Distress in Organ Transplantation:

Impacts on Patients, Families, and Medical Teams

TODAY'S PANELISTS

Adam Mills
PhD
Clinical Health Psychologist

University of Nebraska Medical Center
BREAKTHROUGHS FOR LIFE.®

Jasmine Silva
LCSW, MPA
Licensed Clinical Social Worker

University of Nebraska Medical Center
BREAKTHROUGHS FOR LIFE.®

THE Alliance | *Equipping a Modern Profession of Lifesavers in Organ Donation & Transplantation*

Tuesday, April 25, 2023, 3:00pm – 4:00pm ET

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Deanna Fenton
Senior Manager, Program Development and Operations
THE Alliance

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Contact Us via Zoom Chat, or
info@organdonationalliance.org
786-866-8730

Meet Our Moderator

Talia Giordano MSW, LCSW
Director, Family Services and Caregiver Lifeline Program
GIFT of LIFE Howie's House

Meet Our Presenters

Adam Mills

PhD

Clinical Health Psychologist

University of Nebraska Medical Center

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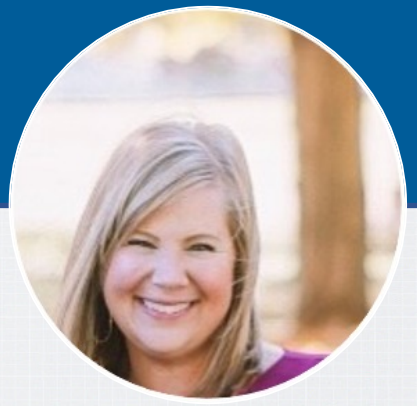

Jasmine Silva

LCSW, MPA

Licensed Clinical Social Worker

University of Nebraska Medical Center

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Psychosocial Challenges Through The Transplant Process

Adam Mills, PhD
Psychology Services

Jasmine Silva, LCSW, MPA
Social Work

Nebraska Medicine, Omaha NE

University of Nebraska Medical Center

Nebraska Medicine

Objectives

- Discuss common/universal stressors through the transplant process
- Discuss unique short-term and long-term stressors specific to transplant patients and their families
- Discuss treatment approaches (psychotherapy, psychogenic medication, support groups) for managing distress
- Discuss distress among transplant staff and symptoms / predictors of burnout

Distress in Organ Failure / Transplant Patients

Patients with organ failure have increased risk of distress, and distress is associated with negative outcomes

- CKD / ESRD patients: 20-30% may report depression (5x more than healthy population), 15-50% may have elevated anxiety (Goh & Griva, 2018)
- Lung failure patients have high rates of anxiety, panic, depression (Søyseth et al., 2016)
- LVAD pts and partners have elevated anxiety and depression (Brouwers et al., 2015)
  - Partner's distress > Patient's distress early on

Distress in Organ Failure / Transplant Patients

Patients with organ failure have increased risk of distress, and distress is associated with negative outcomes

- Over 30% of liver transplant patients experience post-txp distress (Annema et al., 2014)
  - Mostly in first 2 years posttransplant
- PTSD / Trauma/stressor-related distress
  - Generally elevated in transplant patients (Davydow et al., 2015)
  - Can be premorbid or due to medical-related stressors
  - Higher in those with poor support, hx of distress

Transplant Process / Continuum

- Pre-, peri-, and post-evaluation
- Post-listing (inactive, waitlist management, de-listing)
- Post-transplant
- Short-term hospital recovery
- Post-discharge / longer term recovery
- Long-term complications, disease progression
- End-of-life

Pre-Listing, Pre / Post Evaluation

- **Medically**
  - Patient's health may continue to decline
  - Need to be "sick enough" but not "too sick"

- **Psychologically**
  - Increased stress through evaluation period
    - Increased worry / anxiety learning about txp risks
  - Increased anxiety as health continues to decline
  - Frustration with 'jumping through hoops,' changes
  - Discouragement with setbacks

Pre-Listing, Pre / Post Evaluation

- **Psychological treatment approaches**
  - **Cognitive behavioral therapy, acceptance and commitment therapy**

    - Focus on values behind wanting transplant
    - Reframing the purpose of the "hoops"
    - Encourage continued engagement in activity
      - May help mood, motivation, and anxiety
      - May help conditioning, strength, & endurance
      - Sets stage for pushing oneself despite discomfort

Pre-Listing, Pre / Post Evaluation

- **Psychological treatment approaches**
  - **Cognitive behavioral therapy, acceptance and commitment therapy**

    - Relaxation exercises (deep breathing, PMR)
    - Worry management skills (distancing)
    - Care partner referral / intervention if desired

Pre-Listing, Pre / Post Evaluation

Cognitive Behavioral Therapy (CBT) vs Acceptance & Commitment Therapy (ACT)

- Both are evidence-based
- Both teach new skills
- Both encourage **behavioral activation & relaxation**
- CBT more focused on symptom reduction, changing thoughts
- ACT more focused on symptom acceptance, allowing thoughts to come and go

Listed – Waiting for Transplant

- **Medically**
  - Continued anxiety about further deterioration
  - Inactive, delays, canceled cases, complications, and setbacks may be more discouraging at this point

- **Psychologically**
  - Possibly increased anxiety
  - False alarms – frustrating, discouraging
  - De-listings, status 7, etc depressing
  - **Similar psychological treatment approaches**

Transplanted – Short Term Recovery

- **Medically**
  - Surgery, acute recovery, working toward medical stability

- **Psychologically**
  - May be facing delirium or steroid-induced symptoms
  - May be difficult to communicate (intubated)
  - Pain, anxiety, depression can impact motivation
  - Insomnia

Transplanted – Short Term Recovery

- **Psychological Treatment Approaches**
  - Heavier reliance on **medication** to help with pain, sleep, anxiety d/t difficulties communicating, delirium, and/or steroid induced symptoms
  - Simplified CBT/ACT approaches (relaxation)
  - Limited ability to do behavioral activation or insomnia treatments
  - More family education / intervention
  - Environmental changes in hospital room

Post-Transplant Hospitalization

- **Medically**
  - Rejection, comorbidities, rehospitalization, trach, dialysis, feeding tube

- **Psychologically**
  - Growing discouragement/frustration with setbacks
  - Motivation can start decreasing
  - Anxiety can worsen
  - Grief about donor & donor family

Post-Transplant Hospitalization

- **Psychological Treatment Approaches**
  - Oscillating between short-term goals and longer-term motivations
  - Focusing on what one can control
  - Re-focusing on values behind transplant

Discharge – Short Term

- **Medically**
  - Rejection, re-hospitalizations, new complications, medication SEs

- **Psychologically**
  - Anxiety prior to discharge – suddenly flying the nest
  - Discouragement with slow progress, hospitalizations, new problems, etc
  - Possible caregiver burnout (now or earlier)

Discharge – Short Term

- **Psychological Treatment Approaches**
  - Focusing on the facts – reassurance
  - Increasing breadth of activity
  - Worry management
  - Caregiver support

Longer Term Issues

- **Medically**
  - Rejection, medical adherence, symptom management, quality of life is fluid, timing of palliative care introduction

- **Psychologically**
  - Health maintenance behavior can be affected by:
    - mood, access, finances, substance use relapse, life events, goal changes
  - Treatment: psychotherapy and support group interventions

Assessing Long-Term Success

- Goal of evaluation: assess suitability for transplant
  - NOT providing treatment

- Assessing the system

- Higher risk for post-transplant psychiatric distress:
  - History of past distress, female gender, longer wait list time, early complications, poor caregiver support

Assessing Long-Term Success

- After the 1st year family/patient shift to reestablish normalcy in everyday life

- Caregiver well-being
  - Caregiver plays major role in patient's life, physical health, and mental health
  - Caregiver also undergoes significant stress in txp

Palliative Care Involvement

When to introduce palliative care?

- Palliative and restorative care are not at odds
- Palliative can optimize QOL through patient's illness and trajectory to reduce distress
- As patient's change focus it allows clinicians to address symptom management
- Early palliative involvement (in liver txp) associated with improved anxiety, depression, appetite, fatigue, and overall well-being (Baumann et al., 2015)

Care Partner Distress & Burnout

- Caregiver “burden” not well-defined, not consistently studied (Jesse et al., 2020)

- Burdens include:
  - Lifestyle changes (work, finances)
  - Feeling responsible to maintain patient’s mood / hope
  - Worries about the patient, uncertainty
  - Neglecting own needs, social life, hobbies

See Jesse et al., 2020 for a review

Care Partner Distress & Burnout

- Burden varies depending on organ, phase in the process, and other contextual factors
  - Higher for patients:
    - With a trach
    - On dialysis
    - With alcohol-related liver failure
    - With vad complications

See Jesse et al., 2020 for a review

Care Partner Distress & Burnout

- Caregivers experience benefits as well
  - Improved priorities / motivations / perspectives
  - Building resilience
  - Quality time with patient

See Jesse et al., 2020 for a review

Care Partner Distress & Burnout

- Much less information on:
  - Changes / trajectory of distress throughout process
  - Effective treatments for caregivers
  - Effect of caregiver burden on mortality

See Jesse et al., 2020 for a review

Care Partner Distress & Burnout

- Pretransplant distress generally low (13% - 17%; Goetzinger et al, 2012)
  - Healthy US population averages between 10-18%
  - Possible minimizing?
  - Increases through post-operative period, decreases about 1 year post-transplant

Distress In Transplant Providers

- **Transplant coordinators** (Silva e Silva et al., 2020) experience:
  - Exhaustion, burnout, distress (anger, irritability, depression)
  - Turnover, sick days
  - Compassion fatigue

- Due to factors including:
  - Low autonomy
  - High # of (unpredictable) work hours
  - Poor work/life boundaries
  - Poor outcomes
  - Difficult patient interactions

Distress In Transplant Providers

- **Transplant surgeons** (Jesse et al., 2015) experience:
  - Moderate-to-high emotional exhaustion (69%)
  - Moderate-to-high depersonalization (48%)
  - Low feelings of accomplishment (47%)

- Due to factors including:
  - Low decisional authority
  - High job demands
  - Low co-worker support

Summary

Each phase of transplant process has different risk factors for distress

Distress Can Be Impacted By

- Various milestones (eval, pre-listing, post-transplant)
- Various situations (deterioration, transplant, complications)
- Patient personal risk factors
- Caregiver support / characteristics
- Post-transplant resources
- Post-transplant trajectory (complications, rejection, etc)

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University of Nebraska Medical Center

Nebraska Medicine

A Special Thanks to Our Presenters

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PhD
Clinical Health Psychologist

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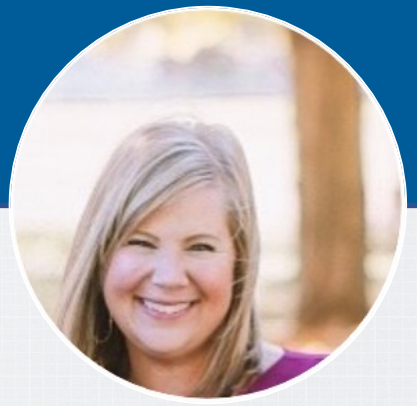

Jasmine Silva
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Q&A
QUESTIONS & ANSWERS