MITIGATING AND MANAGING PSYCHOSOCIAL RISK FACTORS IN SOLID ORGAN TRANSPLANTATION: A CASE APPROACH

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Disclosures

- No disclosures

- Please maintain confidentiality of information disclosed during today’s presentation
Objectives

- Discuss composition and role/utility of psychosocial team within multidisciplinary transplant program
- Provide 3 case examples that illustrate identified psychosocial risk
- Address role of psychosocial team in helping patient to mitigate this risk to work towards most successful transplant outcomes
Background

- The numbers still don’t add up
  - 119,887 on waitlist; 77,208 active (as of 09/18/16)
  - 22,119 transplants from January – August 2016 (optn.transplant.hrsa.gov)

- Critical to allot organs fairly; to those who will achieve most optimal outcomes

- All transplant programs work to minimize morbidity and mortality given scarcity of available organs

- Pre-transplant psychosocial evaluation has important role in identifying appropriate candidates

(Kuntz et al., J Clin Psychol Med Settings, 2015)
Psychosocial Evaluation

- Psychosocial team: social workers, psychologist, psychiatrist
- Identify factors that have potential to affect success of transplant
- Criteria may be different between transplant centers
- Individual organs may have different criteria

(Kuntz et al., J Clin Psychol Med Settings, 2015)
Psychosocial Evaluation Objectives
Continued

- “What can we do to help this patient become a candidate?”
  - Plan to mitigate risk factors
  - Collaborate and communicate with MDC transplant team
  - Psychosocial team may be integral component of plan or may monitor progress

- Art in knowing when progress is being made and when patient would be best served by coming back when readiness for transplant is enhanced
Ethically complex...

- Aim for objective psychosocial assessment
- What are risk areas?
  - Is progress being made towards decreasing high risk factors such that moving towards predicting most successful outcomes post-transplant?
  - Not very successful at predicting behaviors
- Psychosocial evaluation is not
  - To prescribe value to someone's life
- Guideline, protocol, objectivity can become challenging when becomes involved
The Transplant Process

- 3 basic phases
  - Pre-Transplant/Evaluation Phase
  - Waiting-Candidacy Phase
  - Post-Transplant Phase
Case 1

- 52-year-old widowed, Polish male with ESLD secondary to alcoholic cirrhosis presented to clinic early 2016
- Past Medical History: ESLD, esophageal varices, refractory ascites, encephalopathy, chronic kidney disease
- Social History:
  - Born in Poland, moved to US at age of 25
  - Married for 15 years; wife died 3 years ago from cancer; no children
  - Patient is primarily Polish speaking
  - Lives in apartment with roommates
  - Sister, brother-in-law, niece live nearby
Case 1 Continued

- **Substance Use:**
  - Per medical record: Longstanding history of alcohol use disorder, “4 shots vodka regularly,” ED visit following DUI
  - Patient report: age 21-4 years ago when wife became sick; “2-3 drinks of vodka on holidays”
  - Niece unable to confirm his report

- **Understanding of disease**
  - Patient’s understanding of etiology: unsure, “working with chemicals for years”
  - Denied possibility that alcohol could have contributed
Case 1 Continued

- **Psychiatric History:**
  - Major depressive disorder when wife became sick
  - Exacerbation in anxiety and depression as result of physical status
    - Anxiety 8-9/10; Depression 10/10
  - Passive suicidal ideation on daily basis as a result of physical pain, “I don’t want to live anymore”
    - Protect factor: Catholic religious beliefs
    - No history plan, intent, attempt
    - No current plan, intent
  - History of psychotherapy when wife was sick
  - Current treatment? “no point, I won’t go.”
  - Taking 3mg melatonin at night for sleep
Case 1 Continued

- Potential Risk Factors:
  - Motivation for transplant
  - Understanding of etiology of disease
  - Adherence to medical regimen
  - Active psychopathology
  - Alcohol, tobacco, or other illicit substance use disorder: alcohol (openness, triggers, coping mechanisms, motivation/commitment towards lifelong abstinence)
  - Social support
  - Cognitive function
Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT)

- Comprehensive screening tool to assist in the psychosocial assessment of organ transplant candidates
  - Patients Readiness Level
  - Social Support System
  - Psychological Stability & Psychopathology
  - Lifestyle & Effect of Substance Use
- Excellent inter-rater reliability
- Used to predict which patients will have poor outcomes following transplant
- Total Scores
  - 0-6 Excellent candidate
  - 7-20 Good candidate
  - 21-39 Minimally Acceptable candidate
  - 40-68 High Risk candidate, significant risks identified
  - >69 Poor Candidate
- Initial SIPAT: 42

(SIPAT; Maldonado et al., 2012)
Case 1: Identify high risk factors, create plan, discuss with multidisciplinary team

- Identified plan:
  - Substance use:
    - Minimum 6 months abstinence
    - Signed a relapse prevention contract during evaluation
    - Random screening for alcohol to confirm abstinence
    - Relapse prevention treatment required
Key Components of Relapse Prevention

- Triggers for use
- Avoidance high risk situations
- Plan for trigger management
- Benefits of abstinence
- Benefits of use
- Engagement in activities that support abstinence
- Motivation/commitment towards lifelong abstinence
- Stable support system that supports abstinence
Case 1: Identify high risk factors, create plan, discuss with multidisciplinary team

- Identified plan continued:
  - Psychopathology:
    - Engage in individual therapy with Polish speaking provider
    - Achieve period of mental health stability (i.e., absence SI, adaptive coping mechanisms for depression)
  - Understanding of etiology of disease:
    - Continue to receive education
  - Motivation for transplantation: inherent in above
  - Meet monthly with transplant psychologist to assess and monitor progress
Case 1, Month 1

- Inpatient and outpatient education from hepatologist and psychosocial team
- Made therapy appointment with Polish speaking therapist
  - "I will admit that I would drink" but did not provide further details; "vodka is dead to me"
  - Patient continued to believe liver disease from chemical exposure
  - Psychoeducation provided around relapse prevention and understanding of etiology of disease
Team visit

- Saw Polish speaking therapist once
- Education provided on etiology of disease; patient continued to believe ESLD as a result of chemical exposure
- Patient reported sobriety for 3 years; niece not in agreement
- Unable to identify triggers for use
- Working towards adaptive coping mechanisms: cards, carves, chess, cooks, paints
Case 1, Month 3

- Patient sought regular weekly therapy focusing on depression management and relapse prevention treatment
- Collaborated with patient’s niece to understand her impression of patient’s drinking
- Collaborated with patient’s therapist
  - Polish culture, “what's done is done, and why dwell on it”
  - Patient verbalizing ongoing commitment to lifelong abstinence
- Family involvement/efforts
Culturally and Linguistically Competent Care and Transplantation

- Patients referred to transplant centers to learn about transplantation and eligibility for transplantation or donation
- Require education about procedures, risks, benefits and alternatives
- Require informed consent from referral to surgery
- No standardized tool to-date
- “Simply providing education is not sufficient”
- “Education must be delivered in culturally and linguistically competent ways”

Gordon et al., Am Journal of Transplantation, 2010
Culturally and Linguistically Competent Care and Transplantation

- Cultural competency
  - “Set of values, principles, behaviors, attitudes, policies and structures that enable organizations and individuals to work effectively in cross-cultural situations”

- Linguistic competency
  - “The capacity...to communicate effectively and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities and those who are deaf or hard of hearing”

- If bilingual and/or bicultural staff not available, how can we work to achieve these competencies?

Gordon et al., Am Journal of Transplantation, 2010
Case 1, Month 4

- Continued twice weekly treatment
  - Emotional shift as a result of therapy and hope regarding transplantation
    - "more relaxed, more calm, able to look at things more positively"
  - Last drink was August 2015 after “taking close look at calendar” (sobriety approximately 10 months)
  - Trigger awareness: wife being sick, working, and holidays/special occasions
  - Described drinking between 2-8 drinks vodka/setting
  - Depression significantly improved
  - No apparent issues related to adherence
Case 1, Month 5

- Twice weekly treatment
- Understanding of alcohol as etiology of liver disease
  - Feelings of embarrassment and shame
  - Understanding of etiology fueled motivation for lifelong abstinence
  - Balance negative emotions with continuing to move forward and enhance motivation for abstinence
- Shift to preparing for relapse risk post-transplantation
  - Continue in regular therapy
  - Regular transplant psychosocial team follow-up
- Depression in context of physical pain
- No apparent issues related to adherence
- SIPAT: 30 Minimally acceptable candidate: approved for listing
- Transplanted 2 weeks later
Case 1 Process

- Facilitators, collaborators in care
  - Polish speaking therapist
  - Family involvement
  - Hepatologist

- Assessing progress

- Worked to provide culturally and linguistically competent services

- The process...
  - Early in recovery versus cultural factors/ shame & embarrassment
  - Encephalopathy?
Case 2

- 36-year-old single, Latina female with ESRD secondary to tuberous sclerosis. Initiated dialysis 07/2005
- Past Medical History: ESRD, seizure disorder, OSA, secondary hyperparathyroidism, hypertension, history of SVT, bilateral renal cell carcinoma s/p bilateral nephrectomies
- Social/Developmental History:
  - Born in Dominican Republic, moved to US at young age
  - Single
  - Resides in group home, has roommate
  - Completed high school at age of 21; obtained a Graduation Certificate
  - Diagnosed with mental retardation when young; special education services; currently diagnosed with mild intellectual disability
  - Obtained medical guardian
  - Works on days not at dialysis
  - Working to adhere to dietary restrictions and weight management strategies
Psychiatric history:
- Described her current mood as "stable, I feel good"

Carries diagnoses:
- Schizophrenia, chronic and undifferentiated,
- Unspecified anxiety disorder
- History of depression

Hospitalized psychiatrically 11/2013
- Hallucinations, suicidal and homicidal ideation, behavior changes

History of hallucinations when under stress, disorganized in thinking, perseverates on various topics
- Seen by APRN in community since 01/2014; since 03/2104 absence psychotic symptoms

Prescribed:
- 1.5 mg clonazepam twice daily
- 15 mg olanzapine at bedtime
- 100 mg sertraline twice daily
- 200 mg Tegretol three times daily
- 8 mg perphenazine three times daily
- 200 mg gabapentin once daily

Substance use: denies
Case 2 Continued

- Potential Risk Factors:
  - Motivation for transplant
  - Understanding of illness and management of complex regimen following transplant
  - Adherence to medical regimen
  - Active psychopathology
  - Alcohol, tobacco or other illicit substance use disorder
  - Social support
  - Cognitive function
Cognitive Dysfunction and Transplantation

- Absolute contraindication: progressive dementia
- Often no difference in transplant outcomes as long as adequate social support:
  - Low levels of intelligence or literacy
  - Developmental delay (Martens, Jones, & Reiss, 2006)
Psychotic Disorders and Transplant

- Psychotic disorders in transplant setting not well-studied
- N=565 kidney transplant recipients studied
  - Focused on patients hospitalized for severe psychosis after transplant
  - Patients with primary or secondary discharge diagnosis of psychoses
  - Those not hospitalized post-transplant were not studied
  - Graft loss as a result of non-compliance significantly more than in controls

Hospitalized Psychoses after Renal Transplantation in the United States: Incidence, Risk Factors, and Prognosis
Rational guidelines for transplantation in patients with psychotic disorders

- Survey distributed to programs in United States, Canada, and Australia over 2 year period
- 35 cases from 12 centers
- Noncompliance resulting in rejection episodes 14.7%
  - Noncompliance with immunosuppression
    - 45.5% living alone or homeless
    - 9.5% living with someone
- Suicide attempts
  - 35.7% of patients with psychotic symptoms 1 year before transplantation
  - 5.9% for those without psychotic symptoms 1 year before transplantation

Patients with psychotic disorders in solid-organ transplant

- Lifetime prevalence rate: 3.1%
- Potential negative affect on transplant outcomes:
  - Low adherence to medical treatment
  - Interpersonal difficulties
  - Self-injurious behaviors
  - Some concerns related to specific antipsychotic medications
Patients with psychotic disorders in solid-organ transplant

- Largest to-date published case series examining patients with psychotic disorders who underwent organ transplant in single center
- DSM-IV diagnoses included:
  - schizophrenia
  - schizoaffective disorder
  - psychotic disorder not otherwise specified
  - mood disorders with psychotic features (major depressive disorder with psychotic features or bipolar disorder with psychosis)
  - substance-induced psychotic disorder
- Excluded psychotic symptoms only present in context of delirium
Patients with psychotic disorders in solid-organ transplant

- Retrospective study; record review 34 transplant candidates with history psychotic disorder
  - 18/34 accepted for listing during study period
- Psychiatric outcomes post-transplant (N=10):
  - Adherence difficulties to medical or psychiatric treatment: 0
  - Absence psychotic episodes: 5/10
  - 1 episode psychosis: 3/10
  - 2 episodes psychosis: 1/10
  - 3+ episodes psychosis: 1/10
- Medical outcomes post-transplant (N=10):
  - No patient had graft loss
  - No patient deaths
  - 4 patients had 1 episode rejection, not associated with symptoms of psychosis or non-adherence
Patients with psychotic disorders in solid-organ transplant

- Psychosis not associated with infection, rejections, mortality or graft loss post-transplant
- Graft rejection, toxic effects immunosuppressant medications, psychotic episodes, psychiatric hospitalizations were low
- Well-controlled psychotic symptoms
- Monitor adherence
- Close follow-up
Case 2 Recommendations and Plan

- Patient should continue to maintain psychiatric stability (absence of psychosis or if symptoms present, no risk for harm to self or others or interference with medical care)
- Patient should continue to adhere to medical and psychiatric treatment (medication regimen, appointment regimen, dialysis, dietary)
- Patient to continue in regular treatment with psychiatric provider in the community and be monitored/reassessed by transplant psychologist regularly (every 3 months):
  - Insight into psychiatric illness
  - Proactively identify symptoms of recurrence
  - Create plan for possible recurrence
- Continue residing in group home; obtained medical guardian
- Transplant psychologist/psychosocial team to continue to collaborate with multidisciplinary team
- Patient working to complete medical workup
Case 3

- Single, African-American male, mid-20’s, non-ischemic cardiomyopathy, s/p L-VAD 08/2015
- Past Medical History: non-ischemic cardiomyopathy, s/p L-VAD 08/2015, anemia, s/p ICD
- Social History:
  - Currently resides with his parents
  - History of social alcohol use prior to cardiac diagnoses
  - Denied history of tobacco or other illicit substance use
  - Primarily works with various non-profit organizations to promote organ donation
  - Active in gym community
  - Intermittent work at sporting goods store and possibility of receiving further education towards master’s degree
Case 3 Continued

- Patient referred to transplant psychologist for difficulties related to adherence and symptoms of anxiety
- Difficulties related to adherence
  - Medication and medical appointment regimen become less of a “priority”
    - More “routine”
    - Challenge managing all commitments
    - Family less involved in assisting
  - Missing appointments, INR checks, blood pressure checks
- Recurrent nightmares of ICU stay, wakes in panic
  - Spent 4 months prior to L-VAD placement in ICU
  - Avolition, anhedonia and decreased appetite
Pre and Post-Transplant Management

- Similar to models of chronic illness
  - Lifelong engagement in multiple treatment related behaviors

- Age groups generally most at risk for non-adherence:
  - Children
  - Adolescents
  - Older adults (dementia)

- In transplantation: 14-21 years of age particularly challenging
- Developmental vs. chronological age

(Bunzel & Laederach-Hofmann, Transplantation, 2000)

Philips et al., J Behav Med, 2015
Health Behavior Theories

- Health behavior theories have had some success in predicting variance in non-adherence to medications and behavior

- Health Belief Model (Rosenstock et al., 1988)
  - Focusing on attitudes and beliefs of individuals
  - Based on understanding that person will take health-related action (i.e., take medications) if:
    - Negative health condition can be avoided (i.e., episode rejection)
    - Maintains positive expectation that by completing recommended action, patient will avoid negative health condition (i.e., taking medication will be effective in reducing risk of rejection)
    - Patient believes they can successfully take recommended action (i.e., can follow medication regimen, swallow pills, etc.)

- Not as successful at longer-term maintenance of targeted behaviors

Philips et al., J Behav Med, 2015
Health behavior theories focus on initiation factors for behavioral change, less successful with maintenance factors.

- Behavioral intentions and beliefs less predictive once individual has developed strong behavioral habits.
  - Strong behavioral habits are more automatic.
  - Habit in literature vs. in clinical practice.

(Philips et al., *J Behav Med*, 2015)
Psychosocial team assisted MDC in creating “compliance contract” or “behavioral contingency contract”
- Clearly outlines expectations patients must follow
- Enhance adherence by fostering open communication in provider-patient relationships
- Ensure patient understands rationale of each component of medical regimen

Patient continued to have difficulty meeting stipulations of “adherence”
- Placed in inactive status until all components of contract met for period of time; then returned to active status
- Continues to work with Transplant Psychologist and Social Worker on issues related to identity, prioritizing health, anxiety reduction, adaptive coping, and maintaining motivation to prioritize health
- Recently transplanted
In Closing...

- People are complex
- Work towards objectivity
  - Identify risk factors for less successful outcomes
  - Develop plan
  - Monitor progress
    - Not an exact science
- Advocates
- Stewards
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