Psychosocial Issues in Kidney Paired Exchange

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OBJECTIVES

Participants will:
- Identify key ethical and SW practice issues
- Discuss ways in which psychosocial assessment differs for exchange donor
- List SW intervention strategies that contribute to donor readiness and positive outcomes

Renal and Pancreas Transplant Division
Barnabas Health

• Kidney
• Pancreas
• Pediatric
• Altruistic Donation
• Paired Exchange
• Incompatible Program

Transplant Programs

Kidney
Pancreas
Pediatric
Altruistic Donation
Paired Exchange
Incompatible Program
Heart
Lung

Barnabas Health
Kidney Paired Exchange (KPE) Transplants

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<th>2007</th>
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Newark Beth Israel Medical Center

Renal and Pancreas Transplant Division
Barnabas Health

• Kidney
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• Heart
• Lung

Livingston, NJ

Newark, NJ
Variations in KPE

<table>
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<th>Traditional Paired Exchange</th>
<th>Chains</th>
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<td>Two Pair Exchange</td>
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<td>Three Pair Exchange</td>
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<td>Compatible Share</td>
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Donor Psychosocial Outcomes

What do we know?
- Psychosocial outcomes (short and long term) important
- Education
- Informed consent
- Timely interventions
- Limited data available to date (particularly long-term)

What do we need?
- Health Related Quality of Life (HRQOL)
- Financial/Economic Issues
- Outcomes in newer areas (AD, KPE, Bridge)
- Role of informed consent in relation to outcomes

2010 Conference on Living Kidney Donor Follow-Up - Work-group findings:
1. Re HRQOL:
   - On average remains high pre and post donation
   - Likely due to intensive screening
   - Need more research/understanding of the sizable minority of donors who experience psychological distress or other interpersonal difficulties post donation

2. Re Financial/Socioeconomic:
   - 15% of centers do not accept donors without insurance
   - 42% of centers consider lack of insurance a contraindication
   - 4-23% of donors report financial hardship related to donation/recovery
   - 25-30% of employed donors to not have ample leave
   - 18% of donors do not have health insurance coverage
   - 2-9% report problems obtaining health/life/disability coverage after
   - Nearly 12% of donors report stress regarding future health insurability

3. Re Psychosocial Outcomes:
   - Literature on psychosocial outcomes in KPE and AD is almost non-existent
   - Most studies focused on logistics, consent, motives, expectations etc.
   - No clear evidence as to whether these donors differ from standard donors in perceived HRQOL, financial issues etc.

4. Re Informed Consent:
   - Degree of donor understanding and voluntariness may be related to post donation outcomes
   - Acc to 1 survey:
     - 90% of donors understood effects for recipient, donation process and short-term risks
     - Only 31-68% understood long-term medical, psychological, financial risks

Dew, Jacobs "Psychosocial and Socioeconomic Issues Facing the Living Kidney Donor". Advances in Chronic Kidney Disease (July, 2012)
Definitions:

1. Paired Exchange Donor
   a. Incompatible to intended recipient
   b. Willing to enter one or more registries to match and exchange
      kidney with another incompatible pair
   c. May progress to simple or more complex chain
2. Bridge Donor
   a. Willing to donate after intended recipient has received another
      matched kidney – regardless of outcome
   b. May be days/weeks/months after
3. Compatible Share
   a. Donor compatible to intended recipient but offered chance for
      KPE to improve outcome and/or benefit one or more
      incompatible pairs

Psychosocial Considerations in 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

Ethical Challenges

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

Implications for Psychosocial Assessment

- Is donor agreeable to KPE? Is recipient agreeable?
- Explore feelings about poor outcome
  - Intended recipient
  - Actual recipient
- Does psychosocial situation allow for unpredictable timing ?
  (family/daycare/employment/finances)
- Is emotional psyche suitable?
  - prolonged state of readiness (heightened anxiety)
  - Cancelled chains
- Anonymity
  - Is meeting actual recip important?
  - What if actual recip does not wish to meet?
  - If no meeting, donor may never know outcome.
**Recipient - Stanley**

- 59 y.o. WM w ESRD secondary to IgA Neph
- Pre-dialysis – beginning to feel poorly
- Wife offered donation but ruled out medically
- Pt declined offer from children due to nature of his disease (familial)
- Wife’s boss, who is an MD offered to donate but changed his mind

**Case Study**

**KPE Donor - Linda**

- 57 y.o. woman presents for donation to close family friend
- ABO incompatible
- Known recipient for over 30yrs; husbands work together and the two couples dine out almost weekly
- Married X 24yrs to Jim (2nd marriage)
- Two children, son age 32 and dau age 24
- H.S grad – employed FT in an alarm co
- Insured w history of good health care

**Case Study**

- No psych hx or substance abuse
- Two brothers; sis-in-law w/ hx of CKD and 3 previous txpls, now back on dialysis
- Wanted to be a donor to sis-in-law but told pt no longer a candidate
- Husb/children generally supportive of donation decision but she has chosen not to tell brothers or many others
- Entered into registry and is matched right away
- Transplant scheduled. Family mtg held week prior to donation—uneventful, spouse present

**Case Study**

- ILDA rec’d a distressed call from Linda the day before surgery
- She changed her mind

**WHAT WENT WRONG…**

- Donor slow doing work-up
- Offered internal match prior to work-up being completed
- Then began rushing team due to convenience
- Gregarious personality distracted team
- Early decision not to include extended family
The Bridge Donor

Has your center ever been asked…..

“Would your patient be a good bridge donor?”

Implications for Psychosocial Assessment
- Early education about “bridge” potential
- Frank open-in person discussion
- Focus on commitment
- Psychosocial stability and support
- Situational readiness (Financial/Employment)
- Emotional characteristics
  - Altruistic tendencies (selflessness vs egocentric)
  - committed to process
- Trust your intuition!

Case Study

Donor: 52 y.o. WF, “Mom”
Recipient: 22 y.o. son on HD, IGA. + CDC cxn

Logistics:
- Multi-center exchange scheduled Nov ’09
- Mom’s recipient center cancelled OR w/3.48 hr - finance issues
- Mom agreed to Bridge - Son received exchange txp
- Phone conversation only with Mom
- Mom’s donation scheduled Dec ’09 then cancelled – Mom sick
- Rescheduled Jan ’10
- Mom matched with highly sensitized recipient in N.Y.
- N.Y. donor went ahead with donation Nov ’09
- Mom got ‘bad feeling’ about donation & reneged Jan ’10
- N.Y. recipient without donor
Case Study

**WHAT WENT WRONG...**
- No real assessment of donor for bridge
- Phone conversation
- Significant time lag
- Signs of donor ambivalence after intended recip txpl that were ignored

**THE SOLUTION**
- Match run: donor already matched w/ N.J. recip also matches N.Y. recip.
- Donor is pulled from NJ recip. (99 PRA) and donates to N.Y. recip. 3/10
- N.J. pair is still waiting to find a match today

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Strategies for Successful Outcome

**Compatible Share Donor**
- Education, Education, Education!!
- Introduce topic early to avoid “bait and switch” feeling
- Decide as a team who is a candidate and best person to approach
- Focus on benefit to recipient first

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Strategies for Successful Outcome

**The Bridge Donor**

**Education, Education, Education!!**
- Focus on commitment & readiness
- Avoid long delays at all costs
- Select bridge donors carefully
- Review possible scenarios ahead of time w leading questions
  - What would you do if...
  - How would you feel if...

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**The Non-Directed Altruistic Donor**

Definition: A living person’s offer to donate an organ to anyone in need

- Transplant Center Concerns:
  - Decision-making irrational and uninformed
  - Negative psychological impact on non-directed donor
  - Ulterior motive of donor suspicious
  - Possible litigation and liability
  - Potential for commercialization
Studies show consistent results. Non-Directed Altruistic Donors:

- Believe they are offering the gift of life
- Have no expectation of reciprocity or personal gain
- Demonstrate stable, rational decision-making
- Minimize perceived risks
- Wish to preserve anonymity
- Describe positive benefits of personal satisfaction and fulfillment; adoption of healthier lifestyle

Referral process of the Altruistic Donor

- Initial inquiry - screened by R.N.
- SW preliminary screen
- Educational packet sent w questionnaire
- Donor questionnaire mailed back to R.N.
- Suitability of donor discussed by team
- Must have H&P by primary care MD
- Full donor evaluation initiated (blood work drawn)

Referral Process (Con’t)

- Comprehensive SW evaluation – multiple visits
- Psychiatric evaluation
- Medical evaluation/clearance
- Donor and recipient must meet each other (Directed)
- Recipient must be accepting of altruistic donation (Non-directed)
- Family meeting
- Transplant

The Non-Directed Altruistic Donor

Implications for Psychosocial Assessment

- Stability of Decision Making
- Knowledge of Risks
- Motivation
- Support of Family/Significant Others
- Expectations
- Preservation of Anonymity
The Non-Directed Altruistic Donor

- No real benefit to themselves
- Donation decision often complex
  - Motivation/Emotional status needs careful exploration
  - ? Response to loss
  - Need to do good to right a wrong
  - Seeking attention
  - History of mental illness and/or unstable behavior
  - Avoiding incarceration
  - Payment
- Family/support system must be intact and on board
- Expectations – realistic vs. unrealistic
- Altruistic Donors contacting Paired Exchange Registries
  - Some registries are choosing centers which will work donor up fast

Non-Directed Altruistic Donors: Implications for Psychosocial Assessment

**MOTIVATION**
- How did you hear about altruistic donation?
- Can you tell me about the reasons you want to be an altruistic donor.
- Has religion been a significant force in your life? How has this impacted your decision to become a donor?
- Are there any significant events in your family history that might be influencing your decision to become a donor?

**KNOWLEDGE/EXPECTATIONS**
- Do you expect to meet your recipient?
- What if your recipient does not want to meet with you? Would that change your mind about donating?
- Do you have any expectations about publicity related to your donation?
- Do you hope to develop a relationship with your recipient afterwards?

Case Study

- Altruistic NDD – 46yo WF, Diane
- Married to David X 4yrs (2nd marriage)
- 1st marriage at age of 25 lasted 17yrs
- Children – 15 yo fraternal twin sons; 2 adult step-children
- High school grad, some college
- Currently self-employed massage therapist
- Husb employed w software co. and carries good insurance
- Primary care MD aware and supportive of donation decision

**Case Study**

- History of depression and ADHD for which she is managed on medications by psychiatrist. Psych cleared for donation
- Past history of suicide attempt in college (3wk hosp stay)
- One of her sons also w ADH and behavioral issues for which they have received counseling (now lives w Dad)
- Long history of altruistic giving (blood; bone marrow; hospice volunteer)
- Husband initially unsupportive of decision but “came around” following education
- Pt highly spiritual and would like to become an advocate for donation in the future
Case Study

WHAT WENT WRONG:
- NP received a call from hospital PR Dept that Diane’s “publicist” had called
- Staff missed clues of her desire for publicity
- Used phrases like “I want to save lives”; “the body is the sheath and the spirit the sword”

THE SOLUTION:
- Diane/publicist told no immediately. Reminded of privacy policy
- Transplant took place w Diane starting as NDD and ending in a chain 3 transplants taking place
- Diane later revealed that NY hosp had inadvertently released her identity to recip and recip subsequently contacted her on facebook
- Diane still planning to write a “memoir” of her experience