Post-Operative Psychosocial Needs of Living Liver Donors

Sandy Weinberg, LCSW & Jaime Cisek, RN

We have no financial interests or relationships to disclose.
Timeline of Donor Experience

- Pre-donation Evaluation & Preparation
- Immediate Recovery Period < 6 weeks
- Long-term Recovery Period 2 months +

Most donors report it takes 10-12 weeks to recover.
Age, social history and fitness level can affect this.
Pre-donation Evaluation & Preparation

Psychosocial impacts begin as soon as a potential donor is considering being a donor.

Feelings often include:

- Ambivalence
- Fear
- Obligation

- Worry/anxiety
- Excitement
- Anticipation
Pre-donation Evaluation & Preparation

Dynamics include:

- A magnifying glass on family system dysfunction and functioning
  - Intensified reflection and evaluation on familial relationships
- Potential fear that they will not be medically able to donate
- Worrying about financial impact of donation
- Underestimating surgery/recovery complexity and risks
- Planning for relocation causing disruptions in work/family obligations

“It’s like a tummy tuck, right?”

“My uncle did this to himself, why should I put myself at risk?”
Unique to Liver Donation Recovery:

Donors have:

- Longer time out of work and for recovery
  - Open hepatectomy vs laparoscopic

- More intensive medical follow up
  - More frequent, etc
Living Liver Donor Recovery

- What does back to baseline actually mean?
- Able to perform ADLs without fatigue?
- Back to baseline fitness level?

Work leave depends on type of work:
- Work-from-home or administrative roles:
  - 6-8 weeks
- Labor intensive roles:
  - 10-12 weeks
Recovery is impacted by:

- Fatigue:
  - Regeneration starts almost immediately, and the body uses a lot of energy to regenerate the liver
- Pain: Abdominal, back & referred
- Nutrition:
  - Oral intake is less in first few weeks, food may taste different, and they may have constipation
  - Food tolerance: intermittent nausea, effects of gallbladder removal
- Sleep: requires a comfortable position, may have night sweats
Immediate Recovery Period < 6 weeks

Positive/comfortable feelings:
- Gratitude
- Higher self-esteem
- Satisfaction
- Connection
- Relief

Challenging feelings:
- Adjustment
- Distress
- Anxiety/worry/fear
- Frustration
- Discomfort
- Disappointment
Immediate Recovery Period < 6 weeks

Dynamics include:

- Recovery is taking longer than expected
- Recovery is linked to recipient outcome
- Adjusting to the look of the scar and donation side effects
- Role change in the family: now needing care/support
- Concern about their physical abilities
  - e.g. preventing a hernia
- Returning to work may take longer than expected

“I feel like I was hit by a Mack truck.”
Long-term Recovery Period 2 months +

Positive/comfortable feelings:
- Increased connection
- Self-esteem
- Satisfaction
- Relief

Dynamics:
- Lessening worry and stress about their health, work and financial concerns
- Lessening concern about caregiving and managing health needs for the recipient
- Increasing sense of wellbeing & purpose

Case: 49 year-old two organ non-directed donor within three years sees the donations as being transformative and meaningful, especially after meeting the kidney recipient.

“I’m getting a tattoo to honor what I’ve done!”
Long-term Recovery Period 2 months +

Challenges:

- Managing long term effects including fatigue, discomfort, soreness and pain
- Impacts on body image
- Depression and anxiety
- Impact of lost wages
- Family system relationship/role adjustments
- Grief/sadness/guilt if recipient dies, especially in the first 1-2 years
How we can support donors:

• Educate Educate Educate
• Validate/normalize their experience
• Referrals for psychotherapy
• Linking with financial resources
• Connect with a mentor
Case Study 1

- 27-year-old woman, former college athlete, employee of a group home
- Donated liver to 30-year-old sister
- Recipient did not leave the hospital, died a few weeks after donation
- Donor became the legal guardian of recipient's son
- Donor had exceptional physical recovery, though significant emotional impact, and the stress caused weight loss
- Donor utilized ILD social worker for supportive/grief counseling for several months. Recipient team referred recipient’s son to supportive services.
- ILD SW referred donor to a psychiatrist, and she started anti-depressant meds
- Donor was out of work for 4 months. Significant financial impact on family system
Case Study 2

- 41-year-old woman, donor to her mother
- No concerns on evaluation nor complications with surgery
- Developed a hernia 3 months post-op
- Hernia incision became infected and required a wound vac
- Wound did not heal properly with vac, admitted for IV antibiotics
- Underwent four subsequent operations for wound debridement including one for removal of infected mesh
- Total of 6 surgeries over the course of her first-year post-op, requiring considerable amount of time off from work
Case Study 3

19yo daughter

41yo kidney patient

Due to anatomy, she was unable to donate her liver to her sister

Knowing the 41yo kidney patient needs a kidney, was approached to do a liver / kidney swap

Genetics prevent her from being the donor

Suggested donating her liver to someone in exchange for a kidney for her mother

50yo liver patient

47yo sister

Multiple in-depth assessments

Ethics

Psychiatry

Financial Resourcing

However, she had no insurance, low income, no careplan and needed to relocate from CO

19yo daughter advocated for this – is it on ethical grounds? How do we approach this?

19yo daughter

41yo kidney patient

19yo daughter

47yo sister

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41yo kidney patient

However, she had no insurance, low income, no careplan and needed to relocate from CO
References:

- Dew MA, DiMartini AF, Ladner DP, et al. Psychosocial outcomes 3 to 10 years after donation in the Adult to Adult Living Donor Liver Transplantation Cohort Study. Transplantation 2016; 100: 1257–1269
Thank you!
Session Survey

Jaime Cisek RN, BSN, and Sandy Weinberg, LCSW | April 19th 2:45 PM-3:30 PM