Donor Organ Shortage Crisis: A Case Study Review of a Financial Incentive-Based System

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ABSTRACT

Introduction. Current organ supply system depends on altruistic noncoercive donation, which has failed to meet the demand of organ transplantation. Providing financial incentives to donors is one of several approaches to address organ shortage. However, its feasibility is debatable as it relates to medical, ethical, and economic dimensions. An incentive-based procurement system (IBPS) applied by the Mobile Donor Action Team (MDAT) was instituted in Riyadh, Saudi Arabia, resulting in a 3-fold increase in donation rate. The goal of this study was to provide a qualitative review of a 7-year experience with IBPS.

Materials and Methods. A qualitative approach was used. Documents were reviewed to create a chronological audit and shape interview questions. Sampling was purposeful and inclusive of MDAT members. Semi-structured interviews were conducted, and findings were subjected to thematic analysis.

Results. Documents reflected the evolution of MDAT. The essence of MDAT is field work and liberal use of financial incentives, which resulted in a 3-fold increase in the donation rate. MDAT members believed that IBPS is the main reason behind this increase. Moreover, IBPS is viewed as acceptable from a moral, ethical, and religious standpoint, with a high degree of professional satisfaction.

Conclusions. Theoretical assumptions doubted the feasibility of IBPS. This real-life experience with IBPS proved the contrary. The findings may be applicable only to the setting in Riyadh, Saudi Arabia, however; further research is thus needed to explore its transferability to other settings. IBPS may be an alternative to altruistic noncoercive donation and should be piloted in different settings.

END-STAGE organ failure is a major health problem leading to substantial social and economic losses. Since the 1950s, organ transplantation has made giant strides to become the standard of care, with remarkable improvements in survival and quality of life for many patients [1]. The benefits of organ transplantation include not only patient survival, as quantitated by life-year gained, but also quality of life, which can be measured by using disease-specific or generic instruments [2–5]. The economic advantage is illustrated by using the example of renal transplantation, wherein the annual cost of transplant can be as low as 10% of that of dialysis.

The limiting step in taking full advantage of organ transplantation is organ shortage. In most countries, the current organ supply system depends on altruistic noncoercive donation. This model of voluntarism has been deficient in meeting an accelerated demand, a demand that is undermining the success of organ transplantation. The extreme demand for organs and the need to combat organ trafficking, transplant tourism, and human exploitation has resulted in the search for effective alternatives by many interested parties. One of these alternatives is the use of financial incentives to increase the rate of donation. The debate continues regarding the feasibility of such an arrangement.
alternative, particularly as it relates to medical, ethical, and economic dimensions.

The population of Saudi Arabia is ~28 million. The need of organ transplant is reflected by the fact that, currently, >15,000 patients are on dialysis. End-stage liver disease is common in Saudi Arabia, with an estimated annual need for transplant of ~500 to 700 [6]. There are no data available regarding number of deaths while on the waiting list. The average number of reported donors has been ~500 annually. The conversion rate (number of donors retrieved/number of donors reported) has been as low as 5%. This is not only due to the refusal of the family of the deceased to donate organs but also due to logistical reasons, such as failure to finish the documentation process or lack of appropriate medical management of the donor, leading to loss before the stage of consent solicitation. The consent rate remains relatively stable at 15% to 20%. The quality of organs has also been an issue because, for example, not all organs are acceptable for liver transplant, thus contributing to the daunting problem of organ shortage.

In the present study, we focused on the outcome, feasibility, and transferability of using an incentive-based system in cadaveric organ donation in Saudi Arabia. Using a case study approach, we aimed to provide a qualitative review of a 7-year incentive-based organ donation system to refine the current system and assess transferability to other settings. This research took place in the setting of cadaveric organ transplantation in Riyadh, Saudi Arabia. Specific objectives included review of program documents, utilizing key informant interviews to fill in the gaps and confirm the results from the document review; assessment of medical, ethical, religious, cultural, and economic issues that have currently and may influence the program in the future; and assessment of issues associated with transferability of the system to other settings.

MATERIALS AND METHODS

A case study of the organ donation system in Riyadh is reported from 2006 to 2013, during which the Mobile Donor Action Team (MDAT) pursued an aggressive approach toward organ donation through field work and provision of incentives for donors’ families and the health workers dealing with the donation logistics; these efforts were associated with a 3-fold increase in donation rate. The methods used were qualitative and based on document analysis and in-depth interview of MDAT members. Short interviews using a semi-structured interview guide were conducted with the MDAT 7-member team (direct implementers of the incentive-based donation program in Riyadh); 2 interviews with the administrators working with MDAT (focus on management and administrative issues); and 1 interview with the director of the National Donation Organization to explore the transferability to other regions of Saudi Arabia. The questions in the interview were based on the review of the documents. Participants were asked to sign a consent form. Ethical approval was obtained from the University of Liverpool ethics committee. Written permission to conduct the study was obtained from the Ministry of Health (Saudi Center for Organ Donation and King Faisal Specialist Hospital and Research Centre). All interviews were recorded and transcribed. Transcripts were analyzed by using a thematic framework.

RESULTS

The results of in-depth interviews were grouped into themes. The first was the reason for the increase in the donation. This was further grouped into 3 subthemes: organization, incentive, and awareness.

The majority of participants put incentives as the most important factor in such an increase. This includes financial incentives to the families of the deceased as well as those to the medical personnel (intensive care unit staff).

“If you are not paying, the people who are supposed to do the EEG, they would not make an effort, it would not be done at 9:00 at night; more likely it will be done the following day.” 2

The weight of this factor was very heavy in the opinion of most participants, with the assertion that if such a strategy was absent, the donation rate would drop remarkably.

“………[T]he incentives are on the top, for your information, even if you do not have the best work organization incentives will make the difference and if you have the best organization and no incentives, no work [organ donation] will be done….I will tell you, 70% [depends on] incentives and 30% organization.” 1

“The system [had an effect on organ procurement] and if there were no incentives even if there was a system, it will not work.” 2

One of the participants emphasized the importance of funeral cost and transfer of the body to country of origin for the non-Saudi subject as a strong motivation for the acceptance of organ procurement.

“For foreigners, the important thing is money, the 2nd thing is to shift the body [sending body back home], they want to see at least the face of the donor, the family back home, and so the shifting goes free.” 3

The second theme was the drawback of incentives. The subtheme brought up by the participants was the absence of contradiction between donation and incentives. Both were viewed as complementary to each other. The concept of “reward after the fact” rather than “monetary price” for the organ was the concept brought up by several participants. The majority of opinions were in agreement with the moral and ethical values. Three participants expressed some concerns about the religious acceptance of incentives and wished that there was an explicit religious declaration supporting incentive for organ procurement. The drawbacks, as described by the participants, were inadequate amount and the explicit expression of the value of organs for patients, which justify an even bigger amount of monetary compensation. There were also issues related to the logistics, including problems related to who should get the money, although this was a rare occurrence.

The third theme was the medical advantages of transplantation. Invariably, all agreed on the medical advantages of using the incentive to save lives. The opinion was
consistent that such an approach not only increases the number but also hastens the process, leading to a better quality organ and subsequently a better organ transplantation outcome.

The fourth theme was the religious and cultural issue. In general, the practice of an incentive-based procurement system (IBPS) among MDAT members was not influenced by ethical concerns, which were expressed by 3 of them. Others saw IBPS as a means to fulfill their ethical obligation to patients who are in need of organs as well as benefiting the donor families. Although some participants did have some moral and ethical concerns regarding the use of incentives, the majority felt that, morally and ethically, they were acceptable. Invariably the concern, if voiced, was more moral and religious in nature (Islamic).

“Primarily I am worried of getting into Haram and Halal [permissible or non-permissible from the religious point of view] and secondarily the issue of dealing with donor as if you are dealing with goods.”

Accepting incentives did not seem to negate or downsize the deed brought about by allowing organ procurement from the deceased. One participant looked at these 2 aspects as complementary to each other.

“…..God ask to say in prayers “Oh God, give us all good things in the World and the hereafter”, so God will give you better for worldly affairs and He said that first, so the person who would do good deed for Allah’s [God] sake, does a big thing, and save the life of a human being, before you thank him in our religion, he should be thanked in the world [incentives] and that is what our religion says…..”

The fifth theme involved economic advantages. Comparisons performed on the cost spent on organ donation versus that of the cost of medical care or sending patients abroad reflected an invariable opinion of the group that an IBPS has a great economic advantage to the country and was cost-effective. It follows, in their opinion, that budget allocation for incentives for organ donation is needed and to all parties involved.

“……. [P]atient on hemodialysis who cost a lot if we transplant them we will save a lot of money some of that money, even a fraction, can make a big difference in organ donation when we use it as incentives.”

The sixth theme was transferability. Most participants expressed strong opinions in terms of transferability of IBPS to other countries. There was a subtheme of linking IBPS success to the social and economic situation of different countries so that the poor and less educated will have more success with the system. When asked about the transferability to Western countries, there was diversity of opinion, with the majority in favor of predicting success of IBPS even in the wealthy Western countries where there is a high level of education.

The seventh theme was degree of satisfaction. All participants were satisfied with the fact that incentives made the difference in the increase in donor procurement. There was, however, some concerns about the ethical and moral aspects expressed in religious terms, but these concerns were not strongly expressed.

“…you should not take it [talking to family for consent] as responsibility that you have to perform but as a hobby” you will find delight in it.”

“This is a social work; I think I am doing a good job. I am very happy. Definitely I am doing a good job, because I am helping both sides the family of the donor and the patients.”

The eighth theme was incentive for MDAT. All participants expressed their desire to have incentives based on the performance of the team (ie, reward per case). There was a feeling of injustice with the fact that incentives are given to other health care professionals but not to the MDAT members.

“The Mobile Team’s basic work is very hard, and I am talking with honesty, their rights are devoured, they are the people who get the least.”

The ninth theme was influence of Western training. Most participants were exposed to Western medical training in various ways. There seemed to be no effect of this training on their attitude toward IBPS.

Finally, when asked about other strategies, all participants agreed that more incentives to the team, families, and intensive care unit staff will enhance the performance and secure more donors. The need for more staffing and better management was expressed by some as important factors in the enhancement of the MDAT work.

DISCUSSION

The 2 contrasting procurement systems are the “routine salvage model” by Jesse Dukeminier and David Sanders in 1968 and the other is the “donation model,” which is the dominant paradigm in organ procurement [7]. In the current Western culture, it is taken for granted that any variation in any organ procurement schemes should not breach the moral premises of the “gift metaphor” [8].

The ethical underpinning of the first model is consequential social utilitarianism, which focuses on the benefit of the society, and that of the second is a combination of virtue and deontological ethics, focusing on the individual autonomy and virtue. The ideal model should have a maximizing power to obtain all potential organs while maintaining moral value. This is the dilemma of organ shortage. The incentive-based model positions itself somewhat between the 2 aforementioned models trying to meet the need to address issues of autonomy, justice, and utility.

Studies on the actual use of incentives in the setting of cadaveric organ donation are lacking. The use of incentives
in the setting of living donor donation, however, was reported in the literature as the “Iranian model” in several publications [9–12]. Empirical data on the subject were based on quantitative studies on public and professional attitudes toward the use of incentives in organ procurement [13–16] rather than studies on the actual practice of IBPS. These studies were scarce, with a tendency toward rejection of financial incentives based on public and professional opinion. Conversely, there is an abundance of literature debating the use of incentives based on theoretical assumption, economic modeling, and predetermined ethical postulation among clinicians, policy makers, economists, and ethicists. Debate among clinicians continues about the feasibility of financial incentives, for example, in 2 influential biomedical journals, *Transplantation* and *BMJ* [17–21].

Earlier on, a panel of ethicists, organ procurement organization executives, physicians, and surgeons formed the Ethics Committee of the American Society of Transplant Surgeons and were unanimously opposed to financial incentives in the setting of cadaveric donation [8]. This opposition was based on “violation of the ideal standard of altruism and unacceptably commercialize the value of human life by commodifying donated organs.” This is an echo of what was voiced by Titmuss in his seminal work, *The Gift Relationship: From Human Blood to Social Policy*, in which he argued that paying for a blood donor will be discouraged and repulsed when it becomes a monetary transaction rather than altruistic [22]. The debate among clinicians seems to be moving toward a more relaxed attitude regarding the idea of incentives wherein discussion now is on details rather than the principle [17].

Economists in general, not surprisingly, have strong opinions regarding the use of incentives. The work of Becker, a Nobel Prize, and Ilias winner, sparked a lot of discussion on the subject when he suggested an economic model based on financial compensation to solve the issue of organ shortage [23]. He used economic connotations to argue that like any other economic system composed of demand and supply, a market for organ donation can be brought to equilibrium by increasing the supply for organs from both cadaveric as well as living procurement. Currently, donation of organs holds the price at zero, and therefore organ shortage is inevitable based on these economic principles. He and others consider the altruistic procurement policy a failure [22,24–26].

The notion of ownership of our bodies and therefore having the right to sell it has been used to argue for organ sale. The extreme of this argument is voiced by calling the ban on selling organs “an act of paternalism at its worst form” [27]. The counterargument to this approach was voiced by a report from the Institute of Medicine on organ donation, which argued against financial incentives and market for organs based on the assumed technical difficulties in establishing a market for such heterogeneous and perishable goods, with transactions being conducted under more pressing and difficult circumstance than that of the familiar commercial transaction. Besides, this approach brings about the issue of commoditization of the human body [28]. This view was supported by others [29].

An incentive-based model cannot be considered altruistic or coercive because it maintains the personal autonomy in terms of accepting or refusing incentives while trying to maximize utility. As opposed to the application of the model to living procurement, it pragmatically creates a win–win situation for the recipients and the family of the deceased, at least from an economic perspective. Although the practice was morally and ethically acceptable in general, some in the present study expressed concerns with regard to the religious aspect because there was no explicit religious declaration. This is understandable, considering the nonsecular nature of Saudi society. In the view of some MDAT members, it seems that there was no contradiction between the act of donation and that of receiving a materialistic gift. One of the participants considered the 2 complementary; the first seeking a deed for second life and the second getting a benefit in the current life. This contrasts with Western studies, which concluded that the 2 concepts collide to the extent that some expressed fear that the introduction of incentive would deter people who otherwise would donate. These assumptions are based on public and professional quantitative surveys, which may not be adequate.

Structural changes in the logistical aspects of donation can increase donation rate. This increase under the current system of altruistic donation has not been sufficient to solve the problem of organ donation shortages. Success of donation initiatives, such as the Organ Donation Breakthrough Collaborative in the United States (which adopted the best practices in the process of organ recovery and allocation) led to a marginal increase in conversion rate from 50% to 60%. Sustainability of such initiatives was a major concern. The Massachusetts Organ Donation Initiative increased the conversion rate from 44.2% before intervention, to 59.5% at its peak, to a low of 37.8% 2 years after the commencement of the initiative; actual number of donors were 73, 103, and 59, respectively [30]. Reflecting on the experience of MDAT in Riyadh, the number of donors...
Table 1. Current Obstacles Against the Use of IBPS

| 1. Ethical constraints (although most agree that these should not be the decisive factor in adopting IBPS) |
| 2. Lack of empirical data to support IBPS |
| 3. Obtaining data is blocked by the reluctance to conduct pilot studies of IBPS because of ethical concerns or because of the fear of setting into motion irreversible societal changes that could undermine current ADS |
| 4. Insistence on the reliance on structural change in the current system to bring about a resolution to the organ shortage crisis such as quality improvements and collaborative initiatives |
| 5. Debate on who should provide the burden of proof: opponents or proponents |

Abbreviations: ADS, altruistic donation system; IBPS, incentive-based procurement system.
Source: Childress and Liverman [28].

increased an average of 3-fold after 2006 compared with the previous years after MDAT started its activities (Fig 1). Other regions in the Kingdom did not have a similar increase. Although the structural changes in the donation logistics (eg, aggressive field work) seem to have influenced this increase, it was the opinion of all participants that the main influence was the liberal use of incentives. More than 1 participant asserted that without incentives, the other strategies would not be productive.

Although IBPS is practiced in full scale in Riyadh, other regions in Saudi Arabia have inconsistent IBPS practices. Considering the similarities in culture, economics, and social norms, it is conceivable that IBPS will bring about similar results. This was clearly expressed by the participants. Other Middle Eastern countries may have a similar outcome as believed by most participants. In Western countries, opinions regarding IBPS are shaped based on premises as summarized in Table 1. Therefore, it is plausible that it will be a long time before IBPS is applied in Western countries.

This study did not look at the demographic characteristics of the decision makers, who are usually the next of kin, or the socioeconomic status of the deceased’s family. Both factors may have an impact on the decision of organ donation. The donation process in Saudi Arabia requires only the proof of relationship of the deceased to the next of kin. This is one of the limitations of the study. Another limitation was the fact that this study did not objectively show the impact of IBPS on altruistic noncoercive donation. It may be expected that it did not have a negative impact, at least at the level of individual cases, because the process of acquiring consent is done systematically starting with the altruistic approach (Table 2). It would, however, be interesting to know whether IBPS created a negative image of organ donation at the societal level and whether this actually affected the donation rate. These factors were not explored and may be the subject of further research. In conclusion, incentive based procurement policy had a positive impact on the donation rate in Riyadh, Saudi Arabia. This approach seems to be ethically and morally accepted. Whether this will be the case in other setting awaits further studies.

REFERENCES


Table 2. Process of Acquiring Consent for Organ Donation*

| 1. Introduction: Coordinator shows condolence and sympathy to family of the deceased |
| 2. Do you understand that your relative is dead although his heart is beating? |
| 3. Do you understand that your relative will never be alive again? |
| 4. Do you know that his organs can save the lives of many patients? |
| 5. Would you be willing to allow his organ to be donated? If the answer is yes, then stop. If the answer is no then: |
| 5.1. Do you know that government gives a gift in appreciation of your noble act (amounting to “USD 14,000 as well as funeral costs”)? |
| 6. Are you willing to sign the consent? |

*The whole process may be repeated on another occasion to give the same chance to the rest of the family to make the decision.