficking in human organs was also discussed. Brief knowledge about how laws in Israel and Spain are criminalising transplant tourism was provided. The Asian Taskforce on Organ Trafficking - Taipei Recommendation of January 2008 was also discussed.

11:00AM-12:30PM

Session 2: Ethical risk management in living organ donation

Chairpersons - Dr. Philip Thomas, Transplant Surgeon, Renaissance Transplant Institute, Texas, USA
Dr. Omprakash Nandimath, Professor of Law & Registrar, National Law School of India University, Bengaluru

Role of psychological evaluation of living donors in managing risk: Practical challenges for effective implementation

Speaker – Dr. Benita Padilla, Past President, Philippine Society of Nephrology; Member, WHO Organ and Tissue Transplantation Task Force; Nephrologist and Member, Philippine Board of Organ Donation and Transplantation

The speaker highlighted that many clinical practice guidelines have been published on the screening and follow-up of living kidney donors, across Australia, New Zealand, Continental Europe, North America, but none from Asia. She elaborated on how most guidelines failed to offer detailed guidance on operationalizing the key principles and that implementation tools were lacking. She listed four key aspects– consent, motivation, psychological health and social support for evaluation of living donors.

She also shared her practical experiences in handling living donation in her hospital in Philippines. She said that during screening of the donors it is important to ensure the quality of their consent. Enough information should be given to the donors to enable them to take the decision. Every transplant centre should have an independent donor advocate.

She also shared some of her experiences where there were disparities between the donor and the recipient. There were cases of absence of common language between the donor and the recipient. Assessing the motivation of the donor is also a challenge for the counsellors. The psychological health of the donor should also be duly considered before the donation. She then spoke about the two psychological assessment tools: ELPAT & EPAT.

Panel Discussion

Negotiating the local terrain in organ donation and transplantation - A case based multidisciplinary panel discussion on the special challenges in South Asia

Moderator – Dr. S. Nagral, Director, Dept. of Surgical Gastroenterology, Jaslok Hospital & Research Centre, Mumbai, India; Publisher, Indian Journal of Medical Ethics; Member Board of Councillors, DICG

Case Scenario 1

A 55-year-old male requires an early liver transplantation (Hepatitis C with tumor). The family was counselled about live donor liver transplant as there was a very low chance of a deceased donor organ being available in time. Both son and daughter were a match to their father. The son just joined a new job so he could not get leave, whereas the daughter even after telling her about the risks involved was interested and fit to donate. But her husband and in-laws opposed the decision. She was a mother of two small children. The husband refused and said who would look after them, when the hospital spoke to him for his consent.

Discussion

Ms. Urmila Mahajan – As per the law we need next of kin consent, but if husband is unwilling, as an individual and as a daughter if she is interested to donate to her father she should be allowed. She has a right to save her father's life.

Dr. Sonal Asthana – This would not go forward in Karnataka because the next of kin permission is absolutely important. It has not been challenged in court yet. But if it was the husband who was in this situation the case would still not go through if the wife did not give consent.

Dr. Astrid Lobo – Ethically speaking the woman has autonomy. There are two aspects. 1. She's an adult, whether male or female, an adult and has the autonomy to make a decision to donate or not. 2. It's always the woman while the son is off somewhere giving the excuse of a job. So if you weigh it, what is more important the son and his job or the mother and her two children.

Ms. Sohini Chattopadhyay – I also agree that it is the woman's choice to make. A question to doctors: would you intervene and ask the son to donate in a situation like this.

Dr. Nagral – Generally everyone was asked, but how strongly is it put is the question.

Dr. Anil Kumar – The statement, 'I am keen to save my father's life,' shows that the daughter is perhaps quite attached to the father. But with regard to our society the father should be equally attached. The father would not want to disturb the daughter's life. If the daughter is so keen it will be allowed legally, interviewing the next of kin is just so that the next of kin is aware.

Dr. Nagesh Simha – I am speaking as a recipient, in my first transplant I received the organ from my wife. As a recipient you feel grateful and guilty. No one is happy to receive a transplant but when you are put in a situation when your life is at stake. The other way to look at it is I want the transplant as I want to live with my daughter for a longer time. In general daughters, are far more considerate than sons.

Dr. Nagral – It is very intimidating for the donor to be in situations like these, in a room with many people and a video camera and asking you questions. Can the authorisation committee methodology be different?

Dr. Lobo – What is the gender composition of the authorisation committee?

Dr. Kumar – It is essential that the authorisation committee has a woman member; it has already been mentioned.

Ms. Chattopadhyay – I have gone through two authorisation committees, they weren't imposing. I took my dad to three hospitals for his transplant and it was expected that my mom or I would donate most of the time. The global deaths of donors in the world are around 0.5%. I felt there was an unsaid coercion that either would donate.

Dr. Nagral – In this case the authorisation committee rejected the donor and the patient was put on the deceased donor waitlist.

Mr. Premdas Pinto – Beyond the legal, cultural and other aspects, we need to keep in mind the ethical point of view. Look at the issues where the autonomy has to be protected.

Case Scenario 2

A 62-year-old, senior executive with an annual income of 82 Lakhs (USD 1,20,000), needs a kidney transplant. His two sons live in the US and are not willing to donate due to 'professional compulsion'. He seeks permission for a second degree relative. His nephew happens to be working as a security guard in a neighboring state with an annual income of 2 lakhs (USD 3000) as the donor. The committee interviews the donor's wife who seems unaware of her husband's family members. There was a partial HLA match between the donor and recipient. The hospital Authorization Committee refers the matter to the state committee, who reject permission citing likely commercial dealing. The recipient builds a counter campaign through media, petitions the 'higher authorities' that it is not his fault that his nephew is a 'security guard'. The higher authorities finally grant permission.

Ms. Mahajan – We should not just look at their financial disparity, we need to look at their past and study their history. Has the uncle helped his nephew in the past for either education or family matters so that we can co-relate that they have been helping each other before the need of the organ came up.

Dr. Asthana – I can see it splitting in several ways, this being a feminist or inequality issue. We assess the donor independently; the donor may not be close to his sons which is not uncommon in India. We would study the dynamics and understand if there is actual closeness or not, if there is any commercial dealings and assess for an emotional closeness.

Dr. Nagral – The committee called the donor's wife and cross-questioned her about her husband's family relation. At this stage would you go by the interview of the donor's wife?

Dr. Kumar – If we do not find a near relation as defined by law, we then look for the association. If there is a long-term association proven, that case can then be approved. We all have the right to save lives. Sometimes transplant coordinators are trying to misguide patients just to create evidence.

Mr. Sivakumar – When the donor dependent is not aware of the recipient's family, probably during the initial discussion the family could have been ruled out. The coordinators are not misleading the recipient families to prepare forged documents; the transplant coordinators discuss all the documents with the donor family. But most of the time the transplant coordinators are the ones who are caught and held responsible.

Ms. Vrinda Pusalkar – We do not ever forge or ask patients to forge documents. The entire list of required documents is given to the donor and the recipient.

Mr. Premdas Pinto – On the face of it, there is no equitable relationship between the donor and the recipient.

Dr. Nagral – This is very typical and we have seen in the past, situations where the transplant coordinators are the ones who are finally trapped.

Dr. Sunil Shroff – Transplant Coordinators are easy targets, hence they are always caught.

Dr. Asthana – Clinicians know if the patient is not going to live and the transplant coordinators are informed. In our hospital we have a donor advocate. In the case of live donors, occasionally we have donors come back telling us that they do not want to donate.

Mrs. Bhavna Jagwani – If the wife is not aware of the nephew then that is evidence that they are not close.

Dr. Thomas Miller – This is an interesting turn on this case. If the couple came to Switzerland they are most likely to get the transplant done there without being questioned much.

Dr. Nagral – Why go to Switzerland, when Sri Lanka is much closer and no one will be questioned there.

Dr. Philip Thomas – Would the level of strictness vary from case 1 and 2? The patient can just stay on dialysis.

Mr. Simha – The Nephrologists most of the time constantly tell patients that it is alright to be on dialysis. But as a person who has been on dialysis, I can say that being on dialysis is terrible.

Mr. Pinto – The question, is the right of the recipient more important or the right of donor who may have had implications for the past so many years.

Dr. Lobo – What must the authorisation committee do, check if there was a financial disparity. Where committee failed was by not making decisions.

Dr. Kumar – Financial disparities cannot be the only cause for ruling out a donor. Recently a case from a hospital was given to the committee, old photographs were given. It was discovered that those were false photographs. The committee also observed their behaviour which led to gaining more evidence.

Case Scenario 3

A 27-year-old construction worker is declared brain dead in the ICU of a private hospital in a small city. The family is approached for donation. The consent for donating all the organs is given, but the family requests for a 'concession' in the hospital bill. Kidneys have been given to a local recipient. The liver and heart have to be transported, but the donor is unstable and organs need to be retrieved early. The cost of the flight is to be borne by the recipient which is around Rs. 6 Lakhs (USD 8500). The cardiac team is willing to travel in a chartered flight, but the top three recipients on the waiting list cannot afford the extra cost of flight, the fourth recipient is a foreign national and willing to bear all the costs. Can we go down the waiting list as an exception?

Dr. Lobo – As per the law you cannot go down the waiting list. Regarding the bill being waived, ethically it becomes an incentive. There are various ways to get help to raise funds.

Mr. Raghuram – It is the policy of the management to decide.

Dr. Asthana – Healthcare is expensive in a private hospital obviously.

Dr. Lobo – The donation should be done altruistically. We see a lot of cases in other countries but the government is paying for their transplants so this issue does not arise. I don't have an answer, but it is a serious problem.

Mr. Pinto – It can become like organ trading. The reality is that the private hospitals are charging really high.

Dr. Asthana - If you looking at it objectively we do not know how much a transplant costs.

Dr. Noble Gracious – If the donor's family does not give the consent for donation initially, but later agree to donate when the hospital offers to give a concession on the hospital bills, is it ethical?

Dr. Kishore Phadke – In some cases there some bad people who tell the family to not pay the full hospital bill and say we will see what we can do about it.

Dr. Asthana – As per the Indian law, we must give the organs to the Indians first.

Dr. S. K. Mathur – If the first 3 patients are from a government hospital and they say they cannot afford it is understandable but if they are getting treated in a private hospital they should be able to afford it. If not there are many crowd funding websites available, if this is the case, most likely the hospital is indirectly trying to allocate to the foreigner.

Dr. Vivekanda Jha – We are hiding behind the laws. One must pay attention to where ethics leads us. We should come together as a community for a broad range of problems. We should discuss the ethical principle behind these situations. We should discuss what the right principle is and not what the law is.

Day 2 – Afternoon Session

Barriers to equity in donation and transplantation

Chairpersons – Dr. S. K. Mathur, HPB & Transplant Surgeon, President, Zonal Transplant Coordination Centre, Mumbai, India;

Dr. Noble Gracious, Nodal Officer, Kerala Network for Organ sharing Thiruvananthapuram, India

a) Inequities in deceased donation: Impact of end-of-life healthcare costs on decision-making

Speaker – Dr. Dominique Martin, Past Co- chair, the Declaration of Istanbul Custodian Group (DICG); Senior Lecturer in Health Ethics and Professionalism, School of Medicine, Faculty of Health, Deakin University, Australia

Dr. Dominique Martin opened the session with her presentation on inequities in deceased donation. The primary focus of the presentation was on the impact of end-of-life healthcare costs on donation decision making. She raised pertinent questions on the ethical implications regarding impact on poorer patients. One of the pressing questions was about the financial support that is provided by governments to preserve opportunities for donation as against providing lifesaving care for critically ill patients. She highlighted the underlying concern as to the way the poor are being treated. In conclusion, Dr. Martin listed possible solutions to the problems of inequities in deceased donation. While she stressed on removing financial barriers to deceased donation by the poor, she also emphasized on the need to support and remove financial barriers to organ transplantation for the poor. She further advocated promoting deceased donation by wealthy, avoiding financial incentives and addressing potential conflicts of interest in end-of-life and deceased donation decision making.

b) Inequities in access to transplantation services: Impact of costs of dialysis, surgery and post-transplant care

Speaker – Dr. Vivekanand Jha, President-Elect, International Society of Nephrology; Professor of Nephrology, Head of Department of Translational and Regenerative Medicine, Officer In-charge, Medical Education and Research Cell at the Postgraduate Institute of Medical Education and Research, Chandigarh)

Dr. Vivekanand Jha presented on the topic of inequities in access to transplantation services. He approached the topic from the perspective of costs of dialysis, surgery and post-transplant care. Dr. Jha opened his case with statistics on the number of transplantations and dialysis received worldwide and the number of organ trafficking cases reported across the globe and established that the gap between need and availability is greatest in Africa and Asia. He further argued that transplant activity in a country increases with the wealth of country. While recording that kidney transplantation is associated with catastrophic out of pocket expenditure in India, Dr. Jha raised questions around new treatments and access to the same; thereby establishing that the system functions in such a way that the affluent and privileged gain from higher rate of accessibility. He additionally highlighted that the state subsidy of dialysis does not provide financial risk protection. In

conclusion Dr. Jha elucidated that treatment costs are the major barriers towards access to transplant and must be addressed.

c) Inequities in organ allocation: Impact of allocation protocols favouring private sector

Speaker – Dr. Elmi Muller, Professor of Surgery, University of Cape Town, South Africa; Past Co-chair, the DICG; Councillor, the Transplantation Society; Past President, South African Society of Transplantation

In the third segment on '*organ donation and transplantation in an unequal world*', Dr. Elmi Muller presented on the topic of inequities in organ allocation, with due focus on impact of allocation protocols that favour private sector. Dr. Muller approached the topic entirely from the perspective of South Africa. By mapping and presenting the economic and healthcare situation of South Africa, Dr. Muller evidentially recorded that the transplant facilities and number of transplants were increasingly growing in private sector, while the state hospitals had remained static. Finally, in sketching the ground reality Dr. Muller cited that transplantation is not a priority for the state and that the emphasis is on primary health care. At the same time, she opined that private hospitals making business decisions should be respected. In conclusion, finding the middle ground and the need for shared waiting lists were highlighted as the need of the hour.

Discussion

Dr. Dominique Martin reiterated that extra efforts are made for people who could be made donors, but providing lifesaving health care is not pursued with the same vigor. She emphasized that this creates mistrust. She argued that issues other than transplantation are not taken as seriously and further stated that transplantation should not be the only healthcare goal.

Subsequently, Dr. Jha answered a question from the audience as to why the Government does not prioritize high cost treatment. In answering the same, Dr. Jha said that the Government is focusing on dialysis and that committing to dialysis is investing in high cost treatment. But then he agreed that the concern circles back to equality and distribution.

Tangentially, the question of leaving the Government's accountability out of the picture with increased emphasis on philanthropy in transplantation was flagged by Dr. Sanjay Nagral. The responses to this raised question were in consensus. The panel and speakers agreed that in developing countries primary healthcare is the priority and that there is a strong public health rationale behind it. There was further agreement in acknowledging that even though vision maybe tunneled; it all comes down to making fair choices. Dr. Nundy concluded the session with his remarks on transplants not being top priority in India and that the primary goal is to achieve equal distribution of healthcare services.

Law and Policy in promoting ethics and equity

Chairpersons: Dr. Anil Kumar, Additional DDG, NOTP Programme Officer, National Organ & Tissue Transplant Organisation (NOTTO), New Delhi, India;

Dr. Samiran Nundy, Surgeon, Academic & Writer, Ex Dean Gangaram Institute of Postgraduate Medical Sciences, New Delhi, India

HOTA & access to transplantation: impact and challenges

Speaker – Ms. Dhvani Mehta, Senior Resident Fellow, Vidhi Centre for Legal Policy, Delhi, India

The first speaker of the session was Dhvani Mehta from Vidhi Centre for Legal Policy. She presented on the Transplantation of Human Organs Act and probed the impact and challenges with respect to access to transplant. The major handicap as highlighted by the researcher was the lack of sufficient data which made a scientific approach to study impact rather difficult. She affirmed that with available data it would be difficult to map the trajectory and have evidentially supported conclusions. Therefore she presented impact from three broad perspectives: (a) popular media (b) news and (c) court cases. Summarizing the observations across the three perspectives, Ms. Mehta highlighted the challenges to access and emphasized the need to improve conviction rates under THOTA; to create a functioning medical regulatory framework and to decriminalize the victims of organ trafficking to promote reporting of the crime.

Financial incentives for donors and donor families

Speaker – Alexander Capron, Scott H. Bice Chair in Healthcare Law, Policy and Ethics, Professor of Law and Medicine, Keck School of Medicine; Co-Director, Pacific Center for Health Policy and Ethics, University of Southern California, USA

Dr. Alexander Capron dwelled on the ethical debate around providing financial incentives for donors and donor families from an international perspective. While strongly advocating against financial incentives, Dr. Capron broke down his arguments with three quintessential questions (a) Why is deceased donation important for equity? (b) Why is financial neutrality essential for equity? (c) Financial incentives vs. equitable treatment of potential organ recipients to incentivize deceased donation. On a closing note, Dr. Capron emphasized that payments based on the donor having “donated” organs are the antithesis of charity and that calling payment a charitable gift cannot disguise that it is not generosity but exploitation.

Discussion

Dr. Daniel posed a question to Dr. Capron about the funeral reimbursements practiced in some countries. He questioned if it can be equated to monetary rewarding and whether it could be considered permissible. In response, Dr. Capron said that when one pays for organs, the families go on and fight and that the honour is taken away from the good act. He reflected on the possibility of people asking how much does one get for the donation and thereby see the act in bad light. To support his argument, he further stated that when the breadwinner dies, families suffer, irrespective of whether the person is a donor or not.

Dr. Nundy recorded his opinion on financial incentives and remarked that the Government of India's health care initiative Ayushman Bharath would cover everyone in need and posed the question - Why not leave it at that. The other aspect that appeared to concern most people in the panel and the audience was misleading information circulating in the media. The need to be careful in the way transplant issues get represented was flagged as essential. Dr. Capron concluded the discussion with a concern that problems around transplant were being dealt with only when there is a crisis and that there is a dire need to take preventive measures.

Legislative Change: how it can make a difference (Case Studies)

Speaker – Dr. Benita Padilla (Philippines)

In this session, Dr. Benita Padilla presented the transplant legislation in Philippines. In comparing the various forms of consent, she remarked that a soft-opt out is preferred against presumed consent. She further added that even though the legislation around brain death is clear, it remains hard to gain acceptance. She briefed that despite having legislation in place, problems continue to persist. Therefore, implementation was the central issue. In conclusion she opined that a universal health care system will remove some of the reasons to sell organs like kidney. While acknowledging the similarity in the transplant scenario in India and Philippines, Dr. Padilla was posed with questions around lack of trust in private sector doctors and healthcare corruption in Philippines. She asserted that the fear and lack of trust is there when registering as a donor; and the fear is that, if the doctor sees the donor card he wouldn't save the potential donor.

Speaker – Dr. Elmi Muller (South Africa)

In contrast to the other presentations on transplant legislation, Dr. Elmi Muller took a case study approach for her presentation on South Africa. The case study that she primarily focused on was the Netcare case which was around 1999 – 2001. She stated that Netcare was the largest private hospital in South Africa at that time. She presented that the hospitals were approached by Israeli brokers and that a deal was subsequently struck. It was reported that the Israeli brokers identified recipients from Israel, donors were identified from Brazil and that the paperwork transferred to Netcare. During investigation it was said that the doctors at Netcare were not aware of the deal. Dr. Muller substantiated that such large-scale scandals helped define the transplant legislation as it is in South Africa.

Speaker – Dr. Mohammad Shakib Uz Zaman Arefin, Kidney Foundation, Dhaka, Bangladesh

As the last presentation for the day, Dr. Mohammad Shakib Uz Zaman Arefin, presented on legislation and transplant in Bangladesh. He provided an overview of the socio-economic background of Bangladesh and highlighted that out of pocket expenditure in cases of ESRD care was 80%. He further highlighted that most kidney transplant centers in Bangladesh were private. He subsequently informed the audience that lack of access to transplant, and death due to the same was alarming. Dr. Arefin then traced the original 1999 transplant law in Bangladesh to the recent amendment bill in 2018. He highlighted that the Brain Death Committee and National Cadaveric Transplantation Committee were formed as part of recent developments. In closure, Dr. Arefin was asked if non-

relatives were not allowed to donate. He affirmed that they weren't allowed to donate as per the Bangladesh transplant law.

Discussion

The discussions continued around brain death and organ donation being linked which brought back the question of when to withdraw treatment/ventilation. Dr. Alexander Capron opined that only a clear definition of death can ease the ventilator dilemma.

Dr. Nundy questioned Dr. Muller if in South Africa people were willing to consent to deceased donation. Dr. Muller responded that the decision did not appear to be influenced by demographics or race and she further highlighted that the younger generation was more willing. Following Dr. Muller's comments, an audience member linked Tamil Nadu's increased deceased donation to persistence.

Closing Remarks

Dr. Dominique Martin thanked one and all for the fascinating two days of learning and sharing. She recorded her hope that every participating member would have had valuable takeaways from the session and would pursue promoting equity and donations in their respective ways.

Following Dr. Dominique Martin, Dr. Sanjay Nagral opined that talking is not going to be enough and that there are a lot of challenges that lay ahead. But, he asserted that such a conference is a unique step forward as it brings together different people working in transplant. He further recorded the apparent similarities in South Asian countries, with respect to transplants. He concluded that the South Asian transplant community is at a critical juncture and meetings like this play an important role and provide hope.



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