

Review Article

Organ and Tissue Donation in India: Towards Eliminating Confusions, Optimizing Resources, and Standing United

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Abstract: This paper stresses the need for eliminating confusions, optimizing resources and standing united in context of organ, tissue and body donation in India. The paper focuses on the plight of people who are required to fill up different forms for pledging to donate organs & tissues, eyes and body as a result of different National Health Programmes and diverse laws that govern donation of body or its parts in India. It advocates States to follow latest laws of the country to give benefits of legislative reforms to all the people of the country and reduce confusions when interstate organ sharing, transportation and transplantations are involved. It suggests renaming “National Organ Transplant Programme” to “National Organ and Tissue Donation and Transplant Programme” with a view to reduce confusions, bring in clarity and to do justice to the altruistic acts of people who donate organs and tissues to save lives and improve the quality of lives respectively. It discusses the need for optimal utilization of resources of various interrelated National Health Programmes and discusses the need for multi-programmatic approach to IEC component of organ and tissue donation. It suggests designating eye donation counsellors associated with National Blindness Control Programme to tissue/organ transplant counsellors akin to Multi -Purpose Workers scheme wherein Basic Health Workers were renamed and reoriented to become Multi -Purpose Workers following recommendations of the Kartar Singh committee in 1973. The paper supports involvement of nursing personnel and nursing training institutions for IEC activities given to understand their core competencies in this field. It stresses on consolidating efforts of different organizations, networks and societies that evolved on their own in the absence of well-structured national initiatives on organ donation and transplantation till 2009 and stresses the need for eliminating confusions that prevail as on date. It calls for integrated cohesive efforts on observance of Indian Organ Donation Day and shows the way for arranging events cohesively.

Keywords: Organ Donation and Transplantation, Optimizing Resources, Standing United, THOA-1994, Indian Organ Donation Day, National Organ and Tissue Transplant Organization (NOTTO)

INTRODUCTION

A number of people are struggling to add years to their lives which are not possible without donation of organs either from living donors or Brain Stem Dead Donors in India. Some of these patients have no choice except to wait for organ donation from deceased donors in India. Organ donation has become one of the focussed affairs of central government in recent years but there is a great need to focus on reducing confusions, putting national resources to optimal use and standing united through certain initiatives as described in this paper.

NEED FOR INTEGRATED APPROACH TO ORGAN, TISSUE AND BODY DONATION

There are different laws that govern donation of body or its parts in India. Body donation for educational and scientific use comes under Anatomical Act of India that was enacted in 1949 and adopted by all States of the Republic of India [1]. On the other hand Organ donation, the donation of body's vital organs for transplantation into people for treatment purposes has been legalized through THOA -1994 [2]. The focus of Anatomical Act is on donation of the whole body after natural death for scientific or educational purpose. The focus of Transplantation of Human Organs Act (THOA) – 1994 is on organ donation from living donors (kidney or a part of liver) and Brain Stem Dead

donors (kidneys, liver, heart, intestines and lungs) for treatment purposes of those patients who need organ transplant. THO amended Act 2011 focuses on tissue donation like corneas from eyes, skin, bones, ligaments, tendons and blood vessels which improve the quality of life for people [3]. Corneas of eyes can be transplanted into people to give them sight, skin can be used for people whose skin is devastated in fire, injuries etc., ligaments and bones can be used for orthopaedic patients for mechanical support and helpful movements of their bodies.

But as a result of these different laws, Form 7 of THOT Rules 2014 (pledge form) which is meant to register the will of people for organ and tissue donation does not contain a column for body donation [4]. People are willing to donate not only organs and tissues but bodies too. National Organ and Tissue Transplant Organization (NOTTO) call centre gets a number of calls where people explicitly communicate their desire to donate bodies after death [5]. But in absence of a column for body donation, such a will cannot be registered. There is a dire need for body donation too in India as anatomical departments of medical colleges do not get the required number of dead bodies for educational purposes as was reported by a number of faculty members of medical colleges and anatomical departments of this country during many awareness programmes on organ and tissue donation [6]. As on date we have three different pledge forms: one for body donation, another for eye donation (under National Programme for Prevention of Blindness) and third for organ / tissue donation (form 7 –that includes eye donation too). There is a need to have a single form for body, organs and tissue donation (that now includes eyes too). USA has Uniform Anatomical Gift Act (ULGA) in place according to which any person is allowed to register a will in a document or driver's license of gifting his body parts or body as an anatomical gift for organ or tissue transplantation, educational or scientific research that was initiated in 1968 [7].

There are a number of people who want to donate bodies. They don't mind whether their body will be used for transplantation or for medical, educational or scientific use. They simply want to donate to return some favours to humanity even when they have a better understanding of every aspect of such donations [5].

STATES NEED TO ADOPT LATEST LAWS OF THE COUNTRY.

As on date India comprises of 29 states and 7 union territories. Health is a state subject and when an act is passed it becomes applicable to all the union territories only. Same is true for organ donation and transplant. The THOA-1994 was passed by the parliament in 1994 and became applicable to all the union territories like Andaman and Nicobar Islands,

Chandigarh, Dadra and Nagar Haveli, Daman and Diu, Delhi (National Capital Territory of Delhi), Lakshadweep and Puducherry (Pondicherry). The states adopted this legislation over a period of several years [8]. Andhra Pradesh and Jammu and Kashmir has not adopted THOA -1994. The THO amendment Act-2011 has been adopted by three states only that is Manipur, Rajasthan and Maharashtra (DGHS NOTP -2015). The amendments were made to ease the process of organ and tissue donation all over the country. Until and unless state assemblies adopt the new amendments the situation is not going to change much in the country. Passing laws in state assemblies is not that easy as it requires political and bureaucratic will besides infrastructure and manpower. As on date some states follow old rules and some follow new rules that creates confusion too especially when it involves interstate organ allocation, sharing, transportation and transplantation of organs of Brain Stem Dead donors, swap as well as domino transplants [9].

“NATIONAL ORGAN TRANSPLANT PROGRAMME”NEEDS TO BE RENAMED AS“NATIONAL ORGAN AND TISSUE DONATION AND TRANSPLANTATION PROGRAMME (NOTDTP)”

India started National Organ Transplant Programme in 2009 [10], sixteen years after passing the THOA act in 1994 [2]. The THOA -1994 and its amended version THO amendment Act 2011 permitted retrieval, transplantation and storage of human organs and tissues respectively [3], National Organ Transplant Programme was started with budget allocation of 149 crores of rupees [11]. There is lack of clarity as to whether NOTP is National Organ Transplant Programme or National Organ and Tissue Transplant Programme even while going through one of the important documents of Govt. of India [12]. Also, transplantation can never take place without donation but the word donation is missing not only in the act but in the programme (NOTP) too. Having done this, we are undermining the altruistic acts of donations by people on whom our whole programme (NOTP) is dependent. With an aim to correct ourselves, signify donation and eliminate confusion it shall be vital to rename the programme as National Organ and Tissue Donation and Transplantation Programme (NOTDTP) to avoid misinterpretation and simultaneously emphasize on altruistic acts of donation too.

OPTIMAL UTILIZATION OF RESOURCES

A number of vertical National Health Programmes have been started in India that has number of strengths and weaknesses too. National Programme for Control of Blindness was launched in the year 1976 as a Centrally Sponsored scheme with 100% central assistance with the goal to reduce the prevalence of blindness from 1.4% to 0.3 % [13]. As on date it has 251 eye banks [14]. It had collected 57250 eyes against

a target of 50000 in 2014-15 [15], thanks to eye donation counselors who are instrumental to counsel the grieving family and motivate them to donate the eyes of their dead relatives. Also under Trauma Scheme of Govt. of India a budget of 732.75 crore in the 11th five year plan was earmarked for developing trauma care facilities in all the states and union territories along the golden quadrilateral highway corridor covering 13562 Kms [16]. Trauma care centers usually receive head injury patients hence are also the places where potential organ donors can be identified, diagnosed and maintained for organ retrieval. National Blindness Control Programme has vast experience in addition to manpower and infrastructure akin to the Trauma Scheme (Assistance to States for Capacity Building for Developing Trauma Care Facilities in Government Hospitals on National Highway) and National Organ Transplant Programme has a will to further the cause of organ and tissue donation. There are a few components in these three programmes which can be integrated not only for reducing the cost but for putting the resources to optimal use and making it more effective and relevant. In DGHS even if the top level senior officers are having few programmes under their jurisdiction, these programmes are from a wide spectrum of domains. It will be worthwhile to give all these three interrelated programmes (Eye, Organ, and Trauma) to a single officer so that some convergence is possible within these three vertical programmes. Convergence at top level not only for professionals but for the infrastructure, training and retraining of manpower available with organ transplant, trauma scheme and blindness control programme is necessary for effectiveness and optimization of resources and overall coordination of the programmes.

REDESIGNATING EYE DONATION COUNSELLORS TO TISSUE/ORGAN DONATION COUNSELLORS

Going down the memory lane we need to recollect how Kartar Singh Committee was constituted in 1973 to form a framework for the integration of various categories of health functionaries like malaria workers, basic health workers, vaccinators, family planning workers etc. The committee recommended an amalgamation of various categories of peripheral health workers into a single cadre of multipurpose workers (male and female). These various types of workers were later on designated as MPHWS (Male) on the introduction of a unique Scheme of Multipurpose Health Workers as per the recommendation of Kartar Singh Committee in 1973 [17]. They were given a smaller population to meet the health needs of the community by ascertaining health linkages with the local community. Getting clues from this, we need to convert eye donation counsellors / coordinators to multipurpose coordinators for organ and tissue donation rather than focusing on training of a new cadre of organ

transplant coordinators only. This will put them to use effectively.

MULTI-PROGRAMMATIC APPROACH TO IEC COMPONENT

We always focus on creating awareness on organ and tissue donation via a single national programme that is NOTP. Some relevance of information, education and communication of organ and tissue donation and transplantation can be seen in a number of other National Health Programmes too. We have national Trauma Scheme, National Programme for Prevention of Burn Injuries, National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases & Stroke (NPCDCS) [16] and IEC is an integral component of all these programmes. It shall be worthwhile to include IEC component on brain stem death and organ retrieval while developing IEC material in trauma scheme, skin donation in National Programme on Prevention of Burn Injuries (NPPBI) and organ donation in NPCDCS also.

There is a need to have multi-programmatic approach to the IEC component of organ and tissue donation. It shall be an added advantage to build in reciprocity in organ and tissue donation the way it has been done in Singapore, Chile, Israel and Japan [18-21]. Registered donors are assured priority in organ/tissue allocation in case they need an organ or tissue themselves. This gives meaning to the registration of will of the person and leads to fruitful results.

INVOLVING NURSING PERSONNEL AND NURSING TRAINING INSTITUTIONS

It is a well-established fact that nursing professionals are the only professionals who are imparted a very comprehensive training on health education. Not only B. Sc Nursing but even GNM students are well trained to give health talks, do role plays, develop health education material for creating awareness on various diseases and health programmes. The three year GNM and four year B. Sc Nursing training courses focus on health education throughout the course. Also in a few health awareness programmes that involved competitions by nursing and medical students it is seen that nursing students usually do well in comparison to medical students as was reported even by a few well known officials of DGHS. It is also important to note that unlike medical degree, nursing degree/ diploma teaches psychology, sociology, educational media and research extensively which makes them highly capable of healthful interactions with people. But it is extremely regretful that these very people are not involved in creating awareness or for developing health education material including material on organ donation. Doctors and nurses do not come to know about what is being taught to each other and the two do not get to know each other's roles and core competencies. As a result the larger proportion of

nursing manpower is rendered underused. There is a great need to understand educational background and core competencies of nurses and utilize their services and expertise in developing health messages on organ donation too and make the most of them as change agents in the society.

CONSOLIDATING EFFORTS OF DIFFERENT ORGANIZATIONS AND NETWORKS, STANDARDIZING SKILLS / PROCESSES AND ELIMINATING CONFUSIONS

In absence of any national initiative towards this great medical cause from 1994 onwards, different organizations, private sector, NGO'S, societies emerged and tried to move ahead at their own pace to increase organ donation for transplantation without any directions from the central government. When National Organ Transplant Programme started, it had no choice except to pick up the pieces together and take a leadership role in the country. In absence of expertise in the field it had the dual responsibility of leading and learning simultaneously. Media supported this cause vehemently. Times of India, a national newspaper took a week long initiative from 2013 onwards to promote organ donation. TOI along with NGOs like Multiple Organ Harvesting Aid Network (MOHAN) foundation and corporate sector encouraged people to pledge to donate organs. The campaigns touched hearts of people. Many other organizations like Shantanu, Gift of Life, Armed Forces Organ Retrieval and Transplant Authority (AORTA), Organ Retrieval and Banking Organization (ORBO), Dadichi Deh Dan Samiti etc. made efforts to motivate people to pledge their organs, tissues and even bodies [22, 23]. The Indian society of nephrology. The Transplantation Society, Indian Liver Foundation, The Indian Society of Organ Transplantation etc. evolved and worked towards this cause. These organizations took their own initiatives to create awareness, develop guidelines, and develop sharing and allocation policies etc. to meet the demand for organ transplantation.

The efforts put by these organizations and societies needs to be consolidated and standardized. Each skill and process involved in organ donation and transplantation requires to be standardized. The humanitarian people are willing to donate organs, tissues and bodies as well. The need of the hour is to stand united and be honest in our cause to improve organ and tissue donation.

Currently there are two national registries too, The Indian Transplant Registry of ISOT supported by Astellas Pharma India Pvt. Ltd [24] and National Organ and Tissue Transplant Organization (NOTTO) registry supported by GOI [25]. A common man gets confused as to which one is authentic and reliable as the mandate of these two registries is same.

COHESIVE EFFORTS ON ORGAN DONATION DAY

India seems divided on observance of organ donation day. Extensive Media coverage has been given to Indian Organ Donation day on 13th August every year from 2013 onwards by "Times of India" through various initiatives and involvement of various partners. Indian Govt. has also been observing Indian Organ Donation Day almost every year from 2010 onwards but there is either no coverage or limited media coverage given to this event. In 2015 also, India observed Indian Organ Donation Day twice on 13th August [26] and 27th November [5]. The former was preconceived and organized by "Times of India" with a wider publicity and weeklong media coverage and latter was organized by GOI. Consolidating efforts by media and GOI is possible and could be more meaningful.

ARRANGING EVENTS AND STANDING UNITED

USA has been organizing sports events like transplant games for a number of years which unites donors and recipients and touches the hearts of every person. We also need to conduct such events by involving sports ministry. It is heartening to mention that the highest gallantry award of India the Parm Vir Chakra (PVC) also signifies donation of body parts as it depicts the motif of Vajra, a weapon which was made with the bones of an omnipotent sage Dadhichi, who donated his bones to destroy a demon called Vrutasur [27]. Our PM has been vehemently preaching organ donation [5]. It shall be worthwhile to showcase to the nation the importance of organ donation through tableaux (Janki) on the eve of Republic Day on 26th January to give it a national platform and wide publicity. The tableaux either by Tamil Nadu Govt. that is doing very well in deceased organ donation or by MOHFW could show to the nation the contribution of families of organ donors who chose to give life to a number of families even at the time when they were grieving for their Brain Stem Dead relative.

CONCLUSION

There is a dire need to focus on organ donation by standing united and eliminating confusions. Optimal utilization of resources of various interrelated National Health Programmes, multi-programmatic approach to IEC component, designating eye donation counsellors to tissue/organ transplant counsellors, involving nursing personnel and nursing training institutions for IEC activities, adopting latest laws of the country, renaming "National Organ Transplant Programme" to "National Organ and Tissue Donation and Transplant Programme", consolidating and standardizing efforts of different organizations, networks and societies, observing Indian Organ Donation Day cohesively and arranging innovative events shall go a long way to help organ donation and transplantation in our country.

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