

The urge for an organized and disciplined liver transplant program in Egypt

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Background:

Chronic liver diseases and cirrhosis leading to end stage liver disease (ESLD) has become a leading cause of death in Egypt during the past two decades. Together with other less common causes, chronic viral hepatitis, mainly due to chronic hepatitis C and to a lesser extent chronic hepatitis B, is the principal cause behind this reality. The prevalence of HCV infection in Egypt is alarming being estimated around 10% of the general population meaning that some 7-8 million citizens are HCV positive. The natural history of HCV infection implies that 20- 25% of seropositive patients will undergo spontaneous clearance of the virus and another 25% will live their productive life normally due to the slow course of the disease. However, the remaining half of the estimated figure (some 3.5 million patients) will suffer chronic liver diseases ending in ESLD. The development of liver tumors on top of liver cirrhosis adds to the problem. Within all the available lines of treatments, liver transplantation (LT) is the only treatment with the potential for cure facing this grave disease.

Unfortunately, the malpractice in kidney transplant in Egypt over the past two decades has led to a bad reputation with consequent public resistance to the concept of organ transplant as a whole in our country. The daily announcements in the newspapers seeking paid donors and the kidney trade that occurred during the 1980s and continued to date, have strengthened the beliefs that a respectable, serious and transparent organ transplant program is not possible in Egypt.

On the other hand, the situation is quite the reverse not only in Western countries but even in nearly all neighboring Arab and Islamic countries where organ transplant is being practiced and has become a reality. It is unacceptable for our country which has long been regarded as a regional leader in medical care and practice attracting patients from all over

the region and African continent to lose this position and stand behind. Organ transplant has become, beyond any doubt, the gold standard for cure of failing organs including heart, lung, liver and kidney together with bone marrow transplant with resultant cure and survival benefit.

A successful organ transplant program is advantageous to the local institution performing it, to the medical practice in the country at large with an inherent social and economic gain. As for the local institution, an excellent level of practice will be fulfilled in all specialties including surgery, anesthesia, ICU, internal medicine, radiology, laboratory and blood banking. This is because no one could afford to be behind and not to cope with the tedious and disciplined needs imposed by liver transplantation. It is a team work that puts everybody in the aimed zone, between the learning zone and the panic zone, with the maximum performance that could be obtained. A concept that is lagging behind in our country and it might be healthy to realize it. This, in a way, is a social benefit.

Nevertheless, the real social and economic benefits are for the huge number of patients with liver failure and malignancy and their families. Currently, these patients, who are usually young and in their productive period of life, are crippled cannot work and are repeatedly hospitalized for bleeding, encephalopathy, ascites control or for unfruitful supportive therapy. The cumulative costs following these repeated hospitalization is high that it breaks even or exceeds the cost of LT which is the only therapy that will return them to a normal quality of life with its impact on their families and the community as a whole.

The threatening expensive nature of a LT program is not a true threat. The argument for this is that the costs will drop with the gained increased experience, with the increasing number of cases being performed per year and

with the aimed national level organization replacing a sporadic institutional practice.

Egypt has been the Makah for all patients seeking good medical care in the Middle East, Africa and the Arab World. Although we have, at least partly, lost this status during the past 10-15 years, it is now our chance to regain our place and it is our belief that we can compete to our success in this field. This practice, if successful and well organized, will attract patients with chronic liver diseases in the region and thus could turn out to be a foreign currency revenue source to our national economy rather than being a burden. Moreover, most international medical and scientific directed funds would be interested to share and invest in a truly scientific national based program emerging from an unexplored field in this region.

Objectives:

- 1- To create an organization capable of controlling, organizing and managing LT in Egypt. A "national LT program" guarded by clear guidelines, regulations and restrictions is becoming a necessity in the absence of a transparent legislative law for organ transplant in our country. This program should be centrally managed by a supreme organization that have the power to nominate centers with the capacity to perform this practice according to pre-determined parameters, to turndown existing undisciplined programs and to nominate new centers. Moreover, this organization should review the results and compare it to the international ones, to register numbers of patients, morbidities and mortalities and to gather all centers annually to revise the guidelines and to tune the practice according to the newly occurring ever-changing indications.
- 2- A wider scope would be to create "Egypt Transplant" or "Egyptian Establishment for Organ Transplant" (EEOT) with the prospect to control all centers performing organ transplant including kidneys, livers and bone marrow in Egypt. These are just examples for organizations that could control and regulate organ transplant in Egypt aiming at success of this practice to the extent of attracting foreign patients from

neighboring countries to come over with their donors and undergo this highly skilled mode of therapy in our country. This will serve as a prestigious propaganda to the whole medical practice in Egypt as well.

Proposal for organization:

LT has started in Egypt by the end of 2001 performing only living donor LT (LDLT) as legislation of a cadaveric program is not feasible till now. It is both reasonable and desirable to make LDLT legitimate, organized and transparent at this time for two reasons. First, to show that LDLT is feasible, safe and effective. Second, to prove that such modality could be practiced guarded by the highest possible level of ethics, transparency and efficiency. The following parameters are proposed to fulfill this target:

- 1- Centers based on Geographical distribution: starting by 2-3 centers in greater Cairo serving central Egypt, Alexandria serving west of Egypt and Mansoura serving the Delta region, is only a proposal that could be discussed on a larger scale.
- 2- Nominating a maximum of 5-6 centers in the whole country, for a start, is important because it has been documented that a center performing less than 25-30 cases per year of such demanding practice could never build up a reasonable experience
- 3- Prerequisites: Setting up certain prerequisites for the potential centers that will be nominated in terms of infrastructure, equipment, setup, and well trained experienced and devoted full-time team.
- 4- Precise schedule: should be presented by the nominated center revealing the time needed to prepare and the on-board timing. A fixed protocol including a detailed methodology, a vision for the future with the intent to publish data regularly in a research based practice is a must.
- 5- Expected Cost per Case: a budget- related program should be fixed for every center. It would be unaccepted to perform higher or lesser number of cases than the agreed upon figure. A minimum of 25 cases per year should be considered.
- 6- Waiting lists: should be issued and repeatedly revised by the practicing center in collaboration with the supreme organization

following the known prioritization models universally accepted.

- 7- National registry: should be revised every 6 month documenting all cases performed in Egypt in view of indications, results and commitment to the schedule.
- 8- Combating Organ Trade: this could be accomplished by issuing a rule by the suggested organization that donors must be of the same nationality and blood related and to defer the emotionally related donor to a later stage when the practice becomes mature enough.
- 9- Ethical committee: Every center should have its ethical committee formed of medical personnel not related to organ transplant at all together with non-medical qualified personnel who will revise all steps of the practice and approve or reject every case before surgery in view of medical, technical and ethical considerations. The committee will have the right to question the team director or any other senior member about any unclear data or ask their justification for a given case. The decision should stay totally under control of the ethical committee in the absence of any external pressure. Alternatively, a regional

or even national ethical committee could be discussed although this will have its limitations.

- 10- Donor advocate team: In LDLT, the donor is very precious and it is unaccepted to expose a healthy donor to any danger or complications. Although minimal donor morbidities and sporadic mortalities have occurred allover the world, this did not stop LDLT from going on. Compared to the great benefit to the patients, their families and the whole community at large, the risk-benefit relationship was in favor of continuing the practice. Nevertheless, donor safety stays crucial and every measure should be taken to realize this. A proposed donor advocate team has been, recently, raised with the concept of defining the responsibility and adjusting the focus more on the donor. This team will be formed of members of the transplant team with clear job descriptions.
- 11- The supreme organization will have the right to turn down any center not fulfilling its target or violating the ethical or professional rules guarding this type of practice