1. INTRODUCTION

All over the world there has been an increasing demand for organ transplantation surgeries. This is because of higher incidences of organ failures and increasingly successful outcomes of transplant surgeries. But for any transplant surgery, organs are needed from a willing donor. With the lack of adequate donors, today there are major organ crises.

The number of people on the waiting lists waiting for organs is ever increasing. The number of patients dying while on the waiting list is also increasing. Thousands of patients are denied better quality of life due to unavailability of organs. Many solutions have been suggested to solve this problem. [1]

These include education of the public and hospital staff regarding the need and benefits of organ donation, use of marginal donors, accepting paired organ donation, promoting the concept of "presumed consent”, applying the concept of "rewarded gifting" for the family of the diseased donor and also for the living donor, promoting organ donation taking into consideration the ethical, religious and social criteria of the society etc. If these suggestions are implemented it is believed that the organ shortage crisis will be eliminated and many lives will be saved through the process of organ donation and transplantation. [1]

The unavailability of organs for transplantation is leading to crises in organ transplant activity.

A National survey of organ donation related attitudes and behavior was carried out in USA. They state that men, women and children of different ages and ethnicities have had organ transplants in USA. More than 5,60000 transplant surgeries have been performed with increasing success rate. Many recipients today have survived for more than 25 years after their transplant. But the survey states that it is unfortunate that transplantation cannot be carried out for all those who need it because of lack of donors. [2]

As people become aware that transplant surgeries are not experimental but a viable form of treatment for organ failure, more and more people are registering for transplants. Thus the number of people on waiting list keeps growing. However the number of donors though growing is not keeping pace with this need. Thus the gap between donors and recipients is ever increasing with almost 100 waiting list deaths per week.
Hence a survey was sponsored by U.S. Department of Health and Human Services, Health Resources and Services Administration to find out the opinion and practices of U.S. population in relation to organ donation. The survey provided information on thoughts of the public regarding

- Support for donation
- Granting permission for donation
- Willingness to be donor
- Support for living organ donation
- Attitude towards presumed consent
- Attitude towards financial incentives to donors
- Beliefs related to organ donation
- Sources of information
- Donation of hands and face.

This study was then compared with the earlier surveys conducted in 2005 and 1993. This was able to show the trends and changes over time and evolution of public acceptance of the issue of organ donation. It was also able to give an idea regarding the impact of the outreach efforts on this issue. This would subsequently help shape public policies, outreach messages and campaigns targeting general population and specific subgroups.

Their findings were as follows. 94.9% of sample population were strongly supporting organ donation. 60.1% had granted permission for organ donation on their driving license, 32.1% by signing donor card and 29.7% by registering at their state registry. In all 62.3% had granted permission for organ donation by any of the above three ways. The reasons for wishing to be organ donor were cited to be wish to save another person’s life, not needing the organs after death and wish to do some good. 81% were also willing to discuss their wish to be organ donors with their families. 96.7% were willing to donate their family member’s organs if they knew that this was the wish of that person. 75.6% were willing to donate the organs of a family member despite not knowing the family member’s wishes. 93.5% were willing to be live organ donors for a family member, 85.4% for a close friend, 67.6% for a acquaintance and 54.7% for a stranger.

Some of the reasons for not being willing to be donors were given as being in poor health, need for more information, not being able to decide, being too old and not trusting the medical infrastructure who may harvest organs unlawfully or them not trying hard enough to keep person alive. Many also claimed medical reasons for the unwillingness,
not wishing to have body cut up or disfigured and the activity being against their religious beliefs. [2]

Respondents supporting presumed consent policy of organ donation were 51.1% while 46.6% opposed it. The reasons given for being against presumed consent policy were that such a decision should be individual’s decision, it felt like a violation of rights, felt presumed consent was unethical, it was against their religious beliefs and did not trust the government to follow policy in the right spirit. But in case policy comes into being 23.4% felt that they would opt out as a non donor. [2]

Regarding financial incentives being provided to the donors and / their families in the form of payment of funeral expenses, cash award to the donor’s estate or cash award to the charity of the family’s choice, 25.4% felt that this could make them more likely to donate. 63.6% felt that such incentives would have no effect on their decision. [2]

The important sources of information regarding organ donation were reported to be news coverage via television, radio, newspaper and internet, discussion with family members and friends, advertisements on television, motor vehicles office, movies and through the medical care professionals. The survey also investigated the various beliefs and misbeliefs of the respondents such as the necessity of all organs to be intact at the time of burial of the deceased, disfigurement of the loved one’s body due to organ donation, donor’s family having to pay extra bills, lesser likelihood of the doctors trying to save a registered donor, recipients often being undeserving people, organ donation being against their religion, inability to hold a funeral service for the donor etc. [2]

Thus the study in USA analyzed various factors for and against organ donation in an effort to know how to bridge the gap between the donor and the patient on the waiting list. Such a survey could bring out the misbeliefs prevalent among the people which could be challenging organ donation. This can be followed by medical education of the people to clarify these misbeliefs and thus encourage organ donation. The survey was also able to point out the factors that are favoring organ donation such as higher education. Throughout the survey it was found that college educated respondents were more likely to have a positive response to organ donation related activities. [2]

Discussing organ donation within the Indian scenario, KC Prakash states that today the non-communicable diseases account for higher morbidity and mortality compared to the communicable diseases. Disease such as chronic kidney disease is known to have afflicted almost 1.79% of the Indian population. In such cases replacement treatment in
the form of transplantation is not only most effective but also more economic mode of treatment. But the organ donation and transplant programme in India faces many problems.\textsuperscript{[3]}

One of these problems is the prohibitive cost involved in Organ transplant. The workup to a kidney transplant can cost minimum of Rs 30,000 to 40,000. The surgery itself costs Rs 2 to 3 lakh and thereafter the cost of immunosuppressant drugs initially costs about Rs 15,000 to 20,000 per month. Later the cost may be reduced to some extent depending upon recovery after the transplant surgery. In case of liver transplant this cost is about Rs 20 lakh.\textsuperscript{[4]} The finances for transplant are arranged mainly through family funds, taking of loan, selling property or through charity. Finances through insurance have not taken off in India.

Here Nagral and Amalorpavanathan states that healthcare in India is mainly dominated by the private sector. This is even more so in case of organ transplant surgery. Very few public hospitals limited to a few large teaching hospitals in metros have transplant programmes. Even kidney transplant is performed in very small numbers in public sector. Very few of the Maharashtra government’s large teaching hospitals currently conduct kidney transplants and less than 1% of the liver transplants in India have been carried out in the public sector. The prohibitive costs accord the transplant surgery a very low priority in the public health system. Thus transplantation is a complex and costly procedure with almost no state funding and most of the activity is being carried out in the private sector. Most of the donors and recipients are from private hospitals. The cost demands result in most of the organs obtained from deceased donor going to the rich. The authors state that it is imperative that the state removes this incongruity and makes transplantation accessible and affordable to all regardless of their ability to pay. This incongruity also makes it difficult to call for altruism in the form of organ donation from the public.\textsuperscript{[5]}

Nagral and Amalorpavanathan suggested that if transplantation is to be made available to all, social equity has to be built into our current distribution system. This needs political will and related administrative mechanisms. It should be made mandatory to allocate a portion of the organs obtained by organ donation to the public sector institutions. However this will have to be preceded by development of transplant facilities in the public sector which is presently lacking.\textsuperscript{[5]}
The reason why public sector hospitals do not have established transplant programmes could be because these hospitals do not see transplant surgeries as priority as these cater to very few patients. Perhaps with increasing experience in transplant surgeries, the pre- and postoperative investigations and hospital stay could be reduced and cheaper antibiotics and immunosuppressant drugs could be used reducing the costs involved. [4]

Cadaveric donation in India presently benefits the rich and serves a very minute percentage of the total patients who need the organs. Nagral and Amalorpavanathan state that we must strive to increase the organ donation rates, but we must simultaneously develop a healthcare system that is equitable and transparent that provides an advanced yet affordable healthcare system for all. [5]

Ignorance about medical conditions leads to diseases which lead to organ failures. Ignorance also leads to failure of transplanted organ in case patient was fortunate enough to get an organ for transplant if continuous immunosuppressant drugs are not taken as advised by the medical care professional. [3]

Haagen in his study on organ trafficking in India states that severe shortage of available organs, poverty and all pervading corruption has made India a fertile ground for organ trade. Large scale poverty has led to trafficking in organs. India has an abundance of desperately poor people for whom sale of a kidney represents a possibility to raise cash. India also has many rich patients in need of a kidney and some of the world’s best medical facilities to perform the surgeries. Haagen goes on to state that though trade of organs was prohibited in 1995 by the law, but the organ trade continues having gone underground. [6]

Chugh et al state that despite the Transplantation of Human Organs act in 1994, a large number of “commercial” transplants have been done in India. [7]

K C Prakash states that the ‘transplant’ facilitator who brokers the deal between the donor and the patient is the main person in unrelated commercial renal transplantation and his/her role needs to be strongly condemned. If the deceased organ donation is implemented in a proper manner, the problem of organ trade can be overcome by countering the scarcity of organs. [3]

Lack of organ donors is the biggest problem. Today India lives in form of small nuclear families. It is also home to one of the world’s largest population suffering from diabetes which can lead to organ failure. If there is no related donor willing to donate an organ, a desperate person would be lured by the easy option of unrelated donor. [3]
The success of organ transplantation depends upon the existence of an organ donor. Some of the hurdles in donor availability in India have been described by various authors. Living donation is an option for some organs, but the main source of organs is deceased donation which hinges on consent from family members. The act of such an organ donation needs the consent of the family which in turn depends upon how they perceive the credibility of the organ donation process in that region. This consent is also influenced by cultural, religious and political factors.\textsuperscript{[5]}

K C Prakash states that once the organ has been donated the next challenge is allocating the organ fairly among a very large pool of patients on the waiting list and in sharing organs between private and government hospitals. Many hospitals are not identifying brain dead donors. Communities in India are unaware of concept of brain death. Many neurosurgeons and neurophysicians refuse to certify brain death. Cities and few towns have good public and private tertiary care hospitals with necessary equipments, however most towns and all villages lack such hospitals and this has a negative impact on organ donation and transplant activity. Thus brain dead donors are essentially from big cities and few towns. The area from where a donor could be available is very much reduced. Besides donor availability the patients (potential recipients) from such areas have to travel long distances for treatment increasing their financial burden. The transplant facilitators need to be kept out of the process of organ donation.\textsuperscript{[3]}

Press and electronic media have confined their focus on negative aspects of organ donation and transplant. Instead it could be a facilitator. The energy being used in reporting kidney scams and sensationalizing them can also be better utilized to educate the public and promote deceased organ donation. Public needs to be made aware that transplants are a legitimate therapy for organ failures. Medical fraternity and society at large should shoulder some of the blame for not educating the public and their patients regarding organ donation.\textsuperscript{[3]}

K C Prakash suggested some possible solutions which may help the cause of organ donation in India.

1. Educating the public about organ failure, its prevention and possible solution in relation to organ donation. This could be done via simple lectures through public gatherings, in schools and to college students, or via simple articles in newspapers and magazines and through films. Icons of India such film stars and sports
person, politicians and other famous personalities could be requested to endorse organ donation.

2. Making changes in the law related to organ donation
3. Promoting of deceased organ donation.
4. Keeping the transplant facilitators away.
5. Effective use of media to spread the message of organ donation.
6. Including topics such as brain death and organ donation in school curriculum
7. Strict punishing of the wrongdoers who bring disrepute to the organ donation programme. In case there is a complaint of sale of kidney it is the transplant surgeon and/or physician who get arrested. In such a situation all those involved in this activity, with full knowledge that it was against the law should be punished. This should include the hospital administrator, the donor, the recipient and their relatives who are normally allowed to go scot free. If both donor and recipient are held responsible for illegal transplants, such transplants could be reduced and eliminated over time.
8. Promoting deceased organ donation with ‘presumed consent’ with associated education of the public
9. Solving of problem of finances by bringing in insurance, roping in philanthropists, getting more government help, requesting the pharmaceuticals to reduce cost or related medicines etc
10. Medical fraternity should take strong stand on this issue and start promoting the concept of brain death and deceased organ donation.\[3\]

Thus authors outside India as well as those within accept that today transplant activity is challenged by low organ donation rates and that organ donation needs to be promoted.

All over the world organ donation activity seems challenged by many factors such as religion, misconceptions about life after death, burial rituals, lack of trust in the medical fraternity and their ability to fight to save a patient willing to be a donor among many others. Different researchers are studying each or several of these factors that challenge and also that may be promoting organ donation and policies are being set by various governments according to findings of these research projects.\[8, 9\]

In India too there are many challenges affecting organ donation. However some states seem to be doing better than others in combating these problems and encouraging organ donation. While Maharashtra has a organ donation rate of 0.5 per million population the
southern state of Tamilnadu leads in organ donation activity with their rate of organ donation being 1.9 per million population. [10]

The present study was taken up to research into the challenges affecting organ donation in Pune Revenue division of Maharashtra. The study also attempted to find solutions to these challenges. Solutions provided by this research could be used to shape policies that could help bridge the gap between the patient on the waiting list and the donor by encouraging organ donation in this region.