

When do Next-of-Kin Opt-In? Anticipated Regret, Affective
Attitudes and Donating Deceased Family Member's Organs

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Abstract

This research assessed whether affective factors promote and prevent family members from donating their loved one's organs. Participants (N = 191) imagined that a family member had died and that they had to decide whether or not to donate their organs and body parts for transplantation purposes. The least organs and body parts were donated when the deceased opposed donation. Moreover, participants who were not registered organ donors donated fewer organs than registered donors. This effect was mediated by anticipated regret, disgust, and the perceived benefits of donation. Organ donation campaigns should target such factors to increase donor rates.

Keywords

Emotions, family, health promotion, mediator, beliefs.

Introduction

Throughout the world there is a shortage of donor organs to meet the demand for transplantations. In the US there are currently over 110,000 people on the waiting list for a solid organ transplant and 18 people per day die awaiting an organ (<http://www.organdonor.gov>). Similarly, in the UK there are currently over 10,000 people waiting for a solid organ transplant and 3 people die per day awaiting a donor organ (<http://www.uktransplant.org>). Moreover, the situation is getting worse, with the number of people awaiting an organ increasing each year (NHS Blood and Transplant, 2011; OPTN/SRTR, 2011). Previous research has found that next-of-kin have considerable influence over whether the deceased's organs are donated in both presumed and informed consent countries (Rosenblum et al., 2012). In many countries, medical professionals will not transplant organs if family members oppose transplantation, even when there is no legal obligation to receive family member's consent because the deceased is a registered organ donor. Indeed, researchers have argued that the availability of donor organs may be substantially increased by preventing family members from vetoing their deceased loved one's decision to be an organ donor (Shaw, 2012). Moreover, even when a loved one's wishes are not recorded a considerable number of potential donors are being lost because family members do not consent to donation. For example, in 2010, 43% of UK families refused when asked if their loved one's organs could be used for transplantation purposes (Council of Europe, 2011). It is, therefore, important to identify the factors that promote and prevent family members from donating their loved one's organs in order to increase the number of donor organs, thereby saving lives.

Previous research has focused on the rational, cognitive factors that guide next-of-kin's decision making. For example, research has found that donation was more likely when family

members understood the concept of brain death (Jacoby & Jaccard, 2010), knew the deceased's wishes (Exley et al., 2002; Siminoff et al., 2001), and had positive attitudes towards organ donation (Siminoff et al., 2010). Recent organ donor registration research has found that emotional or affective factors are stronger predictors of people's intentions to register and registration behaviour than rational, cognitive components (Morgan et al., 2008; O'Carroll et al., 2011a, 2011b). Although donating one's organs and consenting for a family member's organs to be donated are separate actions, they are both influenced by similar factors (Mossialos et al., 2008). The aim of the present study was, therefore, to extend previous research by determining whether such emotional and affective factors predict family member's willingness to donate a loved one's organs.

The role of affective factors on organ donation

Recent research has found that people's affective attitudes are likely to guide decisions relating to organ donation (Morgan et al., 2008; O'Carroll et al., 2011a, 2011b; Shepherd & O'Carroll, in press b). These affective attitudes include the anxiety associated with the belief that the body should be kept whole for burial (bodily integrity), fearing that doctors may hasten the death of seriously ill patients in order to harvest their organs (medical mistrust), feeling disgust towards the idea of organ donation (the 'ick factor'), fearing that organ donors may not be resurrected because they do not have all of their 'parts' (jinx), and the positive arousal associated with the belief that organ donors are heroic because they save lives (perceived benefit). Research in the US (Morgan et al., 2008) and the UK (O'Carroll et al., 2011b) has found that registered organ donors are less likely than non-registered participants to feel the negative emotions towards donation and endorse these negative beliefs, and are more likely to believe the positive consequences of organ donation. Moreover, further research has found that the more non-donors

endorse the negative affective attitudes, the less likely they are to subsequently register as an organ donor (Shepherd & O'Carroll, in press b).

To date, this research has focused on the role of affective attitudes in promoting organ donor registration. The first aim of the present study was to enhance previous research by assessing the role of these beliefs on the decision of whether or not to donate a *loved one's* organs. It is likely that the greater the participant endorses bodily integrity and jinx concerns, and the ick factor the less likely they will be to donate their loved one's organs. By contrast, perceived benefit beliefs are likely to increase the likelihood of family members donating their loved one's organs. Medical mistrust is most likely to affect the decision to donate before the loved one has died because family members may believe that doctors may not do everything possible to save the life of their loved one. By contrast, when the decision is made after the family member has passed away medical mistrust is less likely to affect the decision to donate their organs.

Another affective factor that has been linked to organ donation is anticipated regret (O'Carroll et al., 2011a, 2011b). Regret is an aversive counterfactual emotion that is likely to be experienced when people wish that they had acted differently in the past (Zeelenberg, 1999). Research has found that family members may later experience regret for their decision regarding whether or not to donate a loved one's organs, especially if they refuse to donate (Jacoby & Jaccard, 2010; Ormrod et al., 2005; Rodriguea et al., 2008; Shaw, 2012). This implies that regret is relevant in the decision regarding whether or not to donate a loved one's organs. It is also possible to anticipate the amount of regret that is likely to be felt for failing to undertake an action, providing people with a pre-emptive strategy for avoiding this aversive emotion (Simonson, 1992; Zeelenberg & Pieters, 2007). For example, research has found that anticipating

regret for not registering as an organ donor increase people's willingness to register (O'Carroll et al., 2011b) and self-reported registration (O'Carroll et al., 2011a). The present study extends this research by assessing whether anticipating regret for refusing to donate a loved one's organs increases people's willingness to consent to donation.

Another important factor is whether or not the participant is a registered organ donor (participant's organ donor status). As mentioned above, registered organ donors are less likely than non-registered participants to feel the negative emotions towards organ donation and endorse the negative affective attitudes, and more likely to believe the positive consequences (Morgan et al., 2008; O'Carroll et al., 2011b). Based on this research, we hypothesised that registered organ donors would be more willing than non-registered participants to donate their loved one's organs and that this effect would be mediated by their affective attitudes towards organ donation. Moreover, because registered organ donors are more likely than people who are not registered to support organ donation, registered donors are likely to anticipate greater levels of regret for *not* donating a loved one's organs. The desire to avoid this regret may motivate people to consent to donation. The relationship between the participant's organ donor status and their willingness to donate a loved one's organs may, therefore, also be mediated by anticipated regret.

Present study

The aim of this study was to determine the affective factors that promote and prevent people from consenting for their loved one's organs to be used for transplantation purposes.

Approaching family members who have recently lost a loved one is likely to cause excess distress. Because of this ethical issue, we decided that it would not be appropriate to contact such families. Previous research has avoided this ethical issue by using vignette studies (e.g., Harris et

al., 1991). In line with this, we used a vignette study to assess our hypotheses. Participants were asked to imagine that a close family member had died and that they had been asked to decide whether his/her organs could be used for transplantation purposes.

Previous research has found that the deceased's attitude to organ donation is an important predictor of whether or not family members consent to donation (Exley et al., 2002; Siminoff et al., 2001; Siminoff & Lawrence, 2002). We, therefore, also assessed the role of the deceased's organ donation status on people's willingness to donate a loved one's organs. Participants were either a) given no information about this (control condition), b) informed that their loved one was a registered donor (donor condition), c) told that their loved one was not a registered donor (non-donor condition), d) informed that their loved one had not registered because they had concerns about bodily integrity (active non-donor condition), or e) told that their loved one had agreed with donation but that they had not registered (passive non-donor condition).¹ The distinction between active and passive non-donors was made to determine whether people's willingness to donate a deceased non-donor's organs is affected by the reason why the deceased was not registered. Indeed, in opt-in systems inaction (i.e., not registering as a donor) may be ambiguous because it may represent either an objection to organ donation or that someone failed to undertake the action required to show their consent, despite the fact that they were willing to donate their organs.

Method

Participants and design

A total of 191 undergraduate students (41 males and 150 females) participated in this study in exchange for course credit. The age range was 17-64 years, with a mean of 20.77 ($SD = 5.70$). Eleven participants did not state their age. There were 90 registered organ donors and 101

participants who were not registered as an organ donor prior to completing the study. The percentage of registered organ donors in the study (47%) was slightly higher than that of the Scottish general public (38%). The participant's organ donor registration status (registered versus not registered) was a quasi-independent variable. The deceased's organ donor status (control, donor, non-donor, active non-donor, and passive non-donor) was experimentally manipulated. Participants were randomly assigned to one of the five experimental conditions. The study, therefore, used a 2 (participant's organ donor status) x 5 (deceased's organ donor status) between participants design. The dependent variables were the total number of organs and body parts donated, anticipated regret, and people's affective attitudes towards donation (Morgan et al., 2008; O'Carroll et al., 2011b).

Materials and procedure

After giving consent, participants stated whether or not they were a registered organ donor. Next, they were then asked: *"Please imagine that a close family member has passed away and that you have been asked to decide whether his/her organs may be used for transplantation purposes"*. We then manipulated the deceased's organ donor registration status. Participants in the control condition did not receive any information about the deceased's organ donor status. Participants in the donor and non-donor conditions were asked to imagine that the deceased was or was not a registered organ donor, respectively. Participants in the active non-donor condition were asked to imagine that the deceased was not a registered organ donor because they did not like the idea of having his/her organs removed from his/her body. Participants in the passive non-donor condition were asked to imagine that the deceased approved of organ donation, but that they had not registered.

Total number of organs donated. Participants were asked to rate whether or not they would donate their loved one's heart, lungs, kidneys, liver, pancreas, small bowel, eyes, skin, bones and heart valves. A dichotomous response was provided for each body part ('yes' or 'no'). We summed the total number of body parts that the participant was willing to donate.² This variable indicated people's general willingness to donate their loved one's organs.

Anticipated regret and affective attitudes. Anticipated regret was then measured using two items: 'If I did not allow my loved one's organs to be used for transplantation purposes I would feel regret' and 'If I did not allow my loved one's organs to be used for transplantation purposes I would later wish that I had' ($\alpha = .80$). Both items were rated on a 7-point Likert-type scale (1 = *strongly disagree*, 7 = *strongly agree*). Participants then rated their affective attitudes towards organ donation using an established scale (Morgan et al., 2008; O'Carroll et al., 2011b). Bodily integrity is measured with 2 items (e.g., 'Removing organs from the body just isn't right'; $\alpha = .81$). Medical mistrust is measured with 4 items (e.g., 'If I sign an organ donor card, doctors might not try so hard to save my life'; $\alpha = .75$). The 'ick factor' is measured with 3 items (e.g., 'The idea of organ donation is somewhat disgusting'; $\alpha = .84$). Jinx is measured with 3 items (e.g., 'Organ donors may not be resurrected because they don't have all of their "parts"'; $\alpha = .60$).³ Perceived benefit is measured with 4 items (e.g., 'Organ donors are heroic because they save lives'; $\alpha = .72$). All items were rated on a 7-point Likert-type scale (1 = *strongly disagree*, 7 = *strongly agree*). Once participants had completed this scale they were debrief and thanked.

Results

Total number of organs donated

The number of organs donated ranged from 0 to 10, with a mean of 7.08 ($SD = 3.21$). This mean was significantly greater than zero, $t(181) = 29.73, p < .001$, indicating that people

were generally willing to donate their loved one's organs. A 2 (participant's organ donor status: registered versus non-registered donor) x 5 (deceased's organ donor status: control, donor, non-donor, active non-donor, and passive non-donor) ANOVA was conducted on the total number of organ's donated. The total number of organs donated was greater for participants who were registered organ donors ($M = 7.92, SD = 2.49$) than those who were not registered ($M = 6.34, SD = 3.58$), $F(1, 171) = 12.19, p = .001, \eta_p^2 = .07$. The main effect of the deceased's donor registration status was significant, $F(4, 171) = 3.30, p = .012, \eta_p^2 = .07$. Post-hoc analysis revealed that fewer organs were donated when the deceased was an active non-donor ($M = 5.61, SD = 4.07$) than when the deceased was a donor ($M = 7.78, SD = 2.84, p = .021$), a non-donor ($M = 7.38, SD = 3.15, p = .090$), or a passive non-donor ($M = 7.65, SD = 2.73, p = .040$). Active non-donors also donated fewer organs than participants in the control condition ($M = 7.08, SD = 2.66$), but this difference was non-significant ($p = .224$). The interaction between the participant's and the deceased's donor status was non-significant, $F(4, 171) = 0.83, p = .508, \eta_p^2 = .02$.

Affective attitudes towards organ donation

A 2 (participant's organ donor status) x 5 (deceased's organ donor status) ANOVA was performed on the affective attitudes to determine whether they varied between conditions. The deceased's registration status did not have a significant effect on any of the affective attitudes ($ps > .10$). The participant's registration status had a significant effect on all 5 affective attitudes. Bodily integrity concerns were lower for registered organ donors ($M = 1.95, SD = 0.98$) than non-registered participants ($M = 1.95, SD = 0.98$), $F(1, 179) = 22.69, p < .001, \eta_p^2 = .11$. Similarly, registered organs donors were less concerned about medical mistrust ($M = 2.01, SD = 0.88$) than non-registered participants ($M = 2.60, SD = 1.26$), $F(1, 179) = 12.31, p = .001, \eta_p^2 =$

.06. The ick factor was lower for registered ($M = 1.78, SD = 0.95$) than non-registered participants ($M = 2.84, SD = 1.53$), $F(1, 179) = 30.79, p < .001, \eta_p^2 = .15$. Registered organ donors were also less concerned about jinx ($M = 1.42, SD = 0.64$) than non-registered participants ($M = 1.97, SD = 1.12$), $F(1, 179) = 15.04, p < .001, \eta_p^2 = .08$. Finally, registered organ donors endorsed the perceived benefits of organ donation to a greater extent ($M = 5.51, SD = 0.98$) than non-registered participants ($M = 4.93, SD = 1.18$), $F(1, 179) = 14.07, p < .001, \eta_p^2 = .07$. These results reflect the fact that registered organ donors were less likely than non-registered participants to feel the negative emotions and endorse the negative affective attitudes, and were more likely to believe the positive consequences of organ donation. The interaction of the two independent variables did not have a significant effect on any of the affective attitudes ($ps > .10$).

Anticipated regret

A 2 (participant's registration status) x 5 (deceased registration status) ANOVA was conducted on the measured anticipated regret variable to determine whether it varied between conditions. The main effect of the deceased's registration status was non-significant, $F(1, 180) = 1.56, p = .186, \eta_p^2 = .03$. The mean level of anticipated regret was greater participants who were registered organ donors ($M = 5.65, SD = 1.13$) than those who were not registered ($M = 4.65, SD = 1.49$), $F(1, 180) = 27.95, p < .001, \eta_p^2 = .13$. These results reflect the fact that registered organ donor are more likely than people who are not registered to anticipate regret for not allowing their loved one's organs to be donated. The interaction between these independent variables was non-significant, $F(4, 180) = 0.44, p = .783, \eta_p^2 = .01$.

Mediation

We assessed whether the main effect of organ donor registration on willingness to donate was mediated by anticipated regret and the affective attitudes (for descriptive statistics, see Table

1). As mentioned above, the participant's organ donor registration had a significant effect on the mediators (anticipated regret and the affective attitudes) and on the dependent variable (number of organs donated), fulfilling the first two criteria for mediation (Baron & Kenny, 1986).

Crucially, the main effect of the participant's registration status on donation became non-significant when these mediators were entered into the original regression equation ($\beta = .03, p = .496$). In this analysis, the significant predictors of the number of organs donated were anticipated regret ($\beta = .32, p < .001$), the ick factor ($\beta = -.30, p = .001$), jinx ($\beta = .18, p = .019$), and perceived benefit ($\beta = .17, p = .011$). Bodily integrity was a marginally significant predictor of the number of organs donated ($\beta = -.15, p = .076$). Interestingly, medical mistrust did not uniquely predict the number of organs donated ($\beta = -.04, p = .628$). The lowest tolerance value was .43, indicating that the dataset was not biased by multicollinearity (i.e., values above .20; Cohen et al., 2003). Moreover, this model explained 42% of the variance in the number of organs donated, $F(7, 173) = 17.79, p < .001$.

The significance of the indirect pathways from registration to donation, via anticipated regret and the affective attitudes, were assessed using 95% bias-corrected and accelerated confidence intervals, calculated using 5000 bootstrap resamples (Preacher & Hayes, 2008). In this multiple mediator analysis the confidence intervals did not include zero for the indirect effect through anticipated regret ($CI_{95} = 1.26, 0.29$), the ick factor ($CI_{95} = -1.34, -0.30$), jinx ($CI_{95} = .07, .81$), and perceived benefit ($CI_{95} = .64, .09$), indicating significant indirect effects through each of these variables. The confidence intervals for the indirect effects through bodily integrity and medical mistrust included zero ($CI_{95} = -0.84, 0.01$, and $-0.40, 0.17$; respectively), indicating that these indirect pathways were non-significant. These results reflect the fact that registered organ donors are more likely to donate their loved one's organs in comparison to people who

have not registered because they anticipated greater regret, are less likely to feel disgust towards donation, and are more likely to endorse the positive consequences of donation. Registered organ donors are also more likely than non-registered donors to endorse jinx beliefs. However, contrary to previous research and our expectations, we found that jinx, in turn, *positively* predicted donation.

Discussion

The aim of this research was to examine the factors that promote and prevent organ donor registration. We extended previous research (e.g., Morgan et al., 2008; O'Carroll et al., 2011a, 2011b) by demonstrating that the affective factors that guide organ donor registration also guide the decision of whether or not to donate a loved one's organs. Registered organ donors were more likely than non-registered participants to anticipate regret for not donating their loved one's organs and endorse the perceived benefits of donation, and were less likely to feel disgust towards organ donation and have concerns about jinx. These affective factors, in turn, predicted the number of their loved one's organs that the participant was willing to donate.

In line with previous research (Siminoff & Lawrence, 2002) we found that people were reluctant to donate their loved one's organs when they believed that he/she disagreed with organ donation. In the active non-donor condition participants were informed that the deceased opposed donation because of bodily integrity concerns. It would be interesting to assess whether people are also reluctant to donate a loved one's organs when the deceased endorsed the other negatively valenced affective attitudes (e.g., the ick factor, jinx, and medical mistrust). This question was beyond the scope of this study, but should be considered for future research in this area.

Conventional organ donation campaigns aim to increase registration and donation by providing people with rational, cognitive arguments. For example, campaigns often provide people with the statistics relating to the number of people waiting for a solid organ donor and the number of these people who die waiting for this transplant. This research supports previous findings (e.g., Morgan et al., 2008; O'Carroll et al., 2011a; O'Carroll et al., 2011b) in suggesting that organ donation campaigns may be more effective if they target the affective attitudes and factors that guide decision making. For example, research has found that simply asking people whether they would accept an organ from a deceased donor in order to save their own life increases people's willingness to register as an organ donor by decreasing their concerns about bodily integrity (Shepherd et al., 2012). Such research suggests that the UK NHS Blood and Transplant's campaign that included such reciprocal primes ('Would you take an organ if you needed one?') are likely to be effective and should be used to increase organ donation. However, rigorous evaluation of campaigns that target people's affective attitudes are also urgently required.

Previous research has found that a simple anticipated regret manipulation increases people's intentions to register (O'Carroll et al., 2011b) and the likelihood that the participant will register as an organ donor (O'Carroll et al., 2011a). We enhance this work by demonstrating that anticipated regret also influences the decision of whether or not to donate a loved one's organs. It could, therefore, be argued that anticipated regret interventions should be created to increase people's willingness to donate a loved one's organs. However, this study only found that anticipated regret partially mediates the relationship between the participant's registration status and the number of organs donated. Further research is required to determine whether such manipulations may be implemented to increase organ donation by next-of-kin in people who are

registered *and* not registered as an organ donor. Importantly, previous research has found that family members are unlikely to donate their loved one's organs when they feel pressurised (Siminoff et al., 2001). It is, therefore, important to ensure that any such intervention does not cause families to feel pressurized as this could have a detrimental effect on donation.

It is also worth noting that jinx positively predicted the number of organs donated after controlling for the participant's organ donor registration, the other affective attitudes and anticipated regret. A marginally significant negative correlation was found between jinx and number of organs donated, supporting our expectations. The fact that this relationship became positive in the regression analysis suggests that jinx negatively predicted donation through the other affective attitudes and that removing this variance resulted in a positive correlation.

Although this finding is interesting, future research is needed to determine whether it is reliable and, if so, the mediating process through which it occurs.

In the present research we found that even when the deceased was an organ donor, there was no increase in people's willingness to donate their organs. This may have been due to the fact that the deceased's attitude towards organ donation was not explicitly stated. Indeed, previous research has found that people are more willing to donate their loved one's organs when they believe that the deceased had a positive attitude towards donation (Exley et al., 2002; Siminoff et al., 2001). We may have found an increase in people's willingness to donate their loved one's organs if a positive attitude towards donation was also presented. Moreover, this highlights the importance of discussing organ donation with loved ones and its positive effect on family member's willingness to donate their loved one's organs (Siminoff et al., 2001).

As mentioned above we used vignettes to assess the factors promoting next-of-kin donation. The use of this methodology allowed us to experimentally manipulate the deceased's

organ donor status in order to assess causal relationships. Moreover, this methodology allowed us to avoid the ethical issue posed by contacting family members who had recently lost a loved one. There are also some disadvantages with this methodology. The main disadvantage was that the situation was not real. As a result, it may be argued that the factors outlined above may not predict organ donation by next-of-kin in the real-world. However, there are numerous reasons to suggest that the results may be applicable to the real-world. First, as mentioned above, interviews with family members who have decided whether or not to donate a loved one's organs has found that regret may be associated with this decision (Jacoby & Jaccard, 2010; Ormrod et al., 2005; Rodriguea et al., 2008). The fact that anticipated regret was found to predict next-of-kin donation in the present research, therefore, corresponds with this real-world research. Similarly, the validity of this vignette study is also supported by the fact that the deceased's opinion about organ donation influenced people's decisions in the present study and previous real-world research (e.g., Siminoff et al., 2001; Siminoff & Lawrence, 2002).

It could be argued that the relationship between the affective attitudes and organ donor registration is due to cognitive factors, such as the factor proposed by the theory of planned behavior (i.e., attitude, subjective norm, and perceived control; Ajzen, 1991). Although the affective attitudes are related to attitude and subjective norm, they are stronger predictors of organ donation behavior than these cognitive factors (Morgan et al., 2008). Because of this, it is more likely that the effect of such cognitive factors may be partly due to the affective attitudes than vice-versa.

Although there was a wide age range in this study, the mean age of participants was approximately 20 years. Therefore, the vast majority of participants were young adults. Moreover, a large proportion of participants were female. Therefore, it is worth considering the

effect of such demographics on the results of the study. Research has found that people's willingness to donate their own or a loved one's organs is not predicted by gender (Mossialos et al., 2008; Shepherd & O'Carroll, in press a), suggesting that the large proportion of females is unlikely to have affected the results of this research. However, age negatively predicted both of these organ donation variables (Mossialos et al., 2008; Shepherd & O'Carroll, in press a), thereby suggesting that young adults are likely to support organ donation. Moreover, young adults are less likely to have experienced their next-of-kin passing away. However, as mentioned above the results correspond with interviews that were conducted with family members who have decided whether or not to donate a loved one's organs (Jacoby & Jaccard, 2010; Ormrod et al., 2005; Rodriguea et al., 2008). This suggests that the results of the present study are likely to be applicable to other populations, such as older adults.

In conclusion, this study extends previous research (e.g., Morgan et al., 2008; O'Carroll et al., 2011a, 2011b) by demonstrating the role of the deceased's and next-of-kin's organ donor status and affective factors on people's willingness to donate their loved one's organs. We found that registered organ donors were more willing than non-registered participants to donate their loved one's organs and that this effect was mediated by anticipated regret and their affective attitudes towards organ donation. This research highlights the importance of developing organ donation campaigns that target anticipated regret and the affective attitudes in order to decrease the likelihood of family members refusing to donate their loved one's organs.

Conflicting Interests

No conflicting interests.

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Footnotes

¹ We also manipulated anticipated regret by informing participants in the regret (but not the control) condition that previous research had found that families who donated their loved one's organs were less likely than families who refused to donate these organs to regret their decision. However, this manipulation did not have a significant effect on our anticipated regret manipulation check, $F(1, 189) = 1.22, p = .271, \eta_p^2 = .01$. We, therefore, do not mention this manipulation further. This manipulation was included as a covariate in the analyses outlined below.

² We also analyzed people's willingness to donate each specific organ. The findings of these analyses were similar to those presented. We, therefore, decided to avoid repetition by simply presenting the results for the total number of organs donated.

³ Removing items from this scale did not improve its reliability.