The Psychosocial Evaluation of Living Donors

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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
Health Care Professionals Performing Psychosocial Evaluations
Licensed Social Worker
Psychologist
Psychiatrist
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
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)
- DUls (number, years)
- Propagation/House Arrest
- Past and Current legal problems (example: probation)

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**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

Losses and Pass Experiences with Bereavement

National Kidney Registry/Paired Exchange/Advanced donation
• Understanding of process and potential problems

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
  o General screening questions about medical history
  o Connection (if any) with transplant candidate
    — Potential for secondary gain
  o Reasons for and expectations about donation
  o Donor’s knowledge of basic risks involved in surgery and recovery

• Phase II: On-site evaluation
  o Psychosocial evaluation should be conducted early
    — Invasive medical examinations should be avoided if clear
      psychosocial contraindications are apparent

• Donor “cooling off” period
  o Two weeks

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

**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
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?
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
  o 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 and 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
 o Anxiety, depression and regret of donation among Living Kidney Donors are interrelated conditions
 o 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
  o Up to 35% experienced worsening fatigue
  o 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
  o 14% experienced regret 12 months post-donation
  o Predictors of regret were more negative health perceptions and worse social functioning 6 months post-donation

RECOMMENDATION
• Prevent unrealistic expectations
  o Evidence based information regarding potential consequences of kidney donation
  o Discussion of alternative treatment options
  o 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 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 Jacqueline by her living donor transplant coordinator. Jacqueline 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?

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
  o Generic HRQoL measures
    – Short Form (SF)-36
    – SF-12
    – SF-8
  o Mental Health
    – Patient Health Questionnaire (PHQ)-9
    – PHQ-2
    – Generalized Anxiety Disorder (GAD)-7
CONTACT INFORMATION

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