

# Einfluss der Lebendspende auf das familiäre System- vor/nach der Spende

A.Kiss

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Bern



# The Motivations and Experiences of Living Kidney Donors: A Thematic Synthesis

Am J Kidney Dis. 2012;60(1):15-26

Allison Tong, PhD,<sup>1,2</sup> Jeremy R. Chapman, FRCP,<sup>3</sup> Germaine Wong, PhD,<sup>1,2,3</sup>

- 26 studies , 478 donors
- 6 themes about the decision to donate: **compelled altruism**, **inherent responsibility**, **accepting risks**, **family expectation**, **personal benefit**, and **spiritual confirmation**.
- 3 themes about (post)donation: **renegotiating identity** (*fear , vulnerability, sense of loss, depression and guilt, new appreciation of life, personal growth and self-worth*), **renegotiating roles** (*multiplicity of roles, unable to resume previous activities, hero status*), **renegotiating relationships** (*neglect, proprietorial concern, strengthened family and recipient bonds, and avoidance of recipient indebtedness*).

# Lebenspende von soliden Organen

Medizinisch-ethische Richtlinien und Empfehlungen



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Schweizerische Akademie  
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# Lebendspende von soliden Organen

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## Medizinisch-ethische Richtlinien und Empfehlungen

### 6. Psychosoziale Abklärung

13

6.1. Zielsetzung

6.2. Spezielle Spendersituationen

6.2.1. Spender mit einer psychischen Störung

6.2.2. Spender mit einem Lebenspartner, der eine  
Spende ablehnt

6.2.3. Spender aus einem anderen Kulturkreis

6.2.4. Spender, die Bluttransfusionen ablehnen

6.2.5. Spender, die nicht spenden wollen, dies aber  
nicht eingestehen können

6.3. Adhärenz

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# Sind die Richtlinien für Evaluation ausreichend?

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- Prospektiv alle psychosozialen Evaluationen in Basel, Zürich, St Gallen und Lausanne



	All donors		Guidelines Sufficient: Yes		Guidelines Sufficient: No		
	n	(%)	n	(%)	n	(%)	p-Value*
<b>Basel</b>	101	(32.5)	90	(89.1)	11	(10.9)	0.3554
<b>Lausanne</b>	74	(23.8)	63	(85.1)	11	(14.9)	
<b>St Gallen</b>	29	(9.3)	28	(96.6)	1	(3.4)	
<b>Zürich</b>	107	(34.4)	98	(91.6)	9	(8.4)	
<b>All centers</b>	311	(100.0)	279	(90.0)	32	(10.3)	

		Guidelines sufficient: Yes		Guidelines sufficient: No		
		n	(%)	n	(%)	p-Value*
<b>Past psychiatric history</b>	Yes	55	(19.7)	7	(21.9)	0.7719
<b>Present psychiatric disease</b>	Yes	33	(11.9)	4	(12.5)	0.9999
<b>Past use of psychotropic drugs</b>	None	253	(91.0)	29	(90.6)	0.7796
	Already available	24	(8.6)	3	(9.4)	
	Recommended by Center	1	(0.4)	0	(0.0)	
<b>Psychosocial prognosis (VAS)</b>	Mean ± SD	8.1±1.6		5.9±2.4		<b>&lt;0.0001</b>

Fisher's exact test for categorical characteristics; Kruskal-Wallis test for continuous characteristics



		Guidelines sufficient: Yes		Guidelines sufficient: No		
		n	(%)	n	(%)	p-Value
<b>Relationship with recipient</b>	Parent – child All 67 (100%)	66	(23.7)	1	(3.1)	<b>0.0041</b>
	Child - parent	2	(0.7)	0	(0.0)	
	Partner	104	(37.4)	9	(28.1)	
	Sibling	54	(19.4)	8	(25.0)	
	Friend/relative	35	(12.6)	10	(31.2)	
	Far acquaintance	13	(4.7)	2	(6.3)	
	Altruistic non-directed	4	(1.4)	2	(6.3)	
<b>Emotional relationship (VAS)</b>	Mean ± SD	8.1 ± 1.9		6.6 ± 2.3		<b>0.0003</b>
<b>Conflicts in relationship (VAS)</b>	Mean ± SD	2.1 ± 1.9		3.2 ± 2.4		<b>0.0037</b>
<b>Decision making process</b>	Snap decision	205	(73.7)	16	(50.0)	<b>0.0072</b>
	Other	73	(26.3)	16	(50.0)	

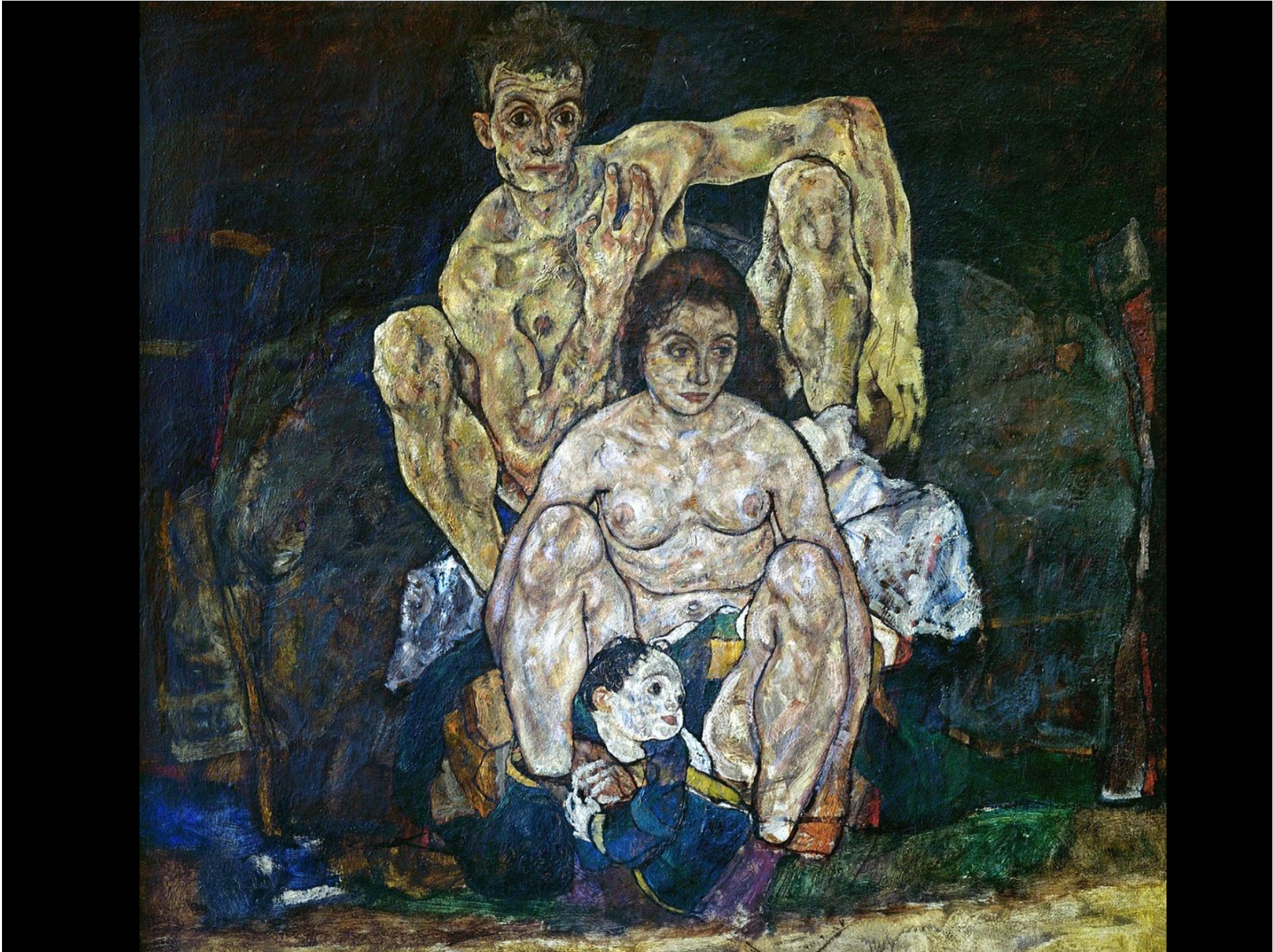
Fisher's exact test for categorical characteristics; Kruskal-Wallis test for continuous characteristics

# Zusammenfassung

- Bei 10% der Evaluationen sind Richtlinien nicht ausreichend
- Spender, bei denen die Richtlinien nicht ausreichen, haben aus Sicht derjenigen, die die Evaluation machen
  - *schlechtere psychosoziale Prognose*,
  - *geringere emotionale Beziehung zum Empfänger*,
  - *mehr Konflikte mit dem Empfänger*
  - *anderen Entscheidungsprozess.*
- Spender, bei denen die Richtlinien nicht ausreichen sind selten bei Spendern die qualifizieren (3 von 206), häufiger bei Spendern mit Auflagen, (22 von 66) und häufig bei Spendern, die nicht qualifizieren (7 von 13).
- **Erweiterung der Richtlinien erscheint sinnvoll.**

# Einfluss der Lebendspende auf das familiäre System- **nach der Spende**



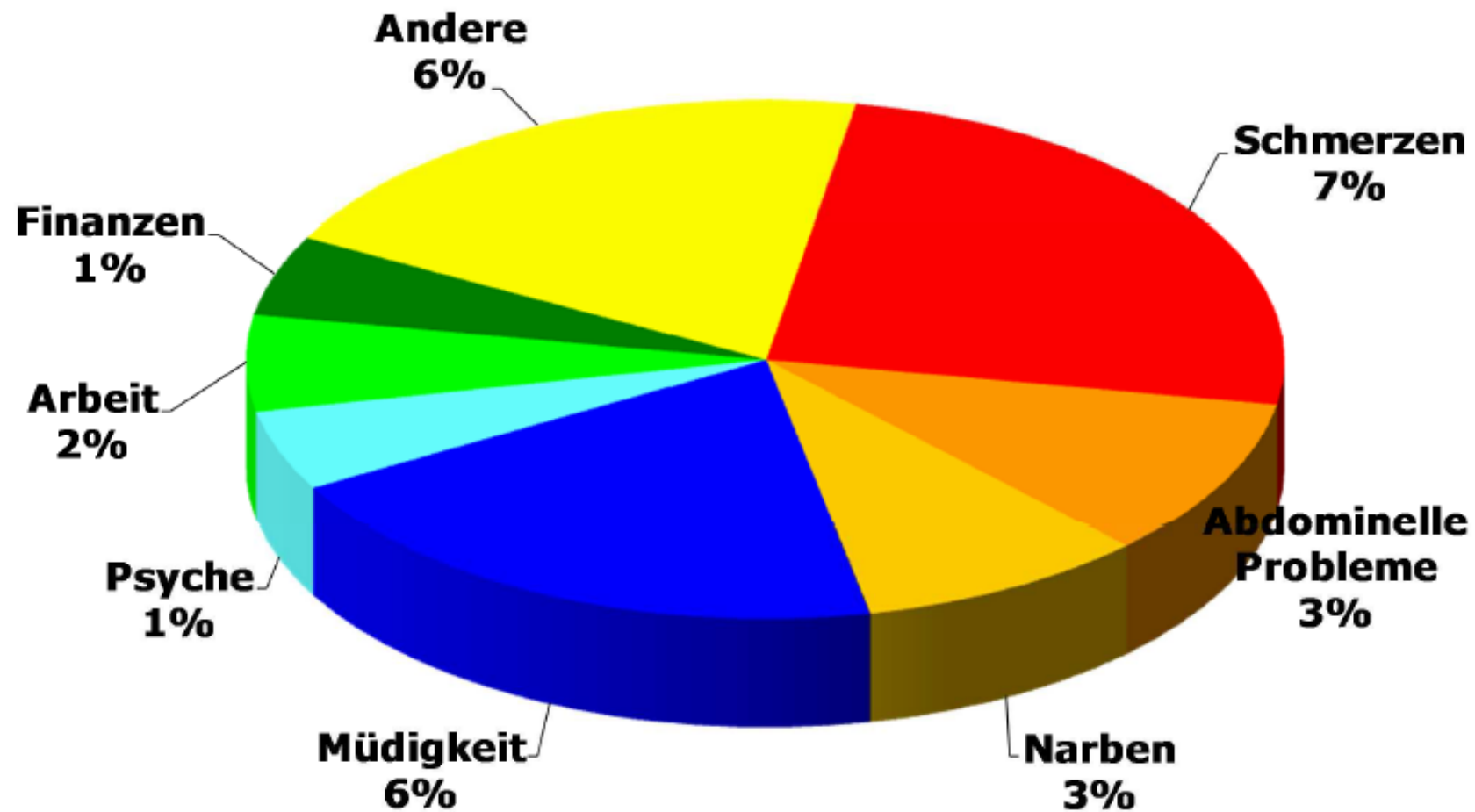




# Welche Probleme haben die Nierenspender?



Swiss Organ Living-Donor Health Registry

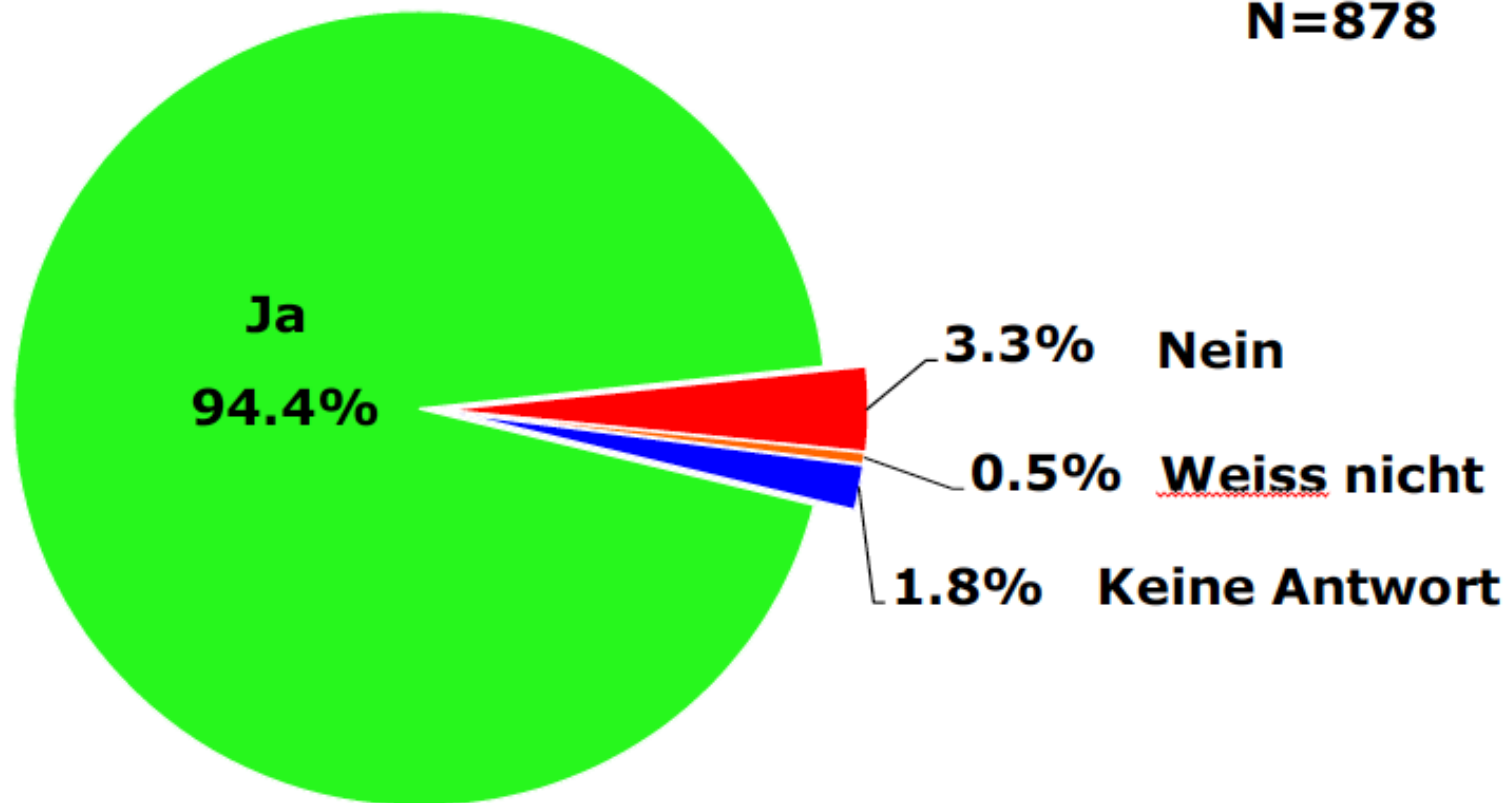


# Würden Sie wieder eine Niere spenden?



Swiss Organ Living-Donor Health Registry

**N=878**



# Long-term experiences of Norwegian live kidney donors: qualitative in-depth interviews

BMJ Open 2017;7:e014072. doi:10.1136/bmjopen-2016-014072

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Käthe B Meyer,<sup>1,2</sup> Ida Torunn Bjørk,<sup>3</sup> Astrid Klopstad Wahl,<sup>4</sup> Annette Lennerling,<sup>5</sup>

- There is a lack of knowledge on long-term consequences described by the donors.
- Provide insight into donors' meanings and their experiences ~10 years after donation.
- 16 donors



**Table 1** Examples from the analysis

Natural meaning unit, statements	Subthemes	Theme
<p>It was not intentionally, I understand that, but my stomach is damaged for life. I had a much better life before this, but my sister is fine, the kidney works well. I think I had given her kidney again. She considers I have given a huge gift, I would say. Thus I believe she felt I was intimate and yes, we have had good relations. I have felt she was very grateful. Even if the kidney doesn't work anymore, you may say it was many years she had a better life, by receiving a kidney.</p>	<p>Experiencing that the recipient had a good life compensated the donor's own adverse experiences.</p> <p>The donation triggers gratefulness from the recipient and his/her family.</p>	<p>The recipient outcome justified long-term experiences.</p>

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# 4 Themes

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1. The recipient outcome justified long-term experiences
2. Family dynamics - Tension still under the surface
3. Ambivalence - Healthy versus the need for regular follow-up
4. Life must go on

# 1.) The recipient outcome justified long-term experiences

Being a donor was not merely a positive experience, and losing contact with the recipient was bothersome. One sibling tried to excuse a brother who had cut-off all contact:

My brother and I have no connection after the donation. I figure this is quite rare. We lost touch completely. I believe he feels so grateful that he rejects me. We used to be very close, but after the donation it is the opposite.  
(F, 3)

## 2.) Family dynamics—tension still under the surface

While donation still was the obvious choice for some donors, others had felt an implicit or explicit pressure.

I decided to be the first one to be tested because I had the impression that my brother thought surgery and hospital was a bit scary. Afterwards we haven't mentioned it. I do love my brother, you know. (E, 14)

### 3.) Ambivalence - Healthy versus the need for regular follow-up

Contradictory opinions among health professionals caused uncertainty about the value of the medical follow-up, as shown by a female informant:

I asked why, what is the point when I am healthy? That is how I feel, but then I think about what they said in the beginning; donors stay healthy because of the medical follow-up. They might uncover other things, so maybe it's wise. I don't worry about the kidney, but it could be high blood pressure or something. (F, 14)

## 4.) Life must go on

over-rated. Although many of the donors still felt attached to the recipient, donors and recipients did not see each other as often as they did shortly after donation. One of the donors reflected on how the significance of the donation waned with time:

Looking back, we were never in doubt; when she received the kidney she would become well. Done! The first years we used to celebrate, one year, five years, but now, it's kind of forgotten. (F, 14)

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## Conclusions:

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- Live kidney donors seemed to possess **resilient** qualities that enabled them to address the long-term consequences of donation.
- Provide more uniform information about long-term consequences.



# **Donor and Recipient Views on Their Relationship in Living Kidney Donation: Thematic Synthesis of Qualitative Studies.**

Am J Kidney Dis. 2016 Nov 23. pii: S0272-6386(16)30563-7. doi: 10.1053/j.ajkd.2016.09.017.

[Epub ahead of print]

## **BACKGROUND:**

- Many donors and recipients report an improved relationship after transplantation;
- However, tension, neglect, guilt, and proprietorial concern over the recipient occurs
- To describe donor and recipient expectations and experiences of their relationship in the context of living kidney donation.

## **STUDY POPULATION:**

40 studies, 1,440 participants (889 donors, 551 recipients)

# 6 Themes

- **"Burden of obligation"** described the recipient's perpetual sense of duty to demonstrate gratitude to the donor.
- **"Earning acceptance"** was the expectation that donation would restore relationships.
- **"Developing a unique connection"** reflected the inexplicable bond that donor-recipient dyads developed postdonation.

- **"Desiring attention"** was expressed by donors who wanted recognition for the act of donation and were envious and resentful of the attention the recipient received.
- **"Retaining kidney ownership"** reflected the donor's inclination to ensure that the recipient protected "their" kidney.
- **"Enhancing social participation"** encompassed relieving both the caregiver from the constraints of dialysis and the recipient from increased involvement and contribution in family life.

**Table 3 (Cont'd). Illustrative Quotations**

**Participants Quotations (Italicized) and/or Authors' Explanations**

*"We've started a new life, and we're really enjoying life. And it's made us do things, like buy a motor home...because life is so short and...it can be taken from you anytime. Do what you want to do now, and we're doing it, and we're loving it"* (Donor<sup>19</sup>)

*"I tend to hide it if I'm not feeling well. I'll get up at four o'clock in the morning, and sit up after they've all gone to bed, just so he [the donor] won't know if I don't feel good."* (Recipient<sup>38</sup>)

*"I don't give up, you shouldn't complain, you don't want to be unthankful"* (Recipient<sup>36</sup>)

*"My husband also said: I expected you to be able to do more things. This led to tension in our relationship."* (Recipient<sup>36</sup>)

*"Now he [the recipient] is a much more open and social person. He focuses a lot more on me as a person, asking me how I am and if things are going well."* (Donor<sup>61</sup>)

Roles in the relationship have changed entirely: the recipient complains, is inactive and unsatisfied; the donor is striving to encourage and support the recipient, takes over his responsibilities or resorts to new activities on her own. The relationship balance, which was asymmetrical even before the transplantation, has shifted to a totally different direction. The new situation is very difficult for both partners.<sup>56</sup>

## CONCLUSIONS

- Living kidney donation can strengthen donor-recipient relationships but may trigger or exacerbate unresolved angst, tension, jealousy, and resentment.
- Facilitating access to pre- and posttransplantation psychological support.

# Preventive Intervention for Living Donor Psychosocial Outcomes: Feasibility and Efficacy in a Randomized Controlled Trial

*American Journal of Transplantation 2013; 13: 2672–2684*

M. A. Dew<sup>1,2,3,4,\*</sup>, A. F. DiMartini<sup>1,5</sup>,

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- Postdonation impact of a preventive intervention utilizing motivational interviewing (MI) to target a major risk factor for poor psychosocial outcomes, residual ambivalence (i.e. lingering hesitation and uncertainty) about donating.
- Of 184 prospective kidney or liver donors, 131 screened positive for ambivalence; 113 were randomized to (a) the MI intervention, (b) an active comparison condition (health education) or (c) standard care only before donation.
- Ambivalence was reassessed postintervention (before donation)

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## **Preventive Intervention for Living Donor Psychosocial Outcomes: Feasibility and Efficacy in a Randomized Controlled Trial**

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- Somatic, psychological and interpersonal domains assessed at 6 weeks and 3 months postdonation.
- MI subjects showed the greatest decline in ambivalence .
- By 3 months postdonation MI subjects reported fewer physical symptoms, lower rates of fatigue and pain, shorter recovery times and fewer unexpected medical problems.
- They had a lower rate of anxiety symptoms and fewer unexpected family-related problems .
- They did not differ on depression, feelings about donation or family relationship quality.



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# Drei Gruppen

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1. Dankbarkeit zwischen Spender/Empfänger
2. Verantwortung des Empfängers für das Spenderorgan
3. Einfluss der Lebendorganspende auf die Beziehung