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Abstract

Most campaigns carried out with the aim of increasing the number of organ donors encouragedeceased organ donation. It is not common that living organ donation is actively promoted through campaigns. The reason for this is complex. The fact that the recipient has to undergo an operation with its medical implications and has a recovery period before resuming normal duties are major reasons. In spite of this fact, most studies carried out with live donors find that following a successful organ transplant, donors feel good both physically and psychologically and have no regrets. In this paper, five participants describe their experiences as live organ donors. Interviews are analysed using Thematic Analysis. The results show that for these participants, giving a kidney was the natural thing to do. The questions whether doctors should actively encourage live organ donation and whether live organ donation should be promoted through campaigns are discussed in light of these results.

1. Introduction

The fact that there is a shortage of organs to meet the need of all patients waiting for a transplant is a known fact. 1,2 The rate of kidnev transplants from living donors worldwide is 42% of the total number of transplants performed. It is twice higher than the rate for the European Union (21%).3This paper will focus on live organ donation and will discuss whether it should be actively promoted by family doctors, medical teams, campaigns and the media. While several campaigns have been carried out in order to promote donor cards and deceased organ donation, there have been no campaigns promoting live organ donation in Malta, in the last thirty years. The media often report cases of road accidents mentioning that the family donated the victim's organs thus keeping deceased organ donation in public discourse. They rarely however cover human stories about living organ donation. The former seems to be knowledge that journalists feel can be shared.However.living organ donation considered a private affair. In this study, the donors proposed live donation before the doctor did in four of the five cases. This research and other studies⁴ show that living donors experience no regret about the action they took. The number of studies that report that donors regret giving a kidney is very small compared to the studies which report that donors feelbetter psychologically after the donation.Live organ donation is a pro-social act and should be actively encouraged.

2. Literature Review

The success rate of living donor transplants is highand even better than that carried out using organs for deceased patients. Data from the Scientific Registry of Transplant Recipients shows that the success rate of kidney transplantation depends on the medical circumstances of the recipients. However, kidneys from living donors generally last longer.

Table 1 Success Rate of kidney Transplant Recipients

Type of Donor	1 Year	3 years	5 years	10 years
Living Donor	Graft survival	95%	88%	80%
	Patient survival	98%	95%	90%
Deceased Donor	Graft survival	90%	79%	67%
	Patient survival	95%	88%	81%

Source: SRTR – ScientificRegistry of Transplant Recipients

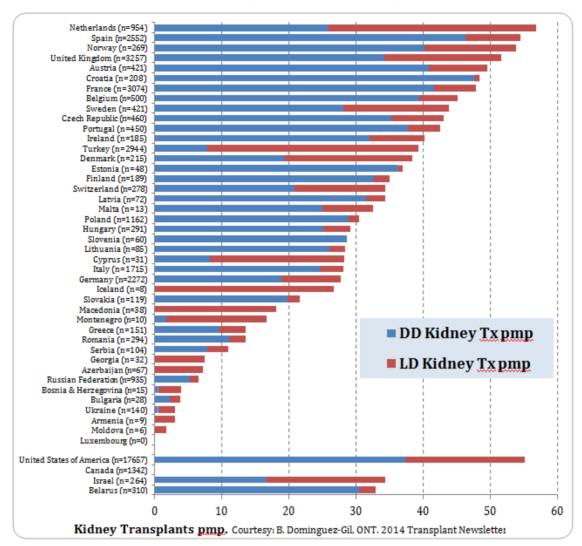
2.1 Deceased and Living Donations in Europe

The first kidney transplant between living patients was carried out in 1952. ⁵Non-related organ donation came later in the 1980's. One of the main issuesinvolved in living donations is ruling out that the donor is being coerced, paid by the recipient and or that he or she is receiving some reward. Altruism is rigorously questioned. Deciding which family member will donate is another issue. While this decision is sometimes straight forward, at other times it puts family members in difficult positions. This is more so

when there are many siblings. The medical implication for the donor isalso taken into consideration.

The rate of living kidney donations in some countries is low compared to others. It is not known whether this is due to more refusals to donate or whether it is because doctors believe that living organ donation should be the last resort. Figure 1 compares the number of living and deceased organ donation rate per million populations in several countries.

Figure 1:Live and deceased kidney transplants in Council of European countries in 2013



Source: European Commission, 2014³

For a relatively long time, the legislation in many countries only allowed live donation from relatives. As the success of organ transplantation improved, there were more donors who were willing to donate their organs. Pressure to allow non-related organ donation increased. In Malta, the first non-related organ donation took place in

2003. Related, non-related and deceased organ donation increased at a steady rate in the last fifteen years. Figure 2 shows the number of organ transplants from deceased and living donors in the EU, from 2004 to 2013. Although the numbers increased, they are still lower than those in other countries like America.

Deceaseddonors Livingdonors 9912 9790 9752 10000 9341 9230 9042 8756 8560 8414 8351 8000 7000 4219 4112 3874 3568 4000 3310 3139 2879 2458 3000 2388 2000 1000 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 Source: Annual Transplant Newsletters 2005 to 2014

Figure 2: Organ transplants from deceased and living donors in the EU, from 2004 to 2013 (All 28 EU Member States in 2013 are captured in this graph, even if they joined the EU after 2004.)

2.2 Motivations

The motivations to donate a kidney are various and depend mainly on the context and the personality of the donor. Lennerling et al.6conducted a qualitative study with 12 potential kidney donors. The motives expressed by the participants for wanting to donate a kidney were a wish to help the patient who was suffering, identification with the recipient, a feeling of moral duty, self-benefit from the relative's improved health, improved self-esteem from doing an altruistic act, external pressure and knowing that one can live a normal life with one kidney. Following this study, Lennerling et al.⁷ conducted a survey with 154 participants who were potential donors. The first two motives, the wish to help and identification with the recipients were the strongest motivations for donating. In this study, the researchers found that having to wait for a long time to receive a kidney from a deceased donor was another incentive to donate. Similar motivations to those found by Lennerling et al. 6were found in a quantitative study by de Groot et al. ⁸ with 114 participants and with a qualitative study by Brown ⁹with 12 living kidney donors.

The decision to donate a kidney may be a different experience for different donors. Gill and Lowes ¹⁰ studied the experience of 11 families who had one member undergoing renal transplantation. They found that for many of these families, the decision to donate a kidney was considered as a natural decision and was not a difficult one to make. The participants said that they did not spend much time in coming to the decision. They were tested and the relatives who could donate gave their kidney voluntarily without experiencing pressure and without spending much time considering the pros and cons of donating. For these relatives it was the 'natural thing to do'. ^{10(pg1611)}

Altruism was also found to be a motive in some studies. Simmonset. al¹¹ carried out a survey among 142 participants and found that 78% of the respondents claimed that they knew right

away that they would be donating one of their kidneys and that they did not have to think it over. Furthermore, over 70% claimed that either the decision was not hard at all, or that there was actually no decision to make. Similarly, Wilmset. al¹² also indicate that people who find themselves in the situation of donating a kidney whilst living, actually think very little about their behaviour. They automatically feel that it is the right thing to do.

2.3 The impact of donating on the donor

Andersen et al.¹³ carried out a study with 12 kidney donors. The researchers interviewed the donors twice, one week after donation and once again a year later. This qualitative study found that 'all participants expressed an overall positive experience' even if there were differences between those who were involved in a successful transplantation and others who had experienced a transplantation failure. 13(pg. 702) similar results were obtained in a longitudinal study carried out by Feltrin et al.14 between 2002 and 2006. Of the 69 participants who took part in this study, 96% said that they had 'a positive global opinion of the experience'. 14(pg 466)In another study by Gill and Lowes, 10 data was collected through a series of three semi-structured interviews with 11 donors and recipients. Interviews were conducted before the transplant and at three and ten months after the transplant. The results showed that all donors made an instantaneous, voluntary decision to donate and found the decision relatively easy to make. Donors derived immense personal satisfaction from this outcome and it helped to confirm to them that what they had done had been worthwhile.

These conclusions also emerged in a systematic review of 51 studies from 19 countries published between 1969 and 2006 carried out by Clemens and his colleagues. ¹⁵ The researchers wanted to find out what impact living kidney donation had on the donors' social functioning, self-concept, body-image, psychological well-being and quality of life. Clemens ¹⁵ found that their perception of the quality of their personal relationships either did not change or else improved. The studies involved 5139 donors who were assessed on average four years after

the donation. These researchers also ound that the notion of self-concept was reported by manyof the donors as having increased. 15(pg ²⁹⁶⁵⁾This was not reported across the board in all the studies reviewed. In one study, donors stated that they did not feel better about themselves after the donation, and a small percentage 'felt that they had given up something for nothing in return'. 15(pg 2971) The authors concluded that when all the studies they reviewed were considered, the psychosocial health of most donors appeared to be either unchanged or positively improved by the donation. Although some participants reported negative outcomes, the proportion of donors who experienced these situations was small and most importantly, the majority stated that they would undergo the experience again. 15(pg 2974)

2.4Promoting living organ donation through social marketing campaigns

Since mosttransplantable organs cannot be manufactured, the only supply is through donors. Persuading people of the value of organ donation and encouraging them to donate their organs is essential. Deceased organ donation has been promoted with positive results. ^{16,17} Living organ donations need to be promoted much more than is happening presently.

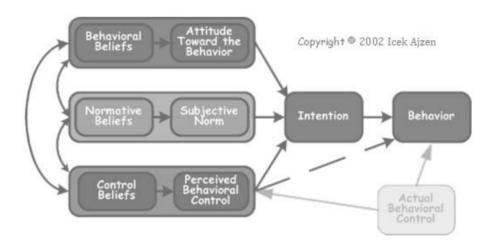
One way how this can be done is by designing and implementing effective social marketing campaigns. These create awareness and provide information. Kotler, Roberto and Lee 18 describe a social change campaign as an organised effort conducted by a group which is attempting to persuade others to accept or modify ideas, attitudes, practices or behaviours. The more the issue of live donation forms part of public discourse as a result of campaigns, the easier it is for people to become live donors. Social marketing was used with positive results in reducing alcohol consumption, ¹⁹ condom use and health, 20 reproductive breastfeeding immunization.²¹ Social marketing was also used in the prevention of, for example, cardiovascular disease ²² and AIDS.²³ Governments in many countries like Australia, Canada, New Zealand, UK and the United States have used a strategic social marketing approach to change public

opinion and behaviour. The same approach can be used to promote live organ donation.

Social marketing campaign may bring about a change in both attitudes and behaviour. The model put forward byAjzen²⁴⁻²⁶is a good framework to understand what happens as a result of an effective social marketing campaign.

According to Ajzen²⁴ there are three factors that influence the intent by a person to perform an action like donating an organ. These are the attitudes of the person, the beliefs and support given by significant others and perceived behavioural control that is how easy or difficult it is to perform the action or behaviour.

Figure 3: The Theory of Reasoned Action by Ajzen



Source: Ajzen, 1991 27

The theory of planned behaviour put forward by Ajzen ²⁷ implies that if social marketing campaigns can change the attitudes of potential donors and the people close to themare in favour of a particular issue like living organ donation, then the probability of donating increases. The potential donor translateshis or her intention to action.

This is more the case for persons who have a vested interest in the behaviour. Crano²⁸ put forward the Vested Interest Theory. In line with this theory, it is the case that while attitudes and self-efficacy are important elements in predicting behaviour, the person's stake or vested interest in the action, increases the attitude – bond behaviour and consequently increases the likelihood that a person will act according to his or her beliefs. In the case of living organ donation, having a vested interest in the recipient becoming healthy and living a normal life

increases the likelihood of the donor deciding in favour.²⁹

3. Methodology

The aim of this qualitative study was to understand the lived experience of five donors who donated a kidney. The five participants were recruited by the help of nurses at the Renal Unit. Interviews were carried out with the five live donors. Three of these donors gave a kidney to relatives while two gave a kidney to an unrelated recipient. The interviews were conducted at the donors' residence and each interview lasted between 60 and 90 minutes. recorded They and transcribed. were Transcriptions were sent to participants to check that there were no misunderstandings.

There are two major limitations in this research. The first is that all the five participants experienced a positive outcome. In all cases the

transplant was a success and therefore participants probably remembered the positive elements more than the negative ones. The second limitation is that since years had elapsed since the transplant, participants may have forgotten negative consequences.

4. Analysis of data and discussion

The live donors came from different backgrounds and had different levels of education. Table 2 provides information about these participants.

Table 2: Participant information

Participant	Age and	Occupation	Relation to recipient	Years since
	Gender			transplant
Participant 1	60	Academic	Sister to brother	11 years
	Female			
Participant 2	28	Sales person	Friend to friend	6 years
	Male			
Participant 3	56	Company Director	Friend to friend	13 years
	Male			
Participant 4	69	Housewife	Mother to daughter	11 years
	Female			
Participant 5	39	Office Clerk	Daughter to mother	9 years
	Female			

The interviews were transcribed and the texts were analysed using Thematic Analysis as used by Braun and Clarke. The discussion of the themes which emerged from the text will be discussed in three sections (i) the decision to donate (ii) pre-transplantation phase and (iii) post-transplantation phase.

The decision to donate

The doctor initiated the possibility of live organ donation in only one of the five cases. In the other four cases it was the family or friend who brought the subject forward for discussion. These participants looked for information on living donation, often on the internet, and kept it to themselves for days or weeks. When they felt that they could seriously consider donating a kidney, they brought up the topic with their family then with their doctors or consultants.

I started doing some "research", on my own, on the internet and I discovered that these patients have the possibility, given that they are on the waiting list, that if they receive a kidney from someone who is dead or alive and the procedure is successful, then there wouldn't be a need to make use of the dialysis treatment...I started to investigate and I made my first appointment with a consultant, after I had talked with my next of kin, meaning my wife and my children ... Participant 3

Participants had various motivations for donating kidney. The main reason why all the five participants decided to find out about the possibility of donating an organ was seeing their relative or friend suffering.

... Because I used to see her suffer too much. The machine, she would spend two days on the machine, two days in bed... The machine, you know what it means, it drains you so much that it does not allow you to perform daily chores and one has to take care of one's son. He already had enough tension, poor child. Participant 4

Another motivation to donate was a sense of duty to help their relative or friend. Doctors, when approached by the prospective donors were very careful not to put pressure on possible donors even when they suggested the idea themselves.

I told him no, I'm ready to donate it to her. I didn't consider the possibility of losing my life or

anything else... I only saw her child... He was still very young, 6 years old. Participant 4

Other motivations mentioned by participants included wanting to help a friend, wanting therelative to get better so that the family goes back to 'a normal life', and knowing that giving a kidney was the only thing one could do to save the life of the patient.

And I knew that, it wasn't, the dialysis is not forever, you know, that eventually there is going to be further deterioration and you know, that's it, basically. So, so I think I felt like, it's not an obligation, I never felt like it is an obligation...I see it very much as a natural process. Participant I

All donors were Maltese. Four of the live transplants were carried out in Malta while one was carried out abroad. Participants felt supported by their family members and also by the medical team.

...I mean, I don't know what it's like in Malta but
... they were extremely supportive. I mean, they
really... you go through the process, you go
through a lot of tests but at the same time,
during that process they...I mean, I saw a
psychologist, and em... the people who coordinate the transplant are very
helpful...Participant 1.

When there is more than one possible donor, the decision who will be the one to donate can be complex. In the case of the five participants in this study, all were determined to donate. They discussed the implications with other possible donors in the family.In four cases, the understanding was that if there is a match,the participants would be the ones to donate. In the other case, there was no other prospective donor.

Support groups were very helpful to prospective donors and recipients. Hearing a testimony from somebody who had gone through the experience compliments the information and reassurance given by doctors and medical professionals.

But then, there was Laura, who had just received a kidney. She had been on dialysis during the time my mother was on the machine, and thank God she was there. I think that the people who really help you are those kind of people. Others try to give encouragement and other things, but when someone shares his or her experience with you, they are the people that encourage you the most. Participant 5

Faith in God was another factor that helped the five participants take the decision. Four were practicing Catholics while one was non-practicing.

Oh, I tell Him "Thank you Lord in all your greatness. I pray to the Lord and thank Him all the time. Him and Padre Pio. I tell the others "Don't stray away from the Lord, because without Him, we can do nothing. He's the one that's there for us. If you don't have faith, you won't keep going on. Faith and patience. Participant 4

Pre-transplant period

Once the decision by the donor is taken, many tests have to be carried out. The wait seemed too long for all the participants. They all said they wanted the operation to take place as soon as possible. Inspite of the determination to give the kidney, donors still had moments of doubtand they questioned whether they made the right decision.

This is why I started worrying, because I started thinking that I would die during the operation, or God forbid that after the operation I would experience a kidney failure... When you have kids, you start thinking about it more and more, as you start looking at them and pondering "Shall I do it? Shall I not?"... So the doubts are there, you know? But I wanted to do it, I wanted to do it for sure. Participant 2

In the case of the non-related donors, the ethics committee took longer to decide to rule out any collusion involving exchange of money or other rewards. One participant was offended by this approach. In his words he felt like a criminal being investigated for a crime.

It's been two years and I am not going to tell you that I didn't feel like giving up... because between the fear and the hospital not supporting you, as well as having to go up to the Board of

Ethics and other things, there are a lot of procedures. You end up spending two years being treated like a criminal, quite literally. Not from the people though! But since he is not related, you can't really blame them, as they would want to know everything. Participant 2.

He said that it was difficult to persuade people that he will not be getting money or other rewards for donating the kidney. It seems that members on the ethics board as well as medical professionals do not believe so much in altruism and therefore are extra careful to make sure that everything is above board.

Participant 1 said that once she had decided to donate her kidney, the Italian authorities asked her to go the tribunal, to sign.

You actually appear before, like a judge... It's not a court ... I don't think it's a judge, but anyway he represents the ... and you actually sign, you know, it's like a contract... Participant

Another common experience among the five participants was the fear that gripped them just before the operations. While they were very determined to donate their kidney, they experienced fear in those hours before the operation. One participant said he was so afraid that he wanted to run away and another said that she was very anxious and distressed. It suddenly hit her and was very afraid.

My mother left and well, I knew the procedure. I was waiting there in order for them to assess and give the "go ahead". They left me in the corridor, out in the cold and it was then when it hit me! During all that anxiety...Participant 5

Post-transplant period

All five donors had clear recollections of the time when they regained consciousness after the operation. In all cases, the first question was always whether the operation was successful. It is a moment they will never forget. They describe it as a very positive experience.

But I feel happy to have done it, I mean, very much so. Participant 2

It's an experience...! I feel proud. I feel happy. I feel emotional. Participant 3

It's a beautiful feeling, a positive one. Participant 5

In one case the donor was not told whether or not it was successful. The kidney had not worked immediately. Relatives tried to avoid telling the truth and this gave rise to great anxiety. When the kidney finally worked, it was a very emotional moment for all.

The participants varied in their recollection of the pain and discomfort they experienced after the operations. None of the five donors regretted the decision. They are so happy that they have helped their friend or relative that they want to do something concrete in order to help others in similar situations to come to this decision. All of them said that if they were asked to take the decision again, they would say yes.

It's not something that... it's sort of something I did and I think I would do it again. Well now I can't because I have one. But it's true, if I had the possibility I would do it again ...Participant 1

Honestly, despite perhaps that little bit of suffering, these things aren't very complicated, however if I could, yes, I would do it again. Participant 3

Perhaps you'll understand me, I mean, we were lucky. Other people comment "What are you saying?" This is how I feel. If I had to do it again, my life I mean, I wouldn't want it to be any other way. Participant 5

Common beliefs, common fears and common emotions

There were many similarities in the experiences of the five participants. The table below gives the common beliefs, fears and emotions shared by the five participants.

Common beliefs	 It is not right that a person should suffer so much I can help this person Anybody in my position would donate a kidney 		
	 God will help me and the operation will be a success 		
Common fears	Something happens to me before I can give the kidney		
	 Tests show that there is no match and Icannot give the kidney 		
	The operation is not successful		
	The kidney is rejected		
	I die during the operation		
	 The recipient dies during the operation 		
	 My one kidney fails and there is nobody to give me one 		
Common positive	I was determined to give the kidney		
emotions	 I was very happy when told that the operation was successful 		
	 I have no regrets about having donated my kidney 		
	I would do it all over again		

The success of kidney transplants from living donors is high as reported in Table 1 above. It is therefore pertinent to propose that health authorities should encourage live organ public communication donations through campaigns.In Malta. notwithstanding introduction of a new legislation regulating organ donation, campaigns continue to focus on promoting deceased organ donation. This situation is similar in many other countries. Campaigns encouraging live organ donations are not common. ³⁰Experiences and testimonials from living organ donors can help in raising awareness about the possibility of donating a kidney while still alive. Social marketing campaigns should exploit living donors' experiences, their common beliefs, fears, and positive emotions. Such campaigns can also provide more knowledge about the implications of living organ donation resulting in attitude changes amongst those who have fears about live donation. 30,31 Campaigns could also be a stimulus to those who have not considered the option. Non-related living donation should be actively encouraged. The fear that people may give their organs for profit should not preoccupy medical authorities. Altruism should be encouraged. Given that there is rigorous checking that no coercion or that any form of reward is involved, then giving a kidney to a relative, friend and even to a non-related other should beendorsed and supported.

Perhaps, more importantly, there should be a change in how the medical profession looks upon living organ donation. The recipients in this study did not experience regret after donating a kidney. Other studies discussed above found similar results and therefore the following questions are pertinent:

- Should family doctorsencourage live organ donationat the time of prognosis?
- Should unrelated living organ donation be actively supported?
- Should we be promoting living organ donation through national campaigns?

5. Conclusion

The majority of live donors, in various studies, have by far been positive about their experience and said that they have no regrets about having donated a kidney. As long as no coercion is

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involved and that family members and potential donors are well briefed, giving a kidney should be treated like any other decision by the medical team. In this paper it is being argued that living organ donation should be promoted and nonrelated organ donation should receive more support. National campaigns should be commissioned to help bring change in public attitudes. What significant others say or believe will have an impact on potential donors but the support by the family doctor is even more crucial. It is therefore important that the attitudes of medical professionals must become more encouraging and forthright of living organ donation.

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