Communication, Comprehension, Capacity, Coercion: The Big C's of Psychosocial Care

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14th Annual Living Donation Conference
Presented by the American Foundation for Donation and Transplantation

Panel

OBJECTIVES

- Identify best practice(s) to ensure informed consent in vulnerable donor populations
- Explore strategies to identify and manage risk of coercion
- Discuss preserving donor autonomy while helping patients navigate their decision

Principles of Medical Ethics

Autonomy (of the individual) – expressed in the value we place on valid consent and confidentiality

Communicate effectively with patients
Obtain valid consent
Maintain and protect patients' information

Beneficence – maximise the good

Put patients interests first
Work with colleagues in a way that is in patients' best interests

Non-maleficence – minimise harm. We owe a duty of care to our patients. Duty may be breached by incorrect treatment and/or of unacceptable standard

Raise concerns if patients are at risk
Make sure your personal behaviour maintains patients' confidence in you and the dental profession

Justice – distributing risk, benefits and costs fairly. Treating all patients with same care and facilities

Have a clear and effective complaints procedure
Maintain, develop and work within your professional knowledge and skills

How do we balance autonomy and harm avoidance/paternalism?

Navigating Complex Family Dynamics in Living Donor Liver Donation: Speedbumps Are Not Always Stop Signs

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“Ideal Donor”

- No medical or psychiatric contraindications
- No financial concerns/strong financial support plan
- Adequate health literacy- “did their homework”
- Firm and simple motivation- ex: the “no brainer”
- Intact and supportive family system

Family Dynamics in Living Donation

- Limited research on family dynamics and their impact on living donor motivation and informed consent when donating to a family member (pertaining to US population)
- Current literature does not adequately address specific ways for centers to evaluate and consider donors who may want to donate to a family member with whom they have a complex or distressed relationship

Bias

- Bias may be towards donors with uncomplicated or traditionally "good" relationships with family member recipient candidates

- May be missing out on the opportunity to complete further assessment or offer additional support in order to allow donors with more complex situations to proceed

Creates Limits on:

- A center's ability to help recipient candidates

- A program's commitment to the value of donor autonomy

Case Study

- Offers an example of how our team approached the evaluation and support of a donor in a distressed family system while prioritizing:
    - Donor Autonomy
    - Informed Consent
    - Donor Safety

UPMC Process

- Potential donor submits information through our website
- Nurse coordinators screen donors based on criteria (age, BMI, health history, etc.)
- ILDA team contacts donor for pre-evaluation conversation
  - Review process, screen for coercion or pressure, discuss medical out
- Evaluation
- Post-Evaluation Follow Up
  - Assess understanding of process and risks

Living Liver Donor: First Evaluation

- Donor evaluated for donation to his biological parent
  - Metastases to the liver from a non-liver primary cancer
- Male, early 40's, married, two children
- Deemed a good medical and surgical candidate
  - Minimal alcohol use, remote rare drug experimentation, quit nicotine the prior year
  - No psychiatric contraindications
- Confirmed caregiver (wife)
- Self-employed
- Lives in a different state from our center
- Donor described his relationship with his recipient as "distant" but intact

Approved But Delayed

- Donor was approved and surgery was scheduled
- Surgery was then cancelled due to medical issues in the recipient
- A little over one year later, recipient was deemed eligible again
  - Donor once again came forward to donate

Second Evaluation

- No changes to donor's health status, caregiver plan, finances, or psychiatric history

- However…
  - Donor disclosed that he and his recipient had a serious falling out and were no longer on speaking terms
  - Donor reported his sibling had considered donating instead because of this rift but the sibling changed their mind
  - Donor expressed a strong desire to avoid any contact with his intended recipient at any point during the donation process
  - Our team had concerns about how this dynamic would impact donor's ability to proceed safely

Essential Areas of Assessment

- Motivation
- Informed Consent
- Pressure or Coercion

Multiple Timepoints

- Before Evaluations
- Evaluations
- After Evaluations
- ILDA team following this donor closely throughout

Motivation

- Donor's motivation was assessed thoroughly by ILDA team, nurse coordinator, social work, and psychiatry
  - First Evaluation- Donor reported that he wanted to help his parent live a longer life
  - Second Evaluation- Donor felt strongly that he wanted to donate because he believed it was the right thing for him to do for himself and his value system
    - Exercise in forgiveness
- Donor denied expectations that donation would improve his relationship with his parent or change it in any way.
  - This was a particularly important assessment point during the second evaluation
- Donor denied experiencing any pressure to donate from his intended recipient or other family members at all time points.

Informed Consent

- Donor was educated on risks of living liver donation and endorsed full understanding
- Donor was provided additional information related to transplant as a treatment of liver metastases via living donation and outcomes
- Discussions were held with the donor about stressors that could occur that were unique to his situation
  - No guarantee that he would not encounter his recipient while inpatient or during follow up
    - Informed donor that some of his specific requests (such as being on a separate unit from recipient immediately post surgery) were not feasible
  - Complications or poor outcome for himself or recipient may be more difficult to process

Extra Support for Donor

- ILDA team offered to assist donor find therapy resources
- ILDA team discussed with donor strategies for navigating communication between donor and recipient prior to surgery should he desire it (such as a family meeting with a moderator or other neutral third party)
- Precautions were arranged by the medical team to minimize the chance of contact
  - Room assignments on opposite ends of transplant units
  - Extra briefing with inpatient staff
- Multiple inpatient post-surgery contacts to offer support and assess coping

Outcome

- Donor was approved
- Recipient was agreeable to proceeding
- Transplant was completed
  - Donor did report unintended contact with the recipient on more than one occasion prior to arriving at the hospital for surgery
  - No additional conflict was reported
- Donor endorsed having a positive experience with donation immediately post donation and during multiple follow ups

Take Aways

- While donor evaluation is in many respects “one size fits all”, much of it is also “case by case”
  - Unanticipated situations often require flexibility and creativity
  - Anticipate speedbumps
  - Standardized guidelines should be partnered with clinical judgement
- When in doubt, more conversations are better
- Teamwork
- Meeting donors where they are whenever possible
  - If we can do it safely, we should strive to let donors make the call

Co-Investigators

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Special thanks to all the living donors who give the gift of life

Thank you

American Foundation for Donation and Transplantation

Patient Autonomy Versus Medical Paternalism Living Liver Donor Transplantation

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Ethical Principles

- Respect for Autonomy
- Beneficence
- Justice
- Non-Maleficence

Autonomy

- The idea that all persons have intrinsic and unconditional worth, and therefore, should have the power to make rational decisions and moral choices, and have the capacity for self-determination.

- It gives us a negative duty not to interfere with the decisions of competent adults, and a positive duty to empower others for whom we're responsible.

- In transplant, autonomy is balanced with the other ethical principles such as beneficence, non-maleficence, and justice.

Case Profile

Autonomy versus Paternalism

Transplant Candidate

- 45-year-old Caucasian male, unmarried and unemployed
- Began consuming alcohol at 12 years of age and heavy consumption between 15-45 years
- Physically abusive to ex-wife and daughter when he was intoxicated
- His ex-wife separated from him when their daughter was 3 years old
- Child Protective Services required supervision between father-daughter visits
- Father ceased contact with daughter at age 3 years when required to be supervised
- Hospitalized for alcohol hepatitis and was so ill he quit consuming alcohol
- Expected wait for a deceased organ donation would likely be a year or longer
- The transplant candidate located his daughter to ask her if she would be a living donor

Living Donor Candidate

- A 20-year-old Caucasian female
- Single mother of 1 year old child
- No chronic medical or surgical contraindications
- History of anxiety and depression but managed with medication
- No history of tobacco or drug use
- Consumes about 5 drinks per week of alcohol
- Motivations include wanting to save her father's life but also establishing a relationship with him

Evaluation and Recommendations

Evaluation

- The multidisciplinary transplant team had significant concerns and planned to decline the donor due to motivations

- The ILDA met with the donor and discussed not only the advantages and disadvantages of donating to her father but her feelings associated with the decision.
  - How she would feel if she donated to her father and he did not maintain contact with her, became abusive, or began consuming alcohol again
  - How she would feel if she did not donate and her father passed away

Recommendations

- Donor was asked not to make a decision at the time of the evaluation
- Team suggested she take time to think and discuss donation with trusted family and friends
- The donor and ILDA agreed they would speak again in two weeks
- Donor decided
  - Not donate in the next six months
  - Take time to establish a relationship with her father
- The father became angry and did not remain in contact with his daughter and began consuming alcohol

Outcome

Allowing the donor to make the decision (autonomy), rather than the transplant team making it for her (paternalism) resulted in…

- The donor feeling empowered to make her own decisions, that while resulted in not developing a relationship with her father, it help clarify their relationship

- Decided not to consume alcohol due to the damage it caused to her father and their relationship

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Special thanks to those who come forward to donate
as well as those who give the gift of life.

American Foundation for Donation and Transplantation

Ethical Implications of a Pediatric Identical Twin Living Donor

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Purpose

Assessment of potential familial coercion and protection of the rights of the minor when an underage donor option is presented

Background

- Pediatric recipient seeking kidney transplant
- Pre-emptive
- Not sensitized
- No other comorbidities requiring further clearances
- 4 potential living donors

Living Donor Options

DONOR A	DONOR B	DONOR C	DONOR D
56 y.o.	17 y.o.	25 y.o.	27 y.o.
ABO compatible	ABO compatible	ABO compatible	ABO compatible
6/10 HLA match	10/10 HLA match, identical twin	10/10 HLA match	6/10 HLA match
Required cardiac and pulmonary clearance	Donor did not qualify for initial evaluation due to age	High risk candidate requiring cardiac clearance	Donor opted to not pursue further evaluation
Completed Evaluation		Adult institution opted to pursue other donor options	

Ethical Concerns

- Parental involvement
- Potential for recipient (identical twin) coercion
- Age of potential donor

Independent Living Donor Advocate (ILDA)

- What is the significance of an ILDA?
- Actions of ILDA
  - Policy Review
  - Called for Multicenter Multidisciplinary Meeting
  - Communicated plan with donor team
  - Initiated communication with donor

Multidisciplinary Meeting Review

- Proceed with 56-year-old living donor
- Wait until identical twin donor turned 18-years-old
- Assess interest of other loved ones to undergo donor evaluation
- Pursue activation on the deceased donor waitlist

Outcome

- Pediatric donor pursued evaluation after their 18th birthday
- Donor approved and recipient transplanted >8 weeks later
- Recipient did not require dialysis and does not require post-transplant immunosuppressive medications

Strategies for coercion management

- Review of precedent
- Online donor health questionnaire age restriction
- Multidisciplinary team approach
- Creation and communication of concrete plan of action

Preserving Donor Autonomy

- Ensured patient confidentiality
- Limited parental involvement
- Established communication plan
- Gave opportunities to withdraw from evaluation
- Obtained informed consent

Implications for Future Cases

- Benefits of dual institution meeting with family
- Importance of utilization of ILDA
- Potential for further psychological evaluation of donor if warranted

Future Considerations

- Does age play a role in recovery expectations?
- Implications of young adult lifestyle
- Twin relationship during simultaneous recovery

Questions?

Strategies for Addressing Ethical Issues

Communication, Comprehension, Capacity, Coercion

- Recognize the problem
- Avoid making assumptions
- Get the facts
- Be knowledgeable about laws, regulations, relevant hospital policies
- Discuss/Communicate w/ stakeholders and team members
- Beware of rumors/unsubstantiated information
- Document facts/new information in EMR
- Know when you need help
- Access appropriate resources
- Patient Services Admin/Legal
- Ethics consult