

# The Psychosocial Evaluation of Living Donors

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**13th Annual Living Donation Conference**  
Presented by the American Foundation for Donation and Transplantation

# OBJECTIVES

**At the end of this presentation, participants will:**

- Investigate and describe guidelines for the psychosocial evaluation of Living Kidney Donors in the United States
- Describe variables in the psychosocial evaluation
  - Liver donor
  - Non-directed donor
  - Paired exchange donor
- Identify risk factors that make a subset of donors at risk for poor post-donation psychosocial outcomes



# ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK (OPTN) POLICIES

## Health Care Professionals Performing Psychosocial Evaluations

Licensed Social Worker

Psychologist

Psychiatrist



# OPTN POLICIES

## Living Donor Psychosocial Evaluation Requirements

- Living donor's occupation, employment status, health insurance status, living arrangements, and social support
- An evaluation for any psychosocial issues
- An assessment of risk criteria for acute HIV, HBV, and HCV infection according to the *U.S. Public Health Service (PHS) Guideline*
- Living donor's history of smoking, alcohol, and drug use, including past or present substance abuse disorder
- Identification of factors that warrant educational or therapeutic intervention prior to the final donation decision



# OPTN POLICIES

## Living Donor Psychosocial Evaluation Requirements

- Decision to donate is free of inducement, coercion, and other undue pressure
- Ability to make an informed decision
- Ability to cope with the major surgery and related stress
- The potential financial implications of living donation
- Short and long-term medical and psychosocial risks for both the living donor and recipient associated with living donation



# CENTERS FOR MEDICARE AND MEDICAID SERVICES(CMS) REQUIREMENTS

## Defines Qualified Social Worker

- Licensed in State of practice
- MSW specializing in clinical practice
  - (with provisions for non-MSWs prior to 06/07)

Psychosocial assessment and planning through **all phases of donation**

- Pre-Donation
- Donor In-patient stay
- Discharge

**Psychosocial assessment and interventions** must address:

- Acknowledgment of risks/benefits of donation
- Ability to adhere to therapeutic regimens
- Psychosocial and mental health history
- Substance use/abuse
- Coping abilities and strategies
- Financial capabilities and resources
- Availability of adequate social, personal, housing and environmental support

Must inform donor of potential **problems obtaining insurance in future**



# DOMAINS OF THE PSYCHOSOCIAL EVALUATION OF LIVING DONORS

- History and current status of the donor
- **Capacity**
- **Psychological status**
- **Relationship** with the transplant candidate
- **Motivation for donation** and other altruistic or voluntary behavior history
- Donor knowledge, understanding, and preparation
- **Social support**
  - Education and availability of post-operative care and transportation
- **Financial suitability**



# PSYCHOSOCIAL EVALUATION

## Psychosocial History

- Born and raised
- Citizenship/language(s)
- Development issues
- Race/Ethnicity/Culture
- Religion Beliefs and Practices
- Losses and Recovery
- Highest grade completed
- Learning deficits and literacy
- Occupation(s)
- Military experience
- Past surgeries/complications
- Competency

## Health Behaviors

- Smoking (duration, frequency, amount)
- Alcohol (duration, frequency, amount)
- Activities of daily living
- Recreational drugs (type, frequency, duration)
- Coping strategies for stress
- Adherence to recommendations





# PSYCHOSOCIAL EVALUATION

## Motivation

- Repair relationship
- Self-esteem
- Complicated bereavement
- Recognition and publicity
- Request from recipient or family
- Consistent with values and beliefs

## Social Support

- Caregiver for assistance and transportation
- Long-term plans in case of complications
- Family support of donation



# PSYCHOSOCIAL EVALUATION

## Housing and Transportation

- Persons in household
- Transportation to and from hospital
- Post-donation housing
- Caregiver and recipient's caregiver
- Barriers to caregiver

## Donor Knowledge and Understanding of Risks

- Short and long term risk for surgery for donor
- Short and long term risk for surgery for recipient
- Alternative treatment for the recipient



# PSYCHOSOCIAL EVALUATION

## Donation Consistent with Past Beliefs/Behaviors

- Donor or Driver's License
- History of Volunteering
- Values, beliefs, lifestyle

## Family History

- Mother and father
- Other caregivers
- Siblings
- Marital Status
- Children
- Current caretaker
- Other significant relationships
- Identified caregiver post-surgery



# PSYCHOSOCIAL EVALUATION

## Relationship with Transplant Candidate

- Duration of relationship
- Type of relationship and closeness
- Expectations for change in the relationship
- Feelings of obligation/desire for forgiveness

## Financial Information

- Primary insurance
- Insurance for medications
- Risks for obtaining short/long term disability
- Prescription drug coverage
- Health/life insurance premiums
- Employer's understanding and compensation
- Employment status if complications occur



# PSYCHOSOCIAL EVALUATION

## Psychiatric Information

- DSM V Disorders/Symptoms
- Past History of Trauma/Abuse/Neglect
- Outpatient Treatment
- Inpatient Treatment
- Suicidal or Homicidal Ideation or Attempts
- Psychiatric Medications

## Pressure/Coercion

- Assistance with living expenses/college
- Employer-employee
- Family or recipient pressure
- Medical team



# PSYCHOSOCIAL EVALUATION

## Power of Attorney/Living Will

- Medical decision maker
- Advanced directives

## Legal

- Incarcerations (reason, duration)
- DUIs (number, years)
- Propagation/House Arrest
- Past and Current legal problems (example: probation)

### Health Care Proxy

#### *Appointing Your Health Care Agent in New York State*

*The New York Health Care Proxy Law allows you to appoint someone you trust — for example, a family member or close friend — to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent's decisions as if they were your own. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions or only certain ones. You may also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ and/or tissue donation.*



# PSYCHOSOCIAL EVALUATION

## Capacity to Make Autonomous Decisions

- Interview or formal testing if warranted

## National Kidney Registry/Paired Exchange/Advanced donation

- Understanding of process and potential problems

## Losses and Pass Experiences with Bereavement



# LIVING LIVER DONOR

## What is the same?

- Regulatory requirements
- Purpose of psychosocial assessment
- Domains of psychosocial assessment
- Red flags

## What is different?

- Risks of donor surgery
  - Heightened anxiety/fear
  - Caregiver responsibilities
- Alternative treatments available to recipient
  - Adds to feelings of pressure/guilt





# PSYCHOSOCIAL EVALUATION

## The Unrelated Donor – Two Phase Psychosocial Evaluation

- Phase I: Initial screening
  - General screening questions about medical history
  - Connection (if any) with transplant candidate
    - Potential for secondary gain
  - Reasons for and expectations about donation
  - Donor's knowledge of basic risks involved in surgery and recovery
- Phase II: On-site evaluation
  - Psychosocial evaluation should be conducted early
    - Invasive medical examinations should be avoided if clear psychosocial contraindications are apparent
- Donor “cooling off” period
  - Two weeks



# PAIRED EXCHANGE DONORS

## Psychosocial Considerations in Kidney Paired Exchange

- Recipient anonymous to donor – *privacy concerns*
- Donors entering registry may or may not be paired – *unfulfilled expectations*
- Timing of donation is not fixed – *unpredictable*
  - Donor/family must remain in state of *sustained readiness*
- Possibility of negative outcome in one (or both) paired exchange transplants - *disappointment*



# PAIRED EXCHANGE DONORS

## Ethical Challenges

- *Pressure* on Donor (perception there is no longer an out)
  - Freedom to withdraw decision
  - *Guilt* – Impact may be tremendous
- Possible outcomes expanded/no guarantee – *Fairness*
- Bridge Donor – Multiply above!



# PAIRED EXCHANGE DONORS

## Implications for Psychosocial Assessment

- Is donor agreeable to paired exchange? Is the recipient agreeable?
- **Untoward outcomes**
  - Intended recipient
  - Actual recipient
- Does psychosocial situation allow for **unpredictable timing**?
  - Family/daycare/employment/finances
  - Prolonged state of readiness
  - Cancelled chains
- **Anonymity**
  - Is meeting actual recipient important?
  - What if actual recipient does not wish to meet?
  - If no meeting, donor may never know outcome.



# THE NONDIRECTED DONOR

## Implications for Psychosocial Assessment

- **Decision-making process**

- Complex

- **Motivation** needs careful

exploration

- Response to loss
- Need to do good to right a wrong
- Seeking attention
- Psychiatric history
- Avoiding incarceration

### **Knowledge** of Risks

- Support of Family/Significant

### Others

- support system must be intact and on board

- **Expectations**

- Preservation of Anonymity



# LIMITATIONS OF THE PSYCHOSOCIAL EVALUATION

- Impression Management
- Deliberate Deception
- Concealment of Important Information
  - Medical and psychiatric history
  - Collateral information
- Culture and Language



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# PSYCHOSOCIAL ASSESSMENT TOOL OF LIVING KIDNEY DONORS

- Not yet been standardized
- Varies widely across providers and institutions
- The live donor assessment tool (LDAT)



# POTENTIALLY UNSUITABLE DONOR PROFILES

- Relationship with the recipient
  - Unclear
  - Unhealthy
  - Hierarchical
- **Cognitively limited or impaired**
- Lacks support system
- Family **unsupportive** of donation decision
- Current/History of **Substance Abuse**
- Current/History of **Trauma/Abuse/Neglect**
- Lack of Health Insurance Coverage
  - Assess for future insurability
- Undocumented
- **Deception/concealment of information**
  - Vague answers to questions
  - Changes history with each consult
- Desperation
  - Donor or recipient aggressive, frequent calls to center pushing for information, date etc.
- Multiple current **life stressors**





# Who Falls Through the Cracks?



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# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Dew et al. (2012)

- Narrative literature review
  - Individuals ambivalent about donation are at risk for poor psychosocial outcomes
- Prevention of poor psychosocial outcomes in the following domains:
  - Psychological distress, somatic complaints, interpersonal relationship
- Preventative intervention
  - Motivational Interviewing



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Lentine et al. (2012)

- OPTN registrations for 4,650 living kidney donors
- Administrative data of US private health insurer

## RESULTS

- Demographic and clinical correlates of increased likelihood of depression diagnoses included:
  - Female gender, white race, some perioperative complications



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

Lentine et al. (2012), continued

## RESULTS

- White donors were twice as likely to have depression diagnoses after donation, compared with non-whites
  - Lower frequencies of clinically detected depression among persons of other racial and ethnic backgrounds may be in part due to non-white donors' reluctance in seeking mental healthcare an indirect, or “culture bound” presentations



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Wirken et al. (2015)

- Systematic review and meta-analysis summarizing prospective studies of the course and predictors of health-related quality of life (HRQoL) in living donors

## RESULTS

- On average kidney donors have high long-term HRQoL
- Donors with low psychological functioning at baseline are more at risk for impaired long-term HRQoL



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Holscher et al. (2018)

- Single center cross-sectional study
- 825 Living Kidney Donors screened for anxiety and depression

## RESULTS

- 5.5% screened positive for anxiety
- 4.2 % screened positive for depression
- 2.1% reported regretting their donation

## CONCLUSIONS

- Anxiety, depression and regret of donation among Living Kidney Donors are interrelated conditions
- Positive screen for one condition should prompt evaluation for others



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Wirken et al. (2019)

- Prospective multicenter study on health-related quality of life (HRQoL), donor-recipient relationships, and regret
- Data for 230 donors were analyzed

## RESULTS

- Donor physical HRQoL was comparable at all points, except for increase of fatigue
  - Up to 35% experienced worsening fatigue
  - Higher fatigue levels were more likely to be found in those presenting with pre-donation fatigue; with worse general physical functioning; and a younger age



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

Wirken et al. (2019), continued

## RESULTS

- Mental HRQoL decreased at 6 months post-donation but returned to baseline at 12 months
  - 14% experienced regret 12 months post-donation
  - Predictors of regret were more negative health perceptions and worse social functioning 6 months post-donation

## RECOMMENDATION

- Prevent unrealistic expectations
  - Evidence based information regarding potential consequences of kidney donation
  - Discussion of alternative treatment options
  - Expectations of the transplantation for the recipient and on the donor





# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

## Jowsey et al. (2014)

- The Renal and Lung Living Donors Evaluations Study (RELIVE)
- Study cohort consisted of 6,909 donors, donated between 1963-2005

## RESULTS

- Pre-donation psychiatric disorders were more common in unrelated donors
- Graft failure did not lead to increased depressive symptoms long-term
- Post-donation predictors of depressive symptoms
  - Non-white race
  - Younger age at donation
  - Longer recovery time from donation
  - Greater financial burden
  - Feeling morally obligated to donate



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

**Jowsey et al. (2014)**

Suggested Interventions

- Mindfulness-based stress reduction
- Frequent monitoring of mood symptoms post-donation
- Problem-solving strategies to address financial stressors
- Motivational Interviewing



# Donors at Risk for Poor Psychosocial Outcomes Post-Donation

**Limited research and findings are inconsistent...**

Who is at risk?

- Ambivalent Donors
- Longer recovery times post-donation
- Negative initial psychological reactions post-donation
- Greater donor body mass index at donation

Mixed evidence

- Recipient status



# “Jacqueline”

Jacqueline is a thirty-nine year old female who presented to clinic for an initial crossmatch visit. Laura hopes to donate to her friend. Labs were drawn and information regarding the donation process was provided to Laura by her living donor transplant coordinator. Laura received crossmatch results over the phone; Laura was a compatible match to her intended recipient. Several days after receiving her crossmatch results, Laura called her living donor transplant coordinator distressed about proceeding with donation.

**What do you do?**



**“Health professionals should be aware that merely raising the issue of live organ donation may instigate powerful psychological processes beyond the potential donor’s voluntary control and leave little room for refusal without psychological cost.”**



# Food for Thought...



- How do we support donors?
- How do we assess the impact this is having on their decision-making process?

# “Jacqueline”

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**What do you do?**

**Does the potential donor’s relationship with the recipient impact your clinical response?**



# “John”

John is a fifty-six year old African American male who donated his kidney to his friend. John suffered from a hernia following surgery and will need additional surgery to repair.

- **If this occurred at your transplant center, how are you informed of the complication and future readmission?**
- **How will you assess for mental health concerns?**





# RECOMMENDATIONS

- **Routine assessment of donors post-donation**
- **Routine use of screening measures**
  - Generic HRQoL measures
    - Short Form (SF)-36
    - SF-12
    - SF-8
  - Mental Health
    - Patient Health Questionnaire (PHQ)-9
    - PHQ-2
    - Generalized Anxiety Disorder (GAD)-7



# CONTACT INFORMATION

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