Psychosocial Outcomes of Living Liver Donation

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ISSUE

Psychological health and social stability are essential factors for donor well-being. Positive outcomes of living donation may be psychological growth, greater resilience to future stress, and better cohesion among family members. Moreover, positive psychological outcomes may be the only medical benefit of living donation. Concerning negative outcomes include psychiatric decompensation, lingering somatic symptoms, body image issues, alcohol/substance relapse, loss of job, economic stress, grief, and family and relationship strains. Data collection of donor outcomes had not historically included all psychosocial variables alongside medical and surgical outcomes, but donor advocacy groups have long called for comparable and comprehensive analysis.

DATA

The Adult to Adult Living Donor Liver Transplantation Cohort (A2ALL) studies provide data on both short and long term psychosocial outcomes. In prospective follow up, the majority of living liver donors recover from the initial functional disruption of hepatectomy with no regret; and after up to two years, 95% report they would make the decision to donate again.(1) Protective features could be psychological benefits such as the high rates of improved self-esteem and personal psychological growth from the donation experience. Half the donors reported improved relationship with their recipients and one third reported better relationships with their own families.(2) Despite these overall positive reports, in an effort to better understand donor outcomes, risks have been described in the following areas:

Risk of adjustment reactions from short term symptoms and functional loss

Donors have reported incisional discomfort, taste alterations, bloating, indigestion, diarrhea, constipation, and sexual dysfunction in the months after surgery. Additionally, a significant number of donors may lament the appearance of their abdomen while others may draw a positive meaning to a large scar as a source of pride. At times, the recipient may improve more quickly than the donor who may continue to struggle with unanticipated fatigue, pain, and other symptoms. Ambivalent attitude prior to donation

may be an independent risk factor for these post donation somatic symptoms, more medical problems, and a slower recovery.(3) With the reported 40% complication rate in the first year after right lobe LDLT, short term physical symptoms can possibly interfere with returning to work and family responsibilities.(4) Risk for hernia may require extended leave from physically demanding jobs and/or delayed return to typical familial roles. Initial positive post donation reactions like higher self-esteem and feelings of gratitude are not sustained and are diminished by 6 months. By the first year post donation, up to one quarter of liver donors report strained family, social, or work relationships.

Risk of long term emotional, somatic, and behavioral symptoms post donation

The prospective A2ALL study reported low rates of major depression and anxiety syndromes in the first two years after donation as they concluded that those accepted are typically physically and psychologically healthy (1). Those experiencing the loss of a closely related recipient, functional loss, or financial burden may be particularly vulnerable. Of donors with recipient death during the first 2 years of prospective follow up, one third felt guilty and one-fifth felt responsible for the death (1). In the longer term A2ALL survey of 3 to 10 years, these feelings were less frequent and were reduced presumably with more time (and perspective) since donation. This long term data also suggested that demographic risk factors like male sex, younger age, and non-Hispanic white race were associated with an increased risk of poor psychological outcomes.(5)

Chronic pain, defined as persistent pain over 3 months, is known to have a strong impact on quality of life and functioning. In one report 27% of liver donors experienced some persistent pain 12 months post donation; but this pain was generally found to be mild and not life interfering.(6) Depression, health anxiety traits, medical concerns prior to surgery and being discouraged to donate may be predictors of early moderate to severe pain. Pain surveyed in the long term cohort was found to be no different than community norms. Cognitive syndromes from delirium are rare and time limited to the inpatient stay; persistent cognitive problems have not been reported. In long term follow up, the incidence of fatigue is lower among donors than in the community norm.

Though behaviors such as relapse to heavy alcohol use in the first two years was noted to be only 2 – 5% in the A2ALL cohort, this is concerning considering the toxicity to the regenerating liver and lack of data on the effects of alcohol use after partial hepatectomy (4). Opioid use, tobacco, and other substances of abuse have not been extensively studied in donors, but have been assumed to be less frequent given the careful selection process prior to donation. While the overall incidence of mortality is rare post donation, suicide had been found in a large retrospective dataset as a concerning cause for death in liver donors compared to healthy controls who did not donate.(7)

Risk of financial loss and insurability

Medicare and the majority of private insurances cover the medical expenses of the evaluation, surgery, and standard post donation medical appointments and tests. Not all follow up medical care will be covered by recipient insurance or the donor’s own insurance. In A2ALL 37% of liver donors incurred out-of-pocket donation-related

medical expenses. Most donors report non-medical expenses due to lost wages, transportation, and lodging for themselves and their support. Endorsement of donation-related financial concerns was highest at 3 months after donation (40%) and lowest at 2 years after donation (19%). Cumulatively, 44% of donors found these expenses burdensome and 24% of the total cohort found the expenses more than expected (2). Donors may not be prepared for this type of economic loss; financial burden was found to be significantly associated with both lower physical and mental quality of life scores post donation.(8) In the A2ALL cohort 7.2% of donors did not have health insurance around the time of donation and only 3.6% reported difficulty securing it at 2 years post donation. In another cohort of 5 regional centers in the New York Center for Liver Transplantation (NYCLT), 12% of donors incurred over $3000 in out-pocket donation-related medical expenses. In this cohort 81% of donors were employed at the time of donation and 76% were working full time after donation with an additional 13% working part-time 6 years after donation.(9) Federal and state tax adjustments may help relieve some donor related expenses. Furthermore, donor-specific grants may offer financial assistance but these are typically means-tested and a small percentage of potential donors qualify.

Risk of reduced donor quality of life

Self-reported quality of life (QOL) measures include physical and mental domains and have been used extensively in kidney and liver donors. Prior to donation, liver donors enjoy a higher QOL than a control adult population across all measured domains. Within the first 3 months after donation, the physical domains are expectedly worse with 15% - 48% reported donation-related physical health problems and concerns while 90% continued to feel positively about donation. Physical QOL measures returned to baseline levels at 6 months in the majority (80-93%) of patients. Mental domains of QOL generally remain slightly lower (but stable) through the donation process.(10) Furthermore, in the A2ALL group of 517 donors, in an average of 6 years post donation, cluster analysis of QOL domains revealed 5 donor groups with only 15% showing high psychological benefit and little endorsement of physical or socioeconomic concerns(5). The most concerning group of 31% who endorsed both physical and financial concerns reported only a modest psychological benefit.(1)

RECOMMENDATIONS

Potential donors want a clear understanding of the probable and possible outcomes of left and right lobe hepatectomy. Data for donor psychological benefits such as improved self-esteem and relationships are encouraging but perhaps already intuitive for potential donors. Improving knowledge about the risks of psychosocial outcomes such as depression, chronic pain, substance relapse, financial loss, and quality of life will improve the integrity of informed consent and help the team assessment process. Assessment of donor motivation requires a thorough review of donor knowledge, feelings, expectations and psychosocial stability. Despite having high motivation, potential donors with unmanaged psychiatric problems and active alcohol/substance abuse have traditionally been excluded or asked to return when psychosocially stable.

The possible inclusion of patients with psychosocial instability could change outcomes. While the authors of the A2ALL recognize this selection effect and also expressed a need to further analyze outcomes after the first decade post donation, the current data provide direction in these areas:

1. Potential donors and their caregivers should be made aware of the known psychosocial risks and expected outcomes. Transplant providers who can provide decision-making support to help plan the recovery are essential to also help prevent negative psychosocial outcomes.
2. Donors with psychosocial instability, financial concerns, or with recipients with complications may require closer post donation psychosocial monitoring.
3. Financial losses can be significant, unexpected, and impact other psychosocial outcomes. Pre-donation financial concerns need to be assessed and interventions need to be explored.
4. Careful assessment of pre-donation psychosocial stability will help appraise future outcomes. A psychosocial team of both psychiatrists/psychologists and social workers can advocate for living donation and safe inclusion of patients with a history of psychiatric problems and substance abuse

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