Living Donor Satisfaction Survey validation and results among European Countries

EULID PROJECT

www.eulivingdonor.eu

INTRODUCTION & BACKGROUND

- **Title:** European Living Donation and Public Health.
- **Acronyms:** EULID, EU-Living Donor.
- **Web:** www.eulivingdonor.eu
- **Duration:** 30 months. April 2007-Sep 2009.
- **Grant proposed by the PHEA:** acting under the powers delegated by the European Commission
Living donor’s opinion through a satisfaction survey can be one of the tools to monitor the quality and safety of the living donation programs and the key to detect all the potential negative consequences of becoming an living organ donor.
To provide the scientific community a tool to homogeneously evaluate a critical point of the quality of living donation programs like the satisfaction of the donor with the process and the impact of this act in their lives.
MATERIALS & METHODS

SURVEY DESIGN

1st. Evaluation of previous questionnaires

- Previous questionnaires
- Topics
- Language
- Analysis
- Survey of 61 questions

Multiple choice answers according to Likert scales
MATERIALS & METHODS

SURVEY VALIDATION

2nd. Delphi’s method for experts evaluation

2 CIRCULATIONS

Each expert grades each question

Importance

Appropriateness

Comprehension

Comments
Punctuation < 5 ≥ 10%

21 questions modified
7 questions deleted

Pilot test of the survey with a LD sample

Definitive survey with 54 questions

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MATERIALS & METHODS

Survey Content

54 questions
Aspects to analyze

Quality of Life (SF-36)

Information received
Decision making

Perception and acceptance of the donation process

Psychological well-being

Validation based on Delphi methodology with experts and donors

Impact evaluation:
- Economical
- Life opportunities
- Work
- Donor-recipient relationship
RESULTS

SURVEY PERFORMED

- 245 surveys have been performed among living donors in 9 countries were performed from March-December/2009
- Only those surveys performed between 6 and 18 months after donation were included, so that 166 were considered.
• Among the non-genetically related (49), the majority were spouses or partners (40) or friends (9).
RESULTS

Information, perception and acceptance of the donation process

GENERAL EVALUATION

INFORMATION RECEIVED

<table>
<thead>
<tr>
<th>Positive</th>
<th>Negative</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>95.5%</td>
<td>3.5%</td>
<td>0.8%</td>
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</tbody>
</table>

SATISFACTION WITH THE INFORMATION GIVEN

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>23%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>73%</td>
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</tbody>
</table>
RESULTS

Decision making
GENERAL EVALUATION

Decision making
EXAMPLES

DID YOU FELL PRESSURED TO BECOME A LD

DESICISION MAKING

<table>
<thead>
<tr>
<th>Positive</th>
<th>Neutral</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>48%</td>
<td>47%</td>
<td>4.6%</td>
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</tbody>
</table>
RESULTS

Social impact
GENERAL EVALUATION

SOCIAL IMPACT

DID THE MEDICAL TEST YOU UNDERGO INTERFERE WITH YOUR DAILY LIFE?

Strongly agree
Agree
Disagree
Strongly disagree

41%
6%
10%
43%
RESULTS

Quality of life

GENERAL EVALUATION

Quality of life

EXAMPLES

ARE YOU FULLY RECOVERED AFTER DONATION?

- strongly agree
- agree
- disagree
- strongly disagree

- 70%
- 25%
- 5%
- 0%

QUALITY OF LIFE

- Good/Better
- Same
- Bad/worse

- 66.7%
- 28.9%
- 4.4%
RESULTS

Psychological well-being

GENERAL EVALUATION

Psychological well-being

EXAMPLES

PSYCHOLOGICAL WELL-BEING

- Positive: 84.1%
- Neutral: 10.7%
- Negative: 5.2%

STRESS FROM DONATION

- Low: 56%
- Moderate: 17%
- High: 27%
CONCLUSIONS

We present a **validated living donor satisfaction survey** that will allow to perform a mid-term and long-term LD follow-up.

Even results show that **the procedure is safe** and the **impact on donors is minimum**, the guard shouldn’t be lowered since a small percentage has to deal with negative consequences, most of them avoidable, that the system should prevent.