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Medical University of South Carolina

Caring for the Whole Child: A Kidney Transplant Case Study

MUSC Pediatric Transplant

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Disclosures

- I have no relevant financial relationships to disclose.

Learning Objectives

- Understand how multidisciplinary teams, families, hospital systems, and policies shape a child's kidney transplant experience.
- Identify social and structural challenges that can impact a child's health and transplant outcomes.
- Explore practical ways to support the child during changes in care and family situations.
- Discuss how care teams can work together ethically and respectfully to provide excellent patient care.

Patient Privacy & Ethical Considerations

- All identifying information has been altered or removed to align with HIPAA and institutional policy.

Relevance to Child and Family Care

- Transplant impacts the entire family and care systems.
  - Changing family dynamics and development can impact adherence.
- Transplant provides better outcomes for children with ESRD.
  - Lifelong follow-up care, medications, and development.
- Ecological Systems Model
  - Micro: child and caregivers
  - Meso: family dynamics, DSS system, healthcare team.
  - Exo: healthcare facilities, policies, resource availability
  - Macro: DSS involvement, laws related to parental rights.

Case Study

- Child with ESRD
- Medical History
  - End stage renal disease secondary to VACTERL syndrome and bilateral cystic renal dysplasia
  - G-tube dependent, Autism Spectrum Disorder
- Dialysis & Transplant
  - Started hemodialysis in 2018.
  - Transplant 2020.
    - Complicated course with severe cellular and antibody mediated rejection and and BK nephropathy.
    - Resulted in graft failure.
  - Restarted hemodialysis in 2025.
  - Re-transplant evaluation 2025.

Social History

- Initial transplant evaluation conducted with biological mother, father, and maternal grandparent.
  - Concerns at time of evaluation: History of parents not being at bedside after child was born and remained hospitalized. SW recommendation for family to be able to display knowledge and understanding of patient's care prior to discharge.
- Transferred care from center where child was transplanted to outside center in another state.
- DSS involvement after rejection and removed from biological parent's care.
- Minimal visitation and communication from family after child removed from home.
- Child placed in medical foster home in 2021.

Social History Continued..

- Transition to adoptive family.
  - Adoption finalized in 2025.
- Second transplant evaluation initiated 2025.
- Barriers
  - Caregiver instability.
  - Changes to support system / home environment.
  - Emotional impact on child.
  - Medication and appointment nonadherence leading to rejection prior to DSS involvement.

Caregiver and Family Changes

- Interruptions in care
  - Moving states and family establishing care with new center.
  - Lack of resources to assist with appointment and medication compliance.
  - Disruption when child was placed into state custody.
  - Caregiver training / expectations for family.
- Monitoring for feelings of being overwhelmed and burnout.

Considerations of Case

- Variety of interactions throughout this case including medical, developmental, and social factors.
- Emphasizes the need for trauma-informed care and family-centered support.
- Continuity of care is critical across medical and social transitions.

Multidisciplinary Intervention

- Why does this matter?
  - Each member of a multidisciplinary team plays a critical role in a smooth and successful transition of care.
  - Coordinated multi-level interventions across medical, psychosocial, and caregiver systems are essential to optimize graft survival and the child's overall wellbeing.
  - Continuing to see and evaluate medically complex children with co-occurring social barriers and instability.
  - Long-term graft survival in children is lower during adolescence and early adulthood due to factors like poor adherence and the transition from pediatric to adult care.
  - Advocacy for policies and resources that support medically complex children and their families.

Implications for Practice

- Continued multidisciplinary care for children with chronic medical conditions.
- Use tools for screening adherence and psychosocial barriers (ex: the Barriers Assessment Tool).
- Develop structured protocols for transitions of care: caregiver handoff meetings, medication/clinic visit checklists, social work follow-up.
- Plan for long-term: monitoring into adolescence/adulthood, transition to adult care, address quality of life, schooling/employment, mental health.
- Policy: advocate for resources for high-risk families, reduce transportation/clinic access barriers, foster/adoptive family training in transplant care.

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Discussion/ Q&A

Thank you!