

The perception of families of patients with ESRD regarding socio-cultural barriers to organ donation in Algeria

Par :

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Abstract

From 2005 to 2011 the kidney transplant in Algeria has steadily increased, reaching 6615 transplant recipients, with an average annual achievement of more than 110 kidney transplants. The advanced figures of kidney transplants performed in 7 years by this country can be achieved by a large hospital in Europe in a single year!

We will try through this paper to reach the opposing factors and obstacles that face organ donation, with a focus on kidney donation for patients with end-stage renal disease / ESRD. To achieve this, we opted for a survey of the families of dialysis patients, in order to identify the causes of these obstacles on the one hand, on the other hand, to highlight the role of the dialysis family in the accompaniment of these patients, including their roles in promoting organ donation for patients with ESRD.

Among the results of this research: the factors of opposition to organ donation in Algeria are not exclusively socio-cultural, but there are other factors of opposition that persist, which are of organizational order.

Key words: Organ Donation, the opposing factors to kidney donation, socio-cultural barriers, end-stage renal disease/ ESRD, Dialysis Families.

1. Introduction

We can consider the experimental surgeries performed by David Hume in 1951 at Harvard University for kidney transplantation, as the beginning of an extraordinary adventure that has begun but will have no end, the aim of which is to alleviate the suffering of thousands of patients suffering from insufficient functioning of one of their organs, because a few years later, humanity had the chance to witness similar transplants for other organs (liver in 1963, the pancreas and lungs in 1964, and the heart in 1968) [Gibbons & Meltzer& Duan, 2000]. Several years later, research focused on solutions that can prevent rejection of transplanted organs. Thus, the discovery of cyclosporine was the key to organ transplant success in the 70^{'s} and 80^{'s}.

The first kidney transplant in Algeria was performed on June 14, 1986 at the Mustapha Basha University Hospital/CHU Mustapha from a living donor (LV), the second was performed a year later at the specialized hospital/ EHS Daksi in Constantine. It was towards the end of 2002 that we had the chance to attend the first renal transplant from a cadaveric donor, by the surgical team of the specialized hospital Daksi/ EHS Daksi at Constantine [www.Santé magreb.com].

Although the number of dialysis patients continues to change from one year to the next, kidney transplant is hardly the rate of change in the prevalence of patients with end-stage renal disease/ ESRD [Bramstedt, 2013]. Several factors contribute to organ donation and organ transplantation in general, in this case the donation of kidneys. We are going through this work to highlight the role of the families of those with ESRD in the accompaniment of their patients, the promotion of organ donation, and among others, to overcome the obstacles that block the donation and transplantation of kidneys in Algeria.

We are quite confident that dialysis families have enough culture and experience to identify the opposing factors and barriers that face organ donation, these assets give these families the right to come up with solutions that can improve the organ donation situation in Algeria.

2. Materials and methods

The main objective of our study is to identify and understand the opposing factors and barriers against organ donation, which in turn constrain organ transplantation for patients who suffer from a disease that affects their organ. Identifying and understanding these oppositional factors among dialysis families will allow us to rectify the situation, to better develop strategies that can address these barriers.

To achieve this, we opted for a descriptive cross-sectional study, based on a methodology that consists of two techniques: the questionnaire and the observation.

We chose the families of the patients with end-stage renal disease/ ESRD, in order to carry out this opinion survey, also in order to properly situate socio-cultural opposition factors in the Algerian society.

We distributed 55 copies of the questionnaire randomly on family members assisting the patient, in the dialysis service at the Mohammed Boudiaf hospital, during the month of June 2018. This hospital is located in the capital of the wilaya of Oum El Bouaghi; the latter belongs to the eastern health region of Algeria. We were able to arrange the same number of interviews with family members of patients with ESRD.

3. Results and discussion

3.1 Socio-demographic distribution assistant / assisted by members of the study

3.1.1 Socio-demographic relationship assistant / assisted

We chose the assistants who are most present in the care path of each patient. In other words, it is family members who are often available to accompany patients with ESRD (see tab.1).

Tab.1: Socio-demographic breakdown assistant / assisted

Assistant Assisted	Grand parents	parents	Broth ers & sister	Descendants	Spouse	Total
<20years	01	02	01	/	/	04
[20, 40[03	12	07	04	05	31
[40, 60[/	02	01	04	09	16
>60 years	/	/	01	02	01	04
Total	04	16	10	10	15	55

3.1.2 Assistant / assisted distribution by gender

We addressed the issue of gender, in order to locate the most affected by this disease between the two genders on the one hand, on the other hand, to focus on who is available frequently of both genders to accompany his patient during the care path (see fig.1).

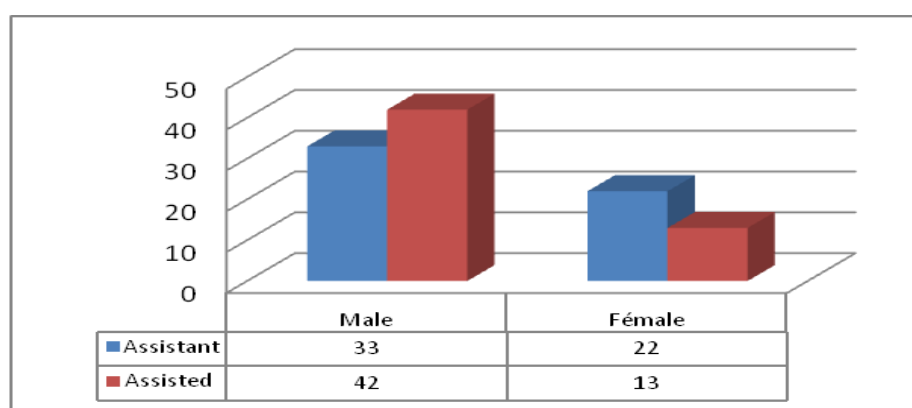


Fig.1: Assistant/ assisted distribution by gender

We can see that man is the most affected by the ESRD in the sample of the study, as we can also see that the same gender provides more help for these patients.

3.1.3 The quality of assistance of family members for each patient

We asked this question in order to gauge the quality of the assistance provided to patients with ESRD by their family members (see fig.2). In other words, is this aid singular or plural?

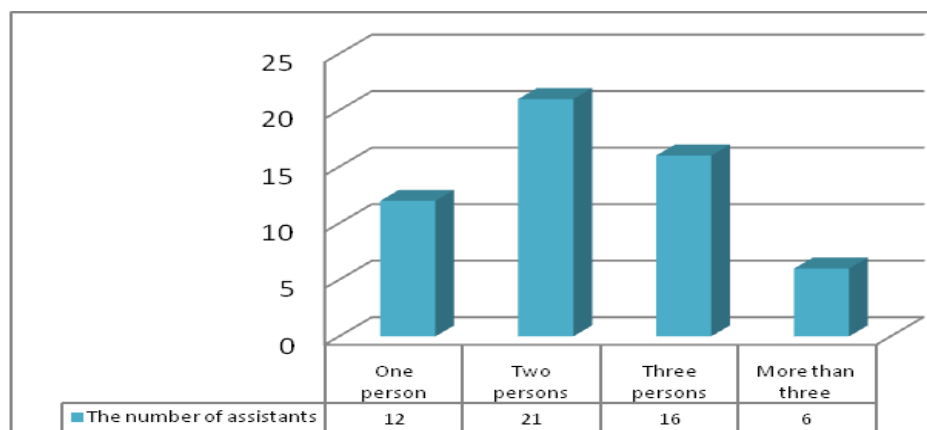


Fig.2: The number of assistants for each patient

We have seen that the family in eastern Algeria is quite close together, so almost the whole family is available to help his patient during his care journey. But there are always one or more people who volunteer to accompany the helper. The results clearly show that there is always someone at least to accompany the one who has ESRD, besides we recorded that more than 78% of patients benefitted from the quasi-permanent assistance of two people of theirs.

3.2 Opinions of the family of patients with ESRD on alternative care

Through this component, we asked four questions about alternative care possible now and in the future, for the patient with ESRD and his family.

3.2.1 Opinions on the two alternatives of care (hemodialysis / kidney transplant)

We asked this question in order to have a clear idea about the culture of families of patients with ESRD on alternative care on the one hand, and on the other hand, the availability of these alternatives in relation with the time factor (see fig.3).

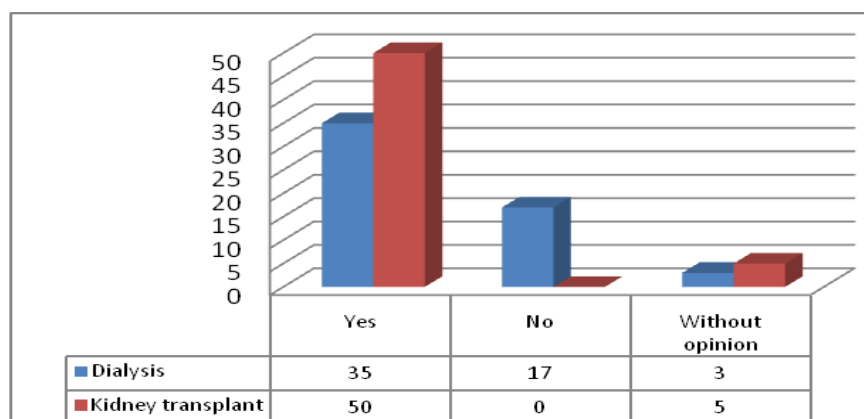


Fig.3: Opinions of families in the sample of the alternative care study

According to figure 3, we can conclude the following results:

* 63% of family responses admit that dialysis is the best solution for their patients, taking into account the time factor. In fact, in the absence of grafts, dialysis is really the only and the best solution for those with ESRD;

* 91% of family responses admit that kidney transplant will be the best solution in the future, provided there is availability of grafts.

So, the families of the patients are realistic and aware about alternative care in relation with time factor.

3.2.2 Opinions on renal transplantation as the best solution for the well being of the patient

We asked this question in order to locate the choice made by the families of these patients, concerning the best possible alternative care that is offered for those who have ESRD and for their beings, with certain objectivity, far from optimistic or pessimistic feelings (see fig.4).

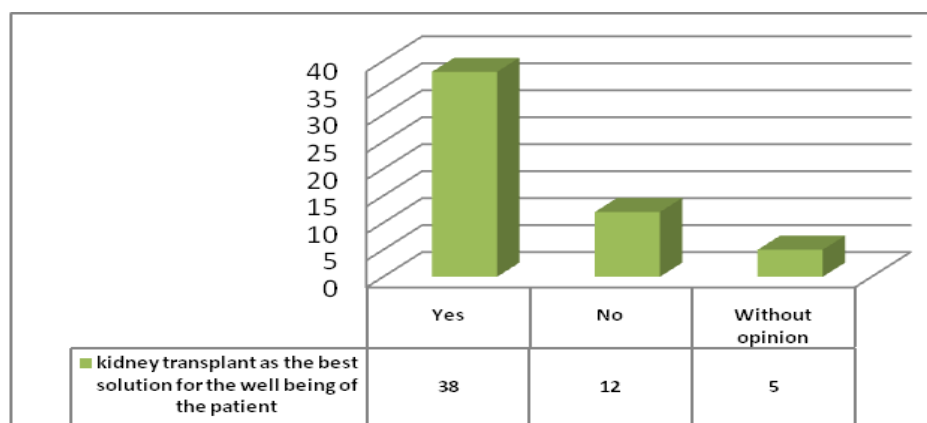


Fig.4: Opinion of the families in the kidney transplant study sample as the best solution for the well being of the patient

The families of the patients were adamant about the best alternative of care for the well being of their patients, with 70% of the answers. Even those who answered "no", they were quite realistic in a time or grafts are scarce.

3.2.3 Opinions on Kidney Transplantation as Best Socio-economic Solution for the assisted

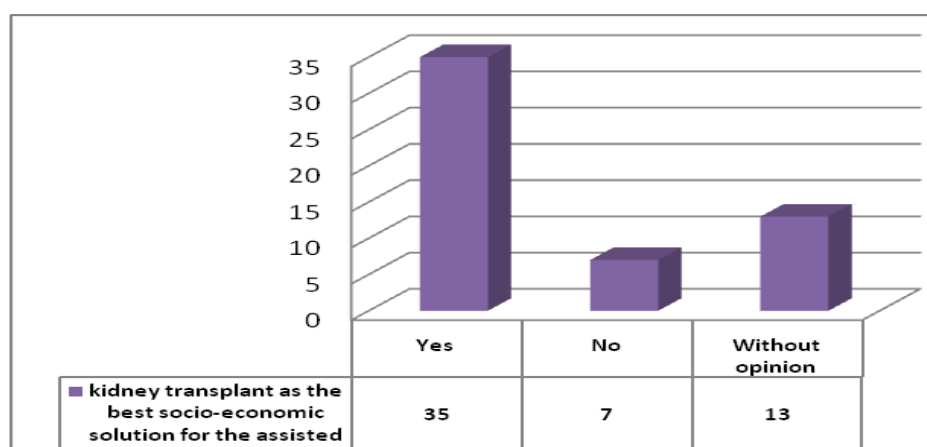


Fig.5: Opinions of families in the renal transplant study sample as the best socio-economic option for assisted living

We asked this question in order to locate the choice made by the families of these patients, concerning the best alternative care possible to improve their socio-economic situations, so that they can have a normal life, which does not require a quasi-permanent assistance of their families (see fig.5).

Although more than 64% of families answered that kidney transplants provide socio-economic relief for the patient with ESRD. While, in this time we recorded 24% of neutral responses. We investigated the cause of this neutrality, the majority had advanced a lack of model, about those who have been successfully transplanted and have led a fairly normal life.

3.2.4 Opinions on renal transplantation as the best socioeconomic solution for the assistant

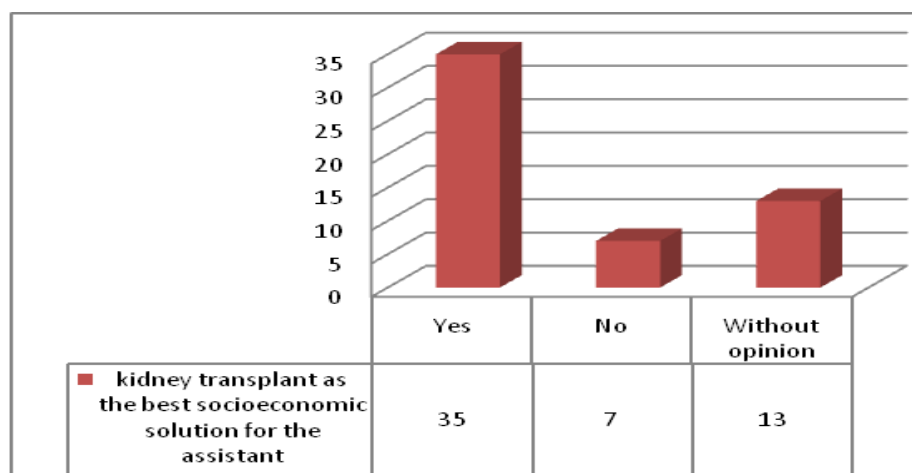


Fig.6: Opinion of the families in the kidney transplant study sample as the best socio-economic option for the assistant

This question was asked to get a clear idea about the alternative care that can constitute a possible independence, or at least, assistance less and less frequent for the family for his patient. Since the availability of one or more family members to accompany their patients two or three times a week to dialysis sessions, it is a burden on these families to lead a normal socio-economic life (see fig.6).

We got the same answers from the presidential question. In other words, families consider that socio-economic situation of the assistants is conditioned by the socio-economic situation of the assisted.

3.3 Opinions of families of patients with ESRD on the obstacles that block organ donation (kidney donation)

This section contains four questions, through which we can situate socio-cultural obstacles according to these families, who face organ donation.

3.3.1 Explicit consent as a factor of opposition for organ donation

Explicit consent has always been a divisive issue, whether at the national or international level. Thus, we asked this question in order to locate the weight of one of the factors that may be an obstacle for organ donation, according to these families (see fig.7).

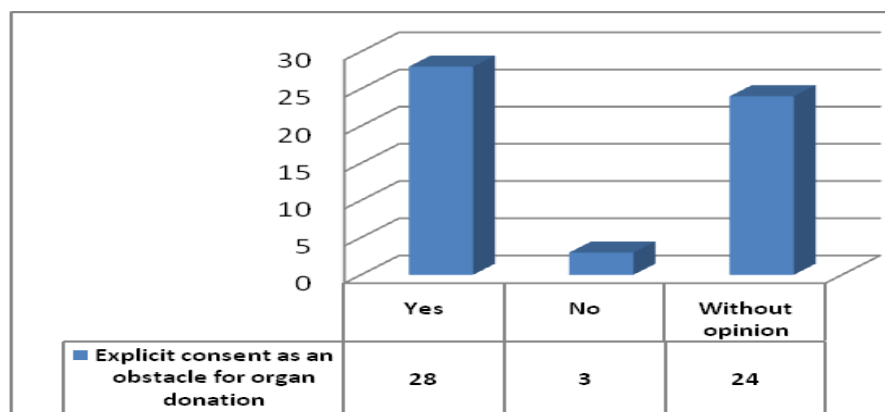


Fig.7: Opinions of families in the study sample on explicit consent as opposing factor for organ donation

According to these families' responses, almost half of the families report that this type of consent is an obstacle to organ donation. On the other hand, we recorded 44% of families who do not have a clear idea about consent in general, in this case explicit consent.

3.3.2 The organization of the health system as a factor of opposition for organ donation

The updating of the law on health, the organization of the offer of care, the availability of care, the register of transplants, the register of organ donors, etc. may be one of the factors of resistance for organ donation. This question can tell us about the organizational difficulties encountered by the families of those with ESRD, in their efforts to reduce the suffering of their patients (see fig.8).

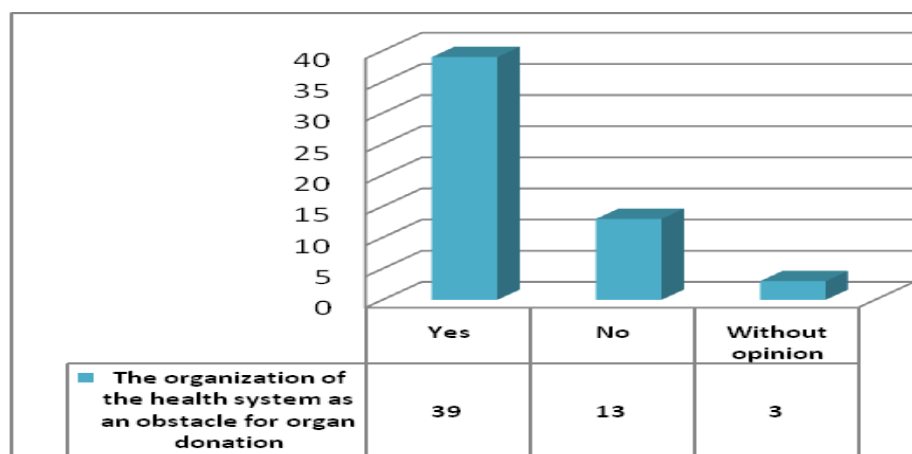


Fig.8: Opinions of the families in the study sample on the organization of the health system as a factor of opposition for organ donation

According to the families of the patients, we recorded more than 70% of the answers that put the finger on the organization of the national health system as a factor of opposition to organ donation. 23% responded with "no", stipulating that the availability of care, in this case of hemodialysis in the public sector, is a very important benefit at this time, especially for those without means or the most diminished. As they show other factors of opposition, in this case the lack of grafts.

3.3.3 Legislation as a factor of opposition for organ donation

The legislation is a double-slicing knife, it can be a factor of opposition to organ donation, especially if it is obsolete, and it cannot play an effective role in promoting organ donation. As a result in the first case, it can contribute to the deaths of hundreds of patients with ESRD every year (see fig.9).

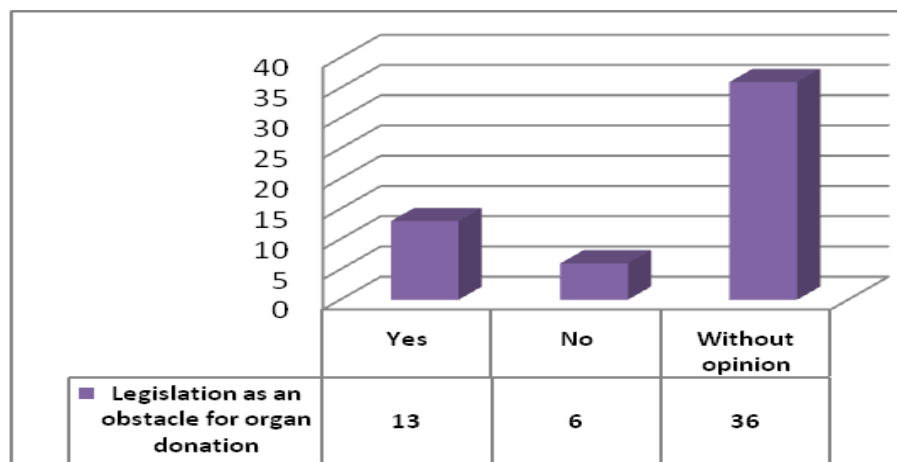


Fig.9: Opinions of the sample families of the study on legislation as a factor of opposition for organ donation

This time we had more neutral answers. So according to 65% of families of patients with ESRD, they completely ignore the content of the Algerian legislation on organ donation. On the other hand, 24% say that the legislation in force does not constitute an obstacle to organ donation.

3.3.4 Religion as a factor of opposition for organ donation

Religion can be an obstacle to organ donation. Although the three monotheistic religions are in favor of the organ donation of a living or cadaverous person, remains the inadequate interpretation of the texts by some religious, that can constitute a factor of opposition for some or most of the general public (see fig.10).

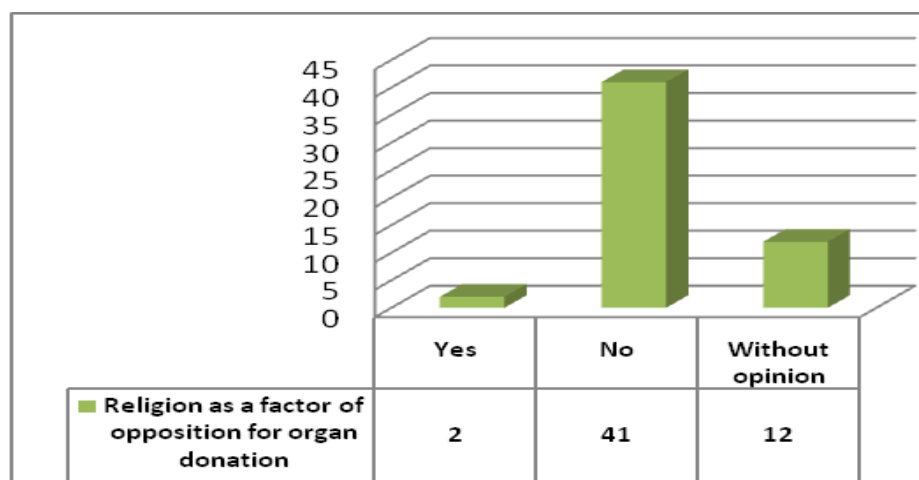


Fig.10: Opinions of families in the study sample on religion as opposing factor for organ donation

This time, we had more response by "no". So according to 74% of the families of patients with ESRD, the problem of organ donation does not lie in the Islamic religion. According to these families, religion is an encouraging factor in organ donation, whether from

a living or cadaverous person. On the other hand, 22% did not give opinions, either they are not practicing, or they have not sought the answer to this question before.

3.4 Opinions of the family of patients with ESRD on solutions that can boost organ donation (kidney donation)

This last section also contains four questions, through these, we will try to highlight the solutions that bring together and those that divide according to the opinions of families. The solutions that constitute unanimity according to these patients and their families can constitute a milestone for the decision-makers, in order to unblock organ donation in this country.

3.4.1 Disclose more relevant and targeted information on organ donation for the general public

We asked this question because we are convinced that there is not enough effort to disclose relevant and targeted information on organ donation, this information must be accessible by the general public (see fig.11).

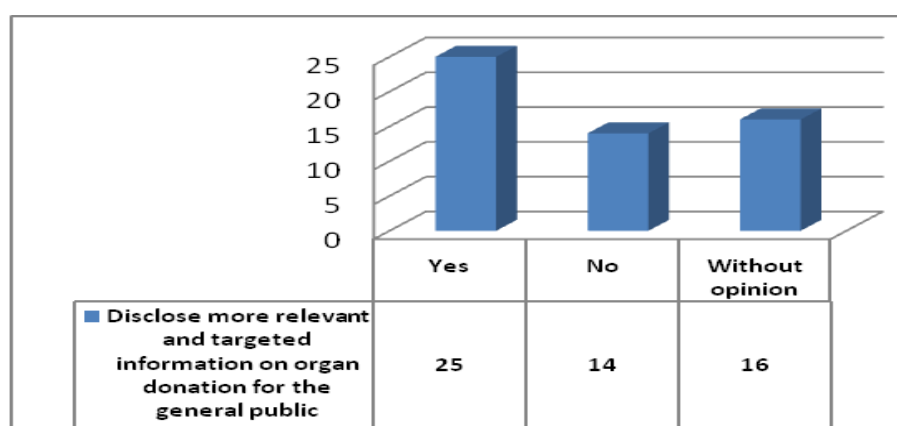


Fig.11: Opinions of families in the study sample on disclosure of information as a factor that can boost organ donation

Among the answers: 45% of families highlight a flagrant lack of information on organ donation. They blame the heavy media, which have not played their role in informing the general public about the precarious situation of those with ESRD, including the obstacles facing organ donation. On the other hand, 25% of the families affirm the existence of considerable efforts throughout the year by the associative work, in the matter of information disclosure through: study day, colloquiums, private media, etc.

3.4.2 Cross-donation as an alternative against incompatibility within the same family

If the debate is launched on the cross-donation a little bit everywhere in the modern world, we are a little bit reserved on such a subject. To alleviate the suffering of thousands of patients with ESRD, we need to start the debate on solutions like this, especially the case of a possible incompatibility between donor and the potential recipient of the same family (see fig.12).

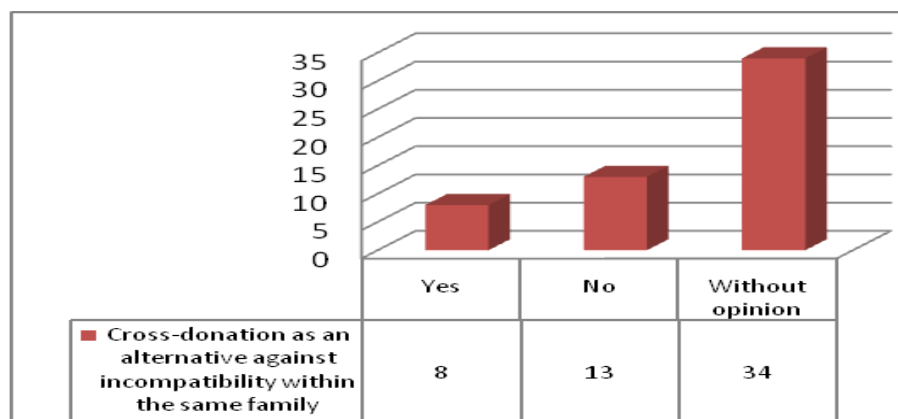


Fig.12: Cross-donation study sample families as a factor that can boost organ donation

A donor D1 wishes to give to his member of family, the receiver R1, but is not compatible with him. On the other hand, a donor D2 also wishes to give his member of family, the receiver R2, but is not compatible with him. If the donor D1 is compatible with the recipient R2, and the donor D2 is compatible with the recipient R1, a transplant can be envisaged between the donor D1 and the recipient R2, and another between the donor D2 and the recipient R1. This is called cross donation.

We had 62% of neutral responses, out of ignorance about what is happening elsewhere. This confirms the results on the previous question. Those who responded with "no" know that Algerian legislation does not intend in the near future to legalize this solution, for fear of organ trafficking, furthermore this solution does not provide an equal guarantee of success for the two families concerned by the cross donation.

3.4.3 Switch to the presumed consent

Several countries have taken the step towards the adoption of the presumed consent as: Spain, the Netherlands, Belgium, Portugal, etc. these countries have recorded better results in organ donation from of cadaveric donors compared to what was achieved in the time of explicit consent. Thus, we can also launch the debate on the adoption of such a solution, at the moment when we record thousands of encephalic' deaths annually (see fig.13).

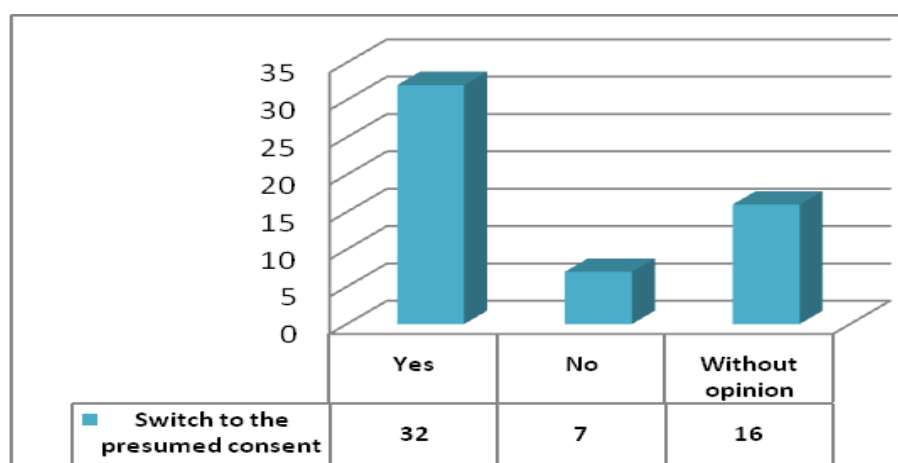


Fig.13: Opinions of families in the study sample on presumed consent as a factor that can boost organ donation

On this subject, we were surprised by the motivation of families to pass such a law in parliament, which allows the adoption of presumed consent, which is a noble and citizenship gesture after the death of each of us. Thus 58% answered with "yes", and 29% still ignore this possibility. All families emphasize Islamic Sharia, which encourages this kind of reaction for a Muslim whether in his lifetime or after his death.

3.4.4 To use more organs road accident victims

The adoption of presumed consent may change the game of organ donation from cadaveric donors. Among the tracks to be exploited, it is that of the victims of road accidents, in the moment where the country records annually between 4000 and 5000 victims on the roads since 2015 (see fig.14).

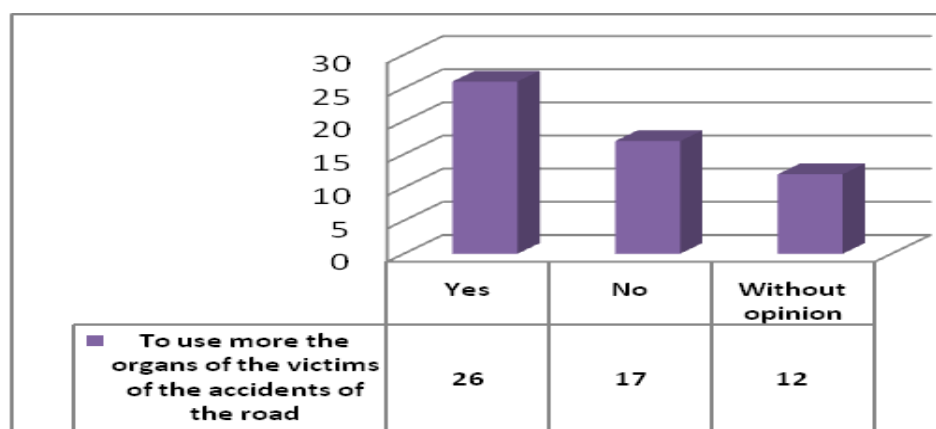


Fig.14: Opinions of families from the study sample about the use of benefit organs of road accident victims as a factor that can boost organ donation

The majority of the families, who answered on the questionnaire, are unaware of the number of victims of road accidents. After the disclosure of the figures of the victims of recent years, which is between 4000-5000 victims, adding the probable adoption of the presumed consent, according to them, it can unlock the situation of the kidney transplant for more than 8000 patients waiting a kidney transplant. So, 47% are in favor, as they add, that they volunteer to show the way for the other families, by registering the names of all the members of their families as potential donors after the encephalic death. Even those who are not convinced by the donation of a cadaverous donor, who answered by "no" or neutrals, they all advance the same sentence "we must move forward, it does not happen only to others ..."

3.5 Discussion

3.5.1 The current situation of the care of patients with ESRD in Algeria

Organ transplantation is in full swing with the advent of new surgical techniques for kidney transplantation from the mid of 50's [NFKF of Algeria].

In all countries, the deployment of medical performance meets a fundamental difficulty, that of the number of grafts, insufficient to cover medical needs. Waiting lists are growing all over the world, and there are many patients who suffer and die waiting for life-saving organs [Fox & Swazey, 1974]. In Algeria the situation is not different from the rest of the world, Perhaps the only difference lies in the opposing factors to organ donation.

More than 23000 chronic kidney disease patients are undergoing hemodialysis sessions across 317 open hemodialysis centers in both the public and private sectors. The number of patients suffering from chronic Kidney failure is clearly increasing from year to year. By definition, this pathology, with heavy consequences, is treated either by

hemodialysis, by peritoneal dialysis, or by renal transplantation [www.efg.sante.fr]. The statistics presented on the occasion of the 24th National Congress of Nephrology at the International Conference Center of Algiers are chilling: two million Algerians have a chronic kidney problem, which is 10% of the adult population over the age of 18 years; no less than 2,000 new cases are treated each year [NFKF of Algeria].

A comparison between statistics of organ transplants in Algeria and those of other Muslim countries is uplifting. Between 2013 and 2015, Algeria carried out 573 kidney transplants, Tunisia 195 and Morocco 189. Even though, by the number of transplants carried out, Algeria is far ahead; our neighbors are ahead of us on a crucial aspect of kidney transplant activity: organ harvesting from deceased donors. Since 1986, Algeria has carried out only two transplants with graft samples taken from cadavers and none between 2013 and 2015, during which time Tunisia made 18 and Morocco 58. In Saudi Arabia, 2,838 kidney transplants were performed in 2015 from deceased donors [www.sandt.asso.dz].

3.5.2 Discussion of the results of the survey

Starting from the results of this survey, grouped in four parts, several reactions can reappear in the comparisons with the results of the other national or international surveys carried out previously.

*** Socio-demographic distribution assistant / assisted by the members of the study**

According to this survey we could have a clear idea about the socio-demographic situation of patients with ESRD and their families, among the most striking results:

- * The most affected of ESRD between the two genders are men, in addition, the most affected among all age groups are young people under 40 years;

- * Among the two genders, those who bring more aid to their patients are men, not for their availability, but because of the mentality that reigns in the wilayas of Aurès, where men are free to move, however women have less freedom to leave their homes;

- * The family is sacred in this part of Algeria; it is welded around his patient. Thus we have noticed that each patient receives help from at least one person in his family. The most striking of which may be: 78% of families who say that two people are less available to take care of their patients.

*** Opinions of the family of patients with ESRD on alternative care**

- * We can consider this component as the milestone of this survey, since through the responses of families; we can highlight the factors of socio-cultural oppositions. Among the most remarkable results of this component:

- * We were shocked by the families' responses to adequate care alternatives for their patients, in this case 63% of families who consider hemodialysis as a fairly effective solution for their patients. After a brief discussion with the assistant of each family, the overwhelming majority of responses were motivated by the availability of care, instead of the well-being of the patient. So, there was a time when dialysis drugs and consumables rare and expensive to procure it, especially for the poorest;

- * About 91% are agreeing for this solution, which can relieve the suffering of their patients. These families have been realistic, in the absence of grafts; they wait as long as hemodialysis is available in the public sector;

* Regarding hemodialysis as the best solution for the well being of the patient and for a better socio-economic situation, the majority of families agree on it. Even those who answered "no", it is for fear of rejection of grafts, which can complicate the situation of the patient more and more.

* According to these families, kidney transplantation can have a positive effect on their socio-economic situation; this is the case where it allows a certain dependency for their patient.

*** Opinions of families of patients with ESRD on the obstacles that block organ donation (kidney donation)**

Algerian law provides that a living person can give only to his parents, his children, his brother, his sister and his spouse, which limits the possibilities of transplantation. In addition, it submits the removal of the organs of a deceased to the agreement of his family, the overwhelming majority opposes for lack of information or for fear of violating a possible religious prohibition. Although in 1980, the High Islamic Council (HCI) issued a fatwa in this sense, later Muslim countries signed the Amman Agreement authorizing the removal of organs from deceased persons. The Algerian religious authorities, meanwhile, pronounced on February 14, 1985, through the Algerian Higher Islamic Council which issued a fatwa authorizing the removal and transplantation of organs [www.agence-biomedecine.fr]. In addition, the complexity of family relations in Algerian society also complicates the situation. Even in countries like France, which has a better organ donation situation, this country has a paradoxical situation, since about 85% of French people say that they agree to give their organs, but at the moment of the death, the doctors face 30 to 40% of refusal. Even more, in the case of a child or a teenager who have just died [www.agence-biomedecine.fr].

According to the results of our investigation, the families of patients with ESRD put their finger on the factors of organizational opposition, in this case the low willingness by all stakeholders to switch to presumed consent. In addition, they accuse the health system that is not ready, especially in the event of availability of grafts on a large scale, to alleviate the suffering of patients with ESRD. The sample members of the study, in general, present a fairly sufficient culture on the position of legislation and religion in organ donation either from living or cadaveric donors.

*** Opinions of families of patients with ESRD on solutions that can boost organ donation (kidney donation)**

The low level of registration in the donor registry, and the high rate of family refusals remain a difficult problem in the donation process, whether at the national or international level. Information campaigns for the benefit of the general public should be able to advance the consent of relatives of potential donors, and encourage public or family discussions about donation in general.

Countries like Netherland are now targeting adolescents under the age of 18, to prepare a conscious generation about organ donation. For them: "the presumed consent system would be a better alternative, because it can reinforce the idea that donation is a socially accepted standard, which would encourage people to get informed, and talk about it with their loved ones. Then, it would avoid forced decisions of relatives at the difficult moment of death"[Kuss, 1996].

According to the results of the survey, we can distinguish:

* There is really a flagrant lack of information on organ donation here in Algeria as elsewhere, which is manifested by families of patients with ESRD. Even those who answered

by “yes”, they welcome the considerable efforts made through associative work. We also note an almost general ignorance of what is being done elsewhere, with regard to the cross-donation between two families, and in terms of new legislation enacted to dismantle the obstacles that block the will of living donors;

* According to these families, the debate on the presumed consent must be launched. These families can play the role of interlocutor between all stakeholders in post-mortem organ donation. They can also set a good example, in terms of willingness to switch to presumed consent, by putting their names and those of their family members in the potential post-mortem donor registry. Victims of road accidents can be a solution to alleviate the suffering of thousands of patients, especially as Algeria records in recent years an annual average of over 4000 deaths in these roads.

Conclusions

We can consider that the care of patients with ESRD is a family affair. In the absence of grafts, family members play a very important role in socio-economic, psychological, and other supports. This family who can even alleviate the suffering of his patient, the case where a member volunteers to give an organ, provided that it presents the appropriate profile for this donation.

Through this survey we have tried to highlight the socio-cultural factors of opposition, and the solutions that will have undertaken according to these families to boost organ donation, and consequently improve the situation of thousands of patients with ESRD. Despite the fact that the factors of socio-cultural opposition are decreasing more and more, a long way is waiting for the leaders of the health sector in Algeria to boost organ donation: to disclose more and often information on the subjects for the general public; explore all the solutions that can improve the situation of patients and their families, starting with the pioneers in legislation, that can unlock the organ donation situation; reorganize the offer of care to be more effective, first of all, in the transplantation of organs from living donors, and later, more organ transplant from cadaveric donors, especially in case there are courageous solutions to exploit the organs of thousands of road accident victims. The organization of the means of care cannot be realized except in the case where there will be an effective information system, which can follow the evolution of the situation of patients with ESRD and potential donors [Aissaoui, 2017].

Acknowledgment

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