Psychological Aspects of Organ Donation

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Liver Disease does not equal alcohol problems!

- Non-Alcoholic Fatty Liver Disease (NAFLD).

- NAFLD is a common chronic liver disease which may affect 20-25% of the population in Western countries.

- The rate of increase in liver transplantation may well see NAFLD overtake Hepatitis C and become the most common primary diagnosis of liver failure in liver transplant recipients by 2020.
Health Behaviour

- High fat diet/ sedentary lifestyle
- Alcohol dependence
- Poor hygiene/ hand washing
- Unprotected sexual intercourse
- Needle sharing

Disease

- Non-alcoholic fatty liver disease (NAFLD)
- Alcoholic cirrhosis
- Hepatitis A
- Hepatitis B
- Hepatitis C

Liver Failure
Organ transplantation– the donor problem

More than 10,000 people in the UK currently need a transplant. 3 a day die because there are not enough organs available.

When asked in surveys, over 90% of general UK public agree that organ donation is "a good thing"

BUT only 31% of people are registered as potential organ donors.

Why is that the case?

Donor Mortality rate 0.5%, morbidity 50%.

“The long term physical and psychological consequences of living organ donation are not established”
Criticisms of living liver donation

• The fundamental end of medicine is to help an individual sick or injured patient; from this prime goal stem the principles of "Do no harm," and "Benefit the patient."

• The surgery is **NOT** for the benefit of the donor's health; the surgery can only cause bodily harm to an individual who would have remained healthy otherwise.
Organ transplantation— the donor problem

When asked in surveys, over 90% of general UK public agree that organ donation is “a good thing”

BUT only 31% of people are registered as potential organ donors.

Why is this the case?
Decision making

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"Facts"

Evidence  Rational Evaluation

"Feelings"

Emotion  Visceral Reactions
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I'm 22 years old and don't get me wrong, I think organ donation is an amazing thing and I admire greatly those people who do it. I'm not yet on the organ donation list, and I know this sounds stupid and pathetic and I feel incredibly guilty about it, but I think it's because I don't want to face my own mortality. …..To contemplate the whole situation makes me very worried and also very sad, but every time I see an advert about it I feel even worse as a person and incredibly guilty! I think my main problem is that the subject of life and death when I was in school wasn't explained as well as it could of been, they made it very scary.

Jenny, Bristol, UK
(From BBC website survey)

Ick Factor

“The idea of organ donation is somewhat disgusting"

Jinx Factor

“The surest way to bring about my own death is to make plans for it like signing an organ donor card”

Medical Mistrust

“If I sign an organ donor card, doctors might take my organs before I’m actually dead”

Bodily Integrity

“The body should be kept whole for burial”

Perceived Benefits of Donation

“Organ donation allows something positive to come out of a person's death”
"Public support for donation is not getting any better and it desperately needs to," he said. "I think the scandals and failures that we've had have wrecked public confidence. There have been a series of scandals and not just Mid-Staffs. We've had Bristol, Shipman, Alder Hey. It goes on. A series of failings in the NHS has rocked the public in everything we do. It's hard to see how any of that could help our cause and improve the chances of families saying yes to organ donation. It's about society's confidence and trust in doctors and nurses."

Dr. Paul Murphy, National Clinical Lead for Organ Donation
Organ Donation Model

Media

Interpersonal Information

Noncog Beliefs

Perceived Benefits

Knowledge

Attitude

Subjective Norm

Signed Donor Card

Organ Donation Model (Morgan et al 2008)
Organ Donation Model

Organ Donation Model, Morgan et al 2008
Experiment 1 - UK Replication

Hypothesis

People registered on the UK organ donor register will score significantly differently from non-donors on all of the “non-cognitive” factors.
Method

• Measures
  • Demographics
  • Organ Donation Questionnaire

• 141 members of the general public (staff and students at adult learning centre, college and University).
  • 56 donors
  • 85 non-donors

• Mean age = 30 years
• Range = 18 to 67
Experiment 1 - Non-Cognitive Factors

All between group comparisons significant
* = <.05, ** = <.01, *** = < 0.001
First, we extended this study to more representative members of the UK general public, (N=138) recruited at a shopping mall (47 donors, 91 non-donors).

Second, we assessed the contribution of the rational-cognitive TPB variables of Knowledge, Subjective Norm and Attitude.

Third, we randomly allocated non-donors to an anticipated regret (AR) manipulation versus a control condition, to test if this results in an increase the intention to become an organ donor in future.
Experiment 2
Cognitive Factors

No significant between-group differences.
Experiment 2 - Non-Cognitive Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>MEAN SCORE (mean, s.e.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jinx</td>
<td>3</td>
</tr>
<tr>
<td>Mistrust</td>
<td>4</td>
</tr>
<tr>
<td>Body integ.</td>
<td>5</td>
</tr>
<tr>
<td>Benefit</td>
<td>2.5</td>
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</tbody>
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** = p < 0.001
Regret is experienced when we imagine that the present situation could have been better had we acted differently.

It is also possible to anticipate regret and thus avoid actually experiencing this unpleasant emotion.

A variety of studies have been conducted testing whether anticipated regret adds to the predictive value of the TPB and the TRA.
• Sandberg and Conner (2009) invited 3 groups of women for cervical screening: a **Control group**, a group sent a **TPB** questionnaire and a group who were sent a TPB questionnaire plus 2 AR questions (**TPB+AR**).

• In the ITT analysis, of those who did not return the questionnaire, screening attendance was **21%**, **26%** and **26%** respectively.

• For those that completed and returned the questionnaire (i.e. were definitely exposed to the intervention) attendance rates were **21%**, **44%** and **65%** respectively.
AR Manipulation

Non-donors were randomly allocated to a control or AR manipulation group.

The control group (N=47) completed the demographic questions and the Ick factor questionnaire.

The experimental AR group (N=44) completed the same questionnaire, with the addition of 2 AR questions.

**AR questions**

"If I didn’t register as an organ donor and someone I cared about died that could have been saved, I would feel regret" and "If I don’t register as an organ donor I will later wish that I had".

**Intention** (1-7 scale) “At some time in the future, I plan to register as an organ donor”.
Experiment 2
The effect of the anticipated regret manipulation on intention to donate. \((F=7.46, p=0.008)\).
Discussion of Experiment 2

Partial replication of Exp. 1, but the effect restricted to the ick factor and bodily integrity, the two factors which showed the greatest effect sizes in Exp 1.

The domains which tap disgust and body integrity may be the strongest and most robust variables in distinguishing donors from non-donors.

There were no difference between donors and non-donors on the standard TRA variables of attitude, knowledge and subjective norm.

This supports the view that these traditional rational-cognitive variables have limited explanatory power when trying to understand organ donor behaviour.

**AR manipulation** - simply adding two questions which encouraged the participant to reflect briefly on the emotion of regret resulted in a highly significant increase in intention to become a donor.
Experiment 3- Ick Factor and AR

Larger replication - 342 members of the Scottish general public recruited at shopping centres etc. and we evaluated non-cognitive factors in 149 donors versus 193 non-donors.

We also tested the hypothesis that non-donors are generally more superstitious than donors.

For the non-donors only, intention to donate in future was compared between those assigned to the control (N=90) versus the AR condition (N=103).
Experiment 3 - Non-Cognitive Factors

** = p < 0.001, *** = p < 0.0001
Experiment 3
Positive and Negative general superstition scores fail to differentiate between people registered as organ donors from those that have not.
Experiment 3
The effect of the anticipated regret manipulation on intention to donate
(F=4.47, p=0.036).
Conclusions

Emotional factors such as the ick factor are neglected and important barriers to organ donation.

General superstitious beliefs do not explain reluctance to become an organ donor.

A simple Anticipated Regret manipulation led to significant increases in intention to donate in future.

But - do AR manipulations lead to actual changes in organ donor registration behaviour?

Intention  MIND THE GAP  Behaviour
Experiment 4

So far we have shown that AR manipulations can lead to short term changes in intention.

The next step is to test if the same brief AR manipulations can lead to changes in behaviour.
Experiment 4

286 non-donor members of the UK general public pseudo randomly allocated via web to 1 of 3 conditions:

**Control** = ick factor questionnaire (N=94)

**TPB** = as Control, plus questions tapping attitudes, subjective norm and PBC (N=94)

**AR** = as TPB, plus 2 AR questions (N=98)

All given a web -ink to the UK organ donor register and all contacted 1 month later and asked about their registration status (yes/no).
Effect of an Anticipated Regret manipulation on self-reported organ donor registrations 1 month later

Intention to treat analysis - Chi square (2) = 6.1, p=0.035.

Experiment 5

Can simple interventions, delivered at the population level, lead to significant increases in verified organ donor registrations?

Working with NHSBT, we recently conducted a large project testing the effectiveness of a simple AR manipulation on NHSBT verified organ donor registrations.
Increasing organ donation via anticipated regret (INORDAR): protocol for a randomised controlled trial

Ronan E O’Carroll¹, Eamonn Ferguson², Peter C Hayes³,⁴ and Lee Shepherd¹*

Abstract

Background: Throughout the world there is an insufficient supply of donor organs to meet the demand for organ transplantations. This paper presents a protocol for a randomised controlled trial, testing whether a simple, theory-based anticipated regret manipulation leads to a significant increase in posthumous organ donor registrations.

Methods: We will use a between-groups, prospective randomised controlled design. A random sample of 14,520 members of the adult Scottish general public will be contacted via post. These participants will be randomly allocated into 1 of the 4 conditions. The no questionnaire control (NQC) group will simply receive a letter and donor registration form. The questionnaire control (QC) arm will receive a questionnaire measuring their emotions and non-cognitive affective attitudes towards organ donation. The theory of planned behavior (TPB) group will complete the emotions and affective attitudes questionnaire plus additional items assessing their cognitive attitudes towards organ donation, perceived control over registration and how they think significant others view this action. Finally, the anticipated regret (AR) group will complete the same indices as the TPB group, plus two additional anticipated regret items. These items will assess the extent to which the participant anticipates regret for not registering as an organ donor in the near future. The outcome variable will be NHS Blood and Transplant verified registrations as an organ donor within 6 months of receiving our postal intervention.

Discussion: This study will assess whether simply asking people to reflect on the extent to which they may anticipate regret for not registering as an organ donor increases organ donor registration 6 months later. If successful, this simple and easy to administer theory-based intervention has the potential to save lives and money for the NHS by reducing the number of people receiving treatments such as dialysis. This intervention may also be incorporated into future organ donor campaigns.

Trial registration number: ISRCTN: ISRCTN92204897
14,520 members of adult Scottish general public invited to complete survey

Randomised (n = 14,520)

No questionnaire control (NQC; n = 3630)
- Measure: socio-demographic

Questionnaire control (QC; n = 3630)
- Measure: socio-demographic & emotions

TPB (n = 3630)
- Measure: socio-demographic, emotions & attitudes

Anticipated regret (AR; n = 3630)
- Measure: socio-demographic, emotions, attitudes and anticipated regret

Excluded
1) Pre-existing registered organ donors
2) Actively withdraw consent

NHSBT search Organ Donor Register database
- Analysed

6-month follow-up

Data analysis
Decision making

“Facts”
- Evidence
- Rational Evaluation

“Feelings”
- Emotion
- Visceral Reactions
Join the
NHS Organ Donor Register
Call 0845 60 60 400
www.uktransplant.org.uk