

# A model for scoring and grading willingness of a potential living related donor

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There are few examples in the literature of objective measures for the assessment of donor willingness. The author describes the scoring system in use at his own renal transplant unit which has brought objectivity to the process of determining the willingness of living related donors. In this system, a total score to determine the degree of willingness or unwillingness is calculated based on responses to a series of questions. The author believes that with minor modifications this system could be implemented by transplant units in different countries and cultures to screen out donors who are acting under duress.

Since our renal transplant service began in 1979, it has been our policy to exclude donors who have been coerced into donation or are unwilling. To this end, we exclude from donation anyone below the age of 18 years or anyone with mental retardation to the extent that he or she does not understand what donation means or involves.

Very often, individuals will not admit to being unwilling, believing such an admission will be viewed as shameful in some societies. For this reason, it is not good practice to ask directly if they are willing or not. The physician should pursue the assessment (of unwillingness) with compassion and understanding and should suppress any negative feelings or feelings of anger or dislike for the donor who is unwilling, and should not be hostile to the donor for “wasting” their time. This feeling of hostility on the part of the physician is more likely to emerge if the donor only reveals his unwillingness at the last hurdle.

There are very few examples, if any, in the literature of objective measures for assessment of donor willingness based on ethical “norms”. The methodologies used in this connection are largely based on the subjective feelings of the transplant team and/or psychiatric assessments. In the few papers that have addressed this concern the basis of the conclusions made depended largely on discussion groups<sup>1</sup> or surveys.<sup>2</sup>

In order to invoke objectivity in the decision making process of determining willingness for donation, we have developed a scoring system based on questions that we have found to be revealing. Each observation or reply to a specific question is then classified as being indicative of “willingness” or “unwillingness” and a positive or negative score is given to the obtained reply or observation. The total score is then calculated which would indicate the grade (degree) of willingness or unwillingness (see table 1). For a special category of vulnerable subjects the grading system is made more stringent. These special categories include: (a) those potential donors at 18 years of age or just above; (b) wives donating to husbands; (c) females as a whole because it was found, even in Western societies, that there is an unexplained preponderance of female donors and male recipients; and (d)

those with normal mental capacity but whom we deem have not understood completely the meaning and impact of donation.

This model was initially developed on the basis of previous experiences and observations which enabled us to judge the importance and significance of the responses to the different questions and of the observations as listed in the text. Based on this, the scoring system was developed initially empirically. The scoring system so designed was further tested by its implementation on the donors. Fine tuning of the model with the addition of further questions and amendment of the scores took place over a long period of time.

Over the last 24 years we have interviewed and observed over 1100 potential donors. Using this model we never had any pre or post-transplant indications of disturbed familial relationships or an unhappy donor despite long term follow up. It is my strong belief that this model of scoring and grading is useful and implemental on a global scale by all transplant centres dealing with living related donation. The elements of the questions and observations would, however require alteration and amendment according to the unit’s policy and the societal attitudes and therefore each centre would have its own scoring and grading systems. The lists of possible responses to the various questions that are listed in the text below are clearly not exhaustive and each unit will have to think about all possible responses according to its past experiences and societal attitudes and score them accordingly.

Clearly underlying the whole business of acceptance and willingness (or otherwise) for donation is the clear need (indeed, the right) of the potential donor to be told, in terms he/she can easily understand, all there is to know about donation, transplantation, the short and long term complications for both the donor and recipients, and the requirement for follow up and so on. This is pivotal because one can only decide about one’s willingness on the basis of full information. That is not just a legal requirement but a human, ethical, and psychological requirement.

## THE COMPONENTS OF THE MODEL

This model has three components: (A) specific revealing questions, (B) observational pointers to willingness, and (C) observational pointers to unwillingness.

### (A) Specific revealing questions

1. *When do you want the operation to be done?*

Now (+4)

After a while (–2)

Generally, willing donors are eager to help their sick relative as soon as possible. Unwilling donors, on the other hand, want the operation to be delayed and but will not provide convincing reasons for this. It is a psychological defense mechanism to delay the occurrence of “bad event”. They also subconsciously hope that somehow the need for their donation will vanish with time.

**Table 1** Scoring system to assess willingness/unwillingness to donate

Degree of willingness*	Score for "normal" potential donors	Score for special donor categories
Extremely willing	+45 to +56	+50 to +56
Very willing	+35 to +44	+40 to +49
Quite willing	+25 to +34	+30 to +39
Borderline willing	+15 to +24	+20 to +29
Borderline unwilling	+1 to +14	+6 to +19
Quite unwilling	0 to -15	+5 to -10
Very unwilling	-16 to -25	-11 to -20
Extremely unwilling	-26 to -56	-21 to -56

\*Highest score for willingness is +56; highest score for unwillingness is -56.

## 2. Do you get loin pain?

No (+2)

Yes (-2)

This is an important question especially in societies where illness and localisation of pain are interlinked (our patients, for example, when suddenly told that they have advanced chronic failure will immediately respond with absolute surprise: "but I have never experienced any pain in my kidneys!"). As such, unwilling donors consider that to state that they have pain over the kidney is tantamount to stating that they have diseased kidneys which would therefore exclude them from donation. On the other hand, we have experienced willing donors who deny having pain over the kidney, whom we have subsequently discovered as having pain causing conditions such as stag horn calculi.

## 3. Why do you want to donate the kidney?

I love him, OR it is my duty, OR so that God may reward me in the hereafter (+6)

Because nobody else would come forward OR because other members of the family were found unsuitable (-3)  
The answer to this question can be very revealing and delve into the psychology of the potential donor. It is an apparently innocuous question to which the donor tends to answer truthfully.

## 4. Why aren't your other siblings donating?

Because I stopped them (+6)

I am perplexed by this myself (-3)

This question gives an opportunity for the unwilling donor to reveal his feelings about other relatives who are not coming forward to donate.

## 5. What does your wife think of this whole business?

She is worried but I don't give a damn (+6)

She is very happy about my decision (+4)

I have not consulted her (+2)

She is against it and that is something that I have been seriously considering (-4)

This question is put forward to give a way out for the unwilling donor.

## 6. Do you have any questions?

No (+6)

Will I have problems having children? (+4)

Are you sure that my loin pain/blood group/my smoking habit etc are not factors against my donating my kidney? (-5)

## (B) Observational pointers to willingness

1. High score for smiling. A smiling happy donor is a willing donor (+10).

2. Arriving to the investigation appointment 15 or more minutes before its time. A willing donor worries about missing appointments lest his "suffering" relative stays longer on dialysis (+8).

3. Only one donor comes forward for donation. We found repeatedly that an extremely willing donor stops other family members from coming forward and finds excuses for them to put them at ease while he comes forward for donation (+3).  
4. Offspring to parent donation (in Eastern Societies, where parents are exalted) and parent to offspring (in Western Societies) (+3).  
5. Persistently calling for results of the investigations or enquiring about the next step (+10).

## (C) Observational pointers to unwillingness

1. Multiple simultaneous donors. All hoping that the "other" will be chosen for donation and yet there is no loss of face on their part (-3).

2. Hostility to nurses. Hostility to nurses is a transference mechanism. The donor is under pressure to donate so the hostility is displaced to the nurses (-10).

3. Frequent postponement or late arrivals to investigations appointments. Psychological delaying tactics, avoiding what might turn out to be bad news (such as being found suitable for donation) (-8).

4. Repeated referral to history of "loin pain" (-10).

5. Never calling for results of the investigations or enquiring about the next step—a "no news is good news" philosophy (-3).

Top score for willingness +56; top score for unwillingness -56.

## DISCUSSION

There have been very few data in the literature about willingness to donate a kidney and in the few papers that have addressed this concern, the basis of the conclusions made depended largely on discussion groups<sup>1</sup> or surveys.<sup>2</sup> Moreover most papers address "theoretical" willingness to donate a person's own or their relatives' kidneys after death. One report suggested that willingness to donate, at least in black Americans, correlated with willingness to volunteer.<sup>3</sup> The differing attitudes towards donation are influenced by many factors such as degree of education,<sup>3</sup> sex<sup>3</sup> and race,<sup>4</sup> and area.<sup>5</sup> In a survey in British Columbia, as many as 29% of those reached by phone supported living anonymous donation and that some would consider becoming living anonymous donors themselves.<sup>5</sup> The introduction of laparoscopic donor nephrectomy has increased the chances of having a willing donor by a factor of 1.9<sup>6</sup> and also increased the chances of recipients having a kidney from a related donor.<sup>7</sup>

It is of paramount interest to most transplant physicians that the living donor of a kidney should be under no pressure whatsoever, be it psychological, social, or financial. The freedom to choose one's course of action and be able to make one's decision free of coercion is a prerequisite for the most mundane decision making situations—let alone one which results in loss of an organ and the undergoing of a relatively major surgical operation.

Although it may be necessary for transplant centres to have one or other mechanisms to ascertain free and carefully thought out willingness to donate, these mechanisms are often lacking or are superficial and left to the most junior doctor in the team. Assessment of willingness often depends on the potential donor merely being told that "we are going to investigate you for your suitability to donate one of your kidneys to your brother/sister/mother/father (etc)". It is left up to the potential donor to express refusal to donation to such a statement whereas I believe it is the transplant team's ethical duty to ascertain willingness, even when the donor ostensibly expresses willingness.

It is true that psychiatrists are often asked to assess the potential donor. The psychiatrist's brief in this setting is, however, to assess the donor's mental and psychological

status and not to assess their willingness, which would require a different set of exploratory tools and techniques.

The transplant team also depends on the assessment and opinion of the team members particularly the transplant coordinator. Although such opinions are often accurate they are almost always subjective and, to a large extent, inevitably influenced by the coordinators' own psychosocial make up and their ethical standpoints. They may even be influenced by aggressive policy of the transplant unit to do "more transplants".

To overcome such prejudices and biases, I have developed this scoring system, which is objective and measurable. The method was initially developed on the basis of long term observations and experience which allowed our unit to judge the importance and significance of the responses to the different questions and of the observations as listed above. Based on this, our scoring system was developed empirically and was further tested by its implementation to donors.

This system has been tested and refined over the years with our potential donors. Even those found unwilling were followed up over a long period of time.

This scoring model has been found to be consistent, reproducible, and has a high degree of sensitivity of judging willingness (100%) with a specificity of 85%. The calculation of the sensitivity and specificity (of judging willingness) was based on willingness being proven when no change of mind before the operation occurred and when no post-transplant psychosocial and/or familial tensions or feelings of guilt occurred after a mean follow up period exceeding 10 years, even when the recipient died or lost the allograft. These figures suggest that none of the potential donors judged willing was proven at a later stage (using the criteria described in the previous sentence) to have been unwilling. And out of every 100 potential donors, this scoring model judged 15 wrongly as being unwilling when they were actually willing, as demonstrated by their subsequent donation to another hospital with no adverse outcome suggesting unwillingness.

It is clearly necessary and important for the different centres to adapt the system to their different societies, ethics, and cultures. The questions, although generic in their nature and wording, may require slight rewording and their scores may need to be redefined. The same could be said about the observations which although again are generic in nature and traverse societies, may need to be rescored. Needless to say, each unit may have to omit, rephrase, and/or add questions as their experience dictates.

I believe that such a scoring system could be applicable in different transplant units in different countries and cultures with minor modifications. After a short pilot experience to validate the system in the different centres, it should be easy to implement.

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