

Attitudes towards organ donation in Malta in the last decade

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Abstract

Organ transplantation is possibly one of the few cases when even though the medical professionals have the expertise to carry out transplants of certain organs, and even though a person may have financial resources to cover every possible cost, the treatment can prove impossible to give because of the absence of an organ to transplant. It is for this reason that many countries spend thousands of pounds on promoting organ donation through health campaigns. In this paper the results of four surveys carried out before and after a national campaign for promoting organ donation will be analysed. A quota sample of 400 participants took part in each survey. The results show that, after the campaign, attitudes towards organ donation became more positive and this phenomenon was maintained for 10 years after the campaign.

Introduction

The use of human organs for transplantation has steadily increased in the past decades. Organ transplantation is now the most cost-effective treatment for end-stage renal failure. It is also the only available treatment for end-stage failure of organs such as liver, lung and heart.¹ Organ donation and transplantation have been studied from the medical and ethical aspects, yet few researchers have studied their psychological implications even though it is clearly evident that some of the problems in procuring organs for transplantation are psychological in nature.

Two of the first researchers to study the willingness of people to donate their organs after their death were Cleveland and Johnson in 1970. In this and later studies, Cleveland found that subjects who were not willing to sign a donor card showed more fear of death and burial than those who said they have signed a donor card. Unwilling donors also avoided acknowledging their own mortality and believed more in life after death.²

Psychological research on organ donation

Various researchers have identified certain psychological variables which are associated with the willingness to donate one's organs after death and with carrying a donor card. Some variables identified included low death and body anxiety³, altruism⁴, empathy⁵ and acceptance of mortality.⁶ It was also found that some of the fears were the result of an illusion of lingering life, an uneasiness at the thought of cutting up the dead body and a certain discomfort about not keeping the dead body intact.⁷

The intention to donate organs after their death is higher in urban dwellers, females who are practicing Catholics, those who do not agree totally with the notion that the body remains intact after death, those who have a favourable attitude towards autopsy, those who are blood donors or who have donated blood in the past, and those who know the 'favourable' opinion of their relatives regarding donation and transplantation.^{8,9}

Attitudes and behaviour

There is a discrepancy between, on the one hand, people's appreciation of transplantation surgery and their willingness to receive organs and, on the other hand, the considerably lower willingness to donate their own organs or organs of a close relative. While most people are in favour of organ donation, yet it is only a small percentage of these people that actually carry the

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donor card.¹⁰ Some of the reasons for the discrepancy between attitudes and behaviour will be discussed below.

i) The opting-in system

The opting-in system of organ procurement may be problematic for various reasons. When approached about organ donation, the family of the deceased are still under shock from the news of the death of their family member. It is for this reason that doctors very often find it difficult to approach the family and ask for permission to take organs. Moreover, the family, in such circumstances, feel that by giving permission to doctors they might be showing disrespect towards the dead person. This happens mostly when they would not know the wishes of the deceased regarding organ donation. Family refusals to donate organs of their relatives varies widely in Europe, ranging from 6% in Portugal to 42% in the UK.¹

ii) Attitudes of hospital professionals

There is little doubt that physicians are in favour of organ donation. Some of these professionals however are not convinced of the cost-effectiveness of organ donation and may argue that there are other interventions which are more worthy of support. Thus these professionals, while agreeing with organ donation in principle, do not support it in practice. The result of this is that a number of organs are lost.

iii) Identification of brain dead patients

One other inefficiency in the organ procuring system is the fact that only a fraction of eligible, brain-dead organ donors are identified by the medical staff.¹¹ One reason for this happening is the lack of co-ordination between one ward and another and between one hospital and another. It is sometimes difficult for doctors to be in touch with transplant teams from other hospitals and thus many potential organ donors are lost due to the lack of timely action taken by a doctor.

iv) Burial traditions

Other major obstacles to organ donation are the ideas that people might hold of what makes a decent burial. In countries where ground burial is very common, some people believe that the dead person should be buried intact. There is a reluctance associated with processes such as organ removal or post-mortems because it is believed that these medical procedures interfere with afterlife.¹²

v) Religion

In addition to rituals and traditions, there might be some misconceptions about the teaching of the Church or the religious obligations of a particular group of people. There was a time when different religions, including the Roman Catholic Church, were not in favour of organ donation.¹³ This teaching has changed in the past years and now many religions advocate organ donation. But because this change in the position towards organ donation is not widely known, many still believe that it is not allowed or encouraged.

Campaigns and organ donation

In order to increase the number of people in favour of organ donation and in order to bridge the gap between intention to sign a donor card and the actual signing of a donor card, those promoting organ donation use health campaigns to help people act on their good intentions.

Campaigns could be effective in several ways with regards to organ donation. They can serve as a reminder for those who, for some reason or other, wish to sign a card but have not done so. Even though donor cards may be easily available, it often happens that one has to be reminded several times before actually signing it. Campaigns could also make people aware of the need for organs. Although many may have heard about organ donation, some may not know about the shortage of donor organs and that, because of this shortage, people may die. Campaigns can thus make people aware of this ever increasing need for more organs. Campaigns, when well planned, put the issue of organ donation on the public agenda. Especially when the topic is of human interest, as in the case of organ donation, the media often take a lead from the campaign and cover stories that appeal to the public.¹⁴

Methodology

As in many other countries, in Malta there is a shortage of organs for transplantation. To address this problem, in 1995 it was decided that there should be a coordinated national campaign to create greater awareness about organ donation and to encourage people to carry a donor card. The organ donation campaign was spread over ten weeks, starting on the 31 of October 1995. Formative research was carried out prior to the campaign. This included interviews with donor families, recipients, and doctors, a national survey with a quota sample of four hundred people and five focus groups with people coming from different walks of life. The campaign made use of newspapers, radio and television.^{15 16}

One instrument used to measure the success of the campaign was the use of surveys. The survey was a Maltese translation and adaptation of the one used by the British Kidney Patient Association.¹⁷ The first survey was carried out before the campaign. The second was held three months after the end of the campaign and measured the short-term effects of the campaign. Another survey was held three years after the campaign and this measured intermediate effects of the campaign while the last survey was held ten years after the campaign to measure long-term effects.

It is to be pointed out that the campaign held in 1995 was followed by a number of initiatives such as those by Life Cycle, programmes on Xarabank and other television and radio programmes and the setting up of an association Transplant Support (Malta). All these initiatives have surely helped to keep the issue of organ donation on the public agenda and to sustain the positive attitudes and behaviour towards organ donation.

Each survey was administered to a quota sample of 400 persons aged eighteen years and over living in Malta and Gozo. The surveys were carried out in twenty areas randomly selected

Table 1: Attitudes towards donor card

| | Survey 1 | Survey 2 | Survey 3 | Survey 4 | Difference between 1st/2nd surveys: p values | Difference between 1st/3rd surveys: p values | Difference between 1st/4th surveys: p values |
|--------------------------------------|----------|----------|----------|----------|--|--|--|
| Have donor card | 7% | 9% | 13% | 14% | n.s. | 0.007 | 0.002 |
| Do not have but consider getting one | 37% | 50% | 49% | 40% | <0.001 | <0.001 | n.s. |
| Do not want to carry a donor card | 17% | 19% | 16% | 19% | n.s. | n.s. | n.s. |
| Not sure | 15% | 15% | 17% | 18% | n.s. | n.s. | n.s. |
| Never heard about it | 23% | 6% | 5% | 10% | <0.001 | <0.001 | <0.001 |

n.s. not significant

Table 2: Attitudes towards opting-out

| | Survey 1 | Survey 2 | Survey 3 | Survey 4 | Difference between 1st/2nd surveys: p values | Difference between 1st/3rd surveys: p values | Difference between 1st/4th surveys: p values |
|----------------|----------|----------|----------|----------|--|--|--|
| Yes definitely | 18% | 30% | 20% | 22% | <0.001 | n.s. | n.s. |
| Probably yes | 25% | 21% | 13% | 20% | n.s. | <0.001 | n.s. |
| No | 53% | 47% | 62% | 52% | n.s. | 0.005 | n.s. |
| Do not know | 4% | 1% | 5% | 7% | 0.009 | n.s. | 0.04 |

n.s. not significant

within the six regions as given in the Demographic Review of the Maltese Islands. The main responses given by the participants in the four surveys are given in the tables above. The base for all percentages is the total number of respondents for each survey.

Results

One of the questions asked to the participants investigated the percentage of respondents who already had donor cards, those who considered getting one, those who did not want to carry a donor card, those who were unsure and those who had never heard about the donor card before.

Survey Question: *You may know that people carry a donor card which they fill in to say which organs they would like to donate after their death. Will you tell me which answer applies to you?*

In comparing the four surveys, the greatest change occurred in the percentage of people who had never heard about the donor card. Before the campaign 23% ($\pm 4\%$) of the respondents had never heard about the card. This percentage went down to 6% ($\pm 2\%$) in the second survey, 5% ($\pm 2\%$) in the third survey and 10% ($\pm 3\%$) in the fourth survey, ten years after the campaign. All intervals given are 95% confidence intervals.

The proportion of respondents who had a donor card increased slowly but steadily over the four surveys: 7%, 9%, 13% and 14%, with the differences between the first and the third and fourth surveys being both significant. All percentages have 95% confidence intervals of $\pm 3\%$. Ten years after the campaign, the percentages of respondents who have a donor

card remained relatively high, thus pointing out that probably this particular message promoting the donor card was received and internalized.

Another question investigated attitudes towards the opting-out system.

Survey Question: *In some countries, one way which is used to increase the number of donor organs is to say that organs could always be taken from adults who had just died, unless they had specifically forbidden it. Do you agree that this procedure be adopted in Malta?*

The number of people who were definitely in favour of the "opting out system" increased significantly from 18% ($\pm 4\%$) in the first survey to 30% ($\pm 5\%$) in the second survey. But this percentage went down to 20% ($\pm 4\%$) and 22% ($\pm 4\%$) in the third and fourth surveys respectively. The above results show that, although some participants were convinced of the benefits of the opting out system after the campaign, they still had ambivalent feelings on the issue. Even some respondents who were totally in favour of organ donation were unsure or downright against the opting out system. Many participants believed that the decision to donate one's organs after death should be a totally free decision. This point was also strongly made during the focus groups.

In another question, the survey investigated whether participants were more or less willing to donate the organs of members of their families. As in the survey carried out by The British Kidney Association, three scenarios were presented. This was done to find out what carries most weight when family members came to make a decision whether or not to donate the

Table 3: Respondents who would donate organs of dead relatives

| | Survey 1 | Survey 2 | Survey 3 | Survey 4 | Difference between 1st/2nd surveys: p values | Difference between 1st/3rd surveys: p values | Difference between 1st/4th surveys: p values |
|-------------|----------|----------|----------|----------|--|--|--|
| Situation 1 | 35% | 44% | 41% | 47% | 0.004 | 0.04 | <0.001 |
| Situation 2 | 56% | 63% | 62% | 67% | 0.03 | 0.03 | 0.001 |
| Situation 3 | 53% | 59% | 62% | 67% | 0.05 | 0.005 | <0.001 |

relative's organs, whether it was the knowledge that the person wanted to donate or whether the deceased actually carried the donor card.

Survey question: Suppose you had a relative who died and the doctors asked your permission to take the organs. Would you give permission in the following situations:

Situation 1: Your relative was not carrying a donor card and had never made his or her views clear.

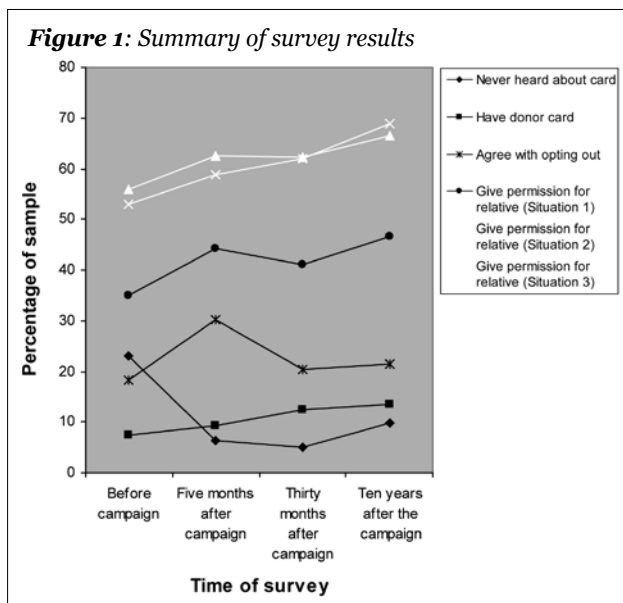
Situation 2: If this time your relative was not carrying a donor card, but had made it clear that he or she is willing to donate their organs.

Situation 3: If this time your relative was carrying a donor card but had not made it clear that he or she was willing to donate their organs.

The results indicate that, in all three situations, the campaign seemed to have a lasting effect on the proportion of respondents who would agree to donate a deceased relative's organs. It is also clear that in situations 2 and 3, when the relatives would have known the wishes of the deceased, this decision would be greatly facilitated.

Changes in attitudes towards organ donation

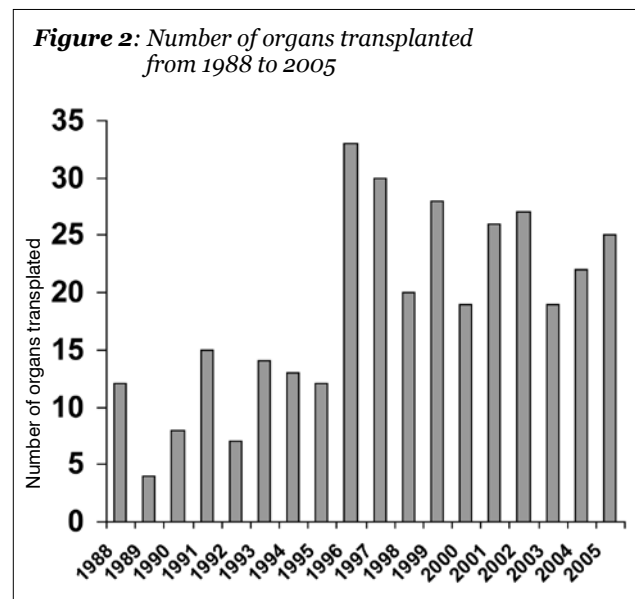
Some of the above results are shown graphically in the diagram below. Where there were internalization of campaign messages, the change in attitudes was sustained.



Other measures of effectiveness

Another measure used to evaluate the effectiveness of the campaign was the number of organs donated and the number of organ transplants carried out (Figure 2). It is of course impossible to claim that the increase in the number of organs donated was solely the result of the campaign. There were other reasons which gave rise to this increase for example the expansion of ITU beds, the appointment of another transplant surgeon and better donor testing. All these factors increased the chance that potential organ donors survive brain testing and recipients could therefore receive an organ transplant. One other factor to be considered is the decision to increase the acceptance rate of suboptimal organ donors, such as elderly patients and those with a history of comorbid diseases such as mild hypertension.

Table 4 shows the number of multi-organ cadaveric donors as well as live donors. It also gives the number of kidney, cornea and heart transplants that were carried out between 1989 (the year data became available) and 2005. It is to be noted that Malta has an agreement with a particular hospital in Italy, and when the organs procured from a cadaveric donor are incompatible with any of the Maltese patients waiting for a transplant, these organs are sent to the Italian hospital. This means that the actual number of organs procured is even higher than the figures shown.



The number of donations in the year 1996, immediately after the campaign, was substantially higher than the previous years. This could have been instigated by the fact that because organ donation was so much part of public discourse, relatives of dead patients themselves initiated the discussion of a possible donation. It is also significant that the first heart transplant was performed in 1996 when the post-campaign morale of doctors and donor families was high.

Conclusion

Public awareness and opinion could have an important role in increasing organ donation.¹ The results of the four surveys on attitudes towards organ donation indicate that the national campaign succeeded in increasing the number of organ card donors and in creating more positive attitudes towards organ donation. It is significant that this increase was sustained over a decade following the campaign, probably with the help of other campaigns like Life-cycle.

These positive attitudes towards organ donation were accompanied by a better morale amongst the physicians procuring organs. Doctors involved in organ procurement and organ transplantation were interviewed before and after the campaign. From these interviews it was clear that an important change had taken place in the attitudes of these doctors. Although they were already doing their best to procure organs, after the campaign, they found it easier to approach families of possible donors. Because the topic of organ donation was very often in the media, the families already knew about organ donation and were expecting the doctors to bring the subject up.

Table 4: Cadaveric and live donations

| Year | Multi-organ cadaveric donors | Live donors | Transplants: | | |
|------|------------------------------|-------------|--------------|--------|-------|
| | | | Kidney | Cornea | Heart |
| 1988 | 1 | 3 | 7 | 5 | 0 |
| 1989 | 1 | 2 | 4 | 0 | 0 |
| 1990 | 2 | 5 | 8 | 0 | 0 |
| 1991 | 4 | 3 | 10 | 5 | 0 |
| 1992 | 1 | 0 | 2 | 5 | 0 |
| 1993 | 4 | 0 | 8 | 6 | 0 |
| 1994 | 2 | 3 | 7 | 6 | 0 |
| 1995 | 2 | 0 | 4 | 8 | 0 |
| 1996 | 7 | 0 | 14 | 18 | 1 |
| 1997 | 4 | 1 | 8 | 20 | 2 |
| 1998 | 3 | 1 | 7 | 12 | 1 |
| 1999 | 4 | 2 | 8 | 20 | 0 |
| 2000 | 5 | 1 | 9 | 9 | 1 |
| 2001 | 6 | 0 | 11 | 14 | 1 |
| 2002 | 6 | 3 | 12 | 14 | 1 |
| 2003 | 5 | 1 | 9 | 10 | 0 |
| 2004 | 4 | 4 | 10 | 11 | 0 |
| 2005 | 4 | 3 | 7 | 17 | 1 |

Source: A. Bugeja (2006), Transplant co-ordinator

This facilitated the discussion on the possibility of a donation and made it much less difficult for the doctors to ask. This change is important because ultimately it is these doctors who must take the initiative to approach the relatives of the patient. If the doctors are not psychologically prepared to deal with this emotion-laden request, the procurement does not take place.

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