Utilization of a Team Approach to optimize the Plan of Care in Pediatric Renal Transplantation

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Disclosures

I have no financial relationships to disclose.
Goals and Objectives

By the end of this presentation, the audience will be able to:

• Understand the unique challenges in managing renal transplants in pediatric patients and families with psychosocial, cultural and clinical complexities.
• Recognize the struggles that pediatric patients face in learning about and adhering to multiple medications.
• Identify strategies that assist pediatric patients and families in being successful pre- and post- transplantation.
• Develop a toolkit of resources that will enhance their practice as nurses in the pediatric renal transplant field.

Demographic info

RICHMOND, VIRGINIA
• 1 in 4 Richmond residents lived in poverty (as per U.S. Census Bureau, 2010)
• The city has 6 large public housing communities
  • Majority of our population live in these housing communities
• Home to 9100 residents – 1/2 of whom are 17 and younger
• Problems with poverty, violent crime

(Richmond Times-Dispatch, September 15, 2016)
It takes a village...

- Key Players
- Doctors
- Nurses
- Dialysis Nurses/Tech
- Social Worker
- Dietitians
- Pharmacists

Psychosocial issues of complex medical needs

- Socioeconomic status
- Parent’s education
- Language barriers
- Burden of a chronic illness
- Communication difficulties
- Emotional/Behavior issues
Chronic Illness

It Takes a Village......

• Social Worker
Is transplant the end of care?

- Adherence post kidney transplant continues to be a challenge
- Estimates of non-adherence in pediatric patients is between 30% to 70%
- Total cost of non-adherence in solid organ transplant between 15-100 million dollars annually.
- Potential solutions include using a Multidisciplinary Team approach

Ist Case: KG, Social Issues

- First seen by Peds Nephrology when an infant
- Medically complex child
- Hypernatremia, Metabolic Acidosis, Hypokalemia, elevated ammonia
- Elevated lactate, elevated bilirubin, renal insufficiency
- Mom has one other child
- Mental Health issues
Compliance Issues

- Multiple missed appointments
- Medications not picked up nor given
- Parent refused to answer her phone
- Patient placed on Hemodialysis after ER visit

Social Work Interventions

- Support and Validation
- Transportation
- Home nursing
- Pairing parents with support from other parents
CPS

- Child Protective Services
- Formed in 1974
- Requires States “to prevent, identify and treat child abuse and neglect”
- Partly funded by Federal Government

https://en.wikipedia.org/wiki/Child_Protective_Services

Legal and Social Implications

- Investigation opened
- Court appearances
- Foster family identified
- Stress and anger from biological Mom
Social Worker responsibilities

- Court appearances with physician
- Frequent communication with Social Services/CPS
- Paperwork
- Consents signed for any procedures

When the day arrives for transplant............

- What happens when child is called for transplant???????
- “Tree of legal representation”
Protective Factors: keys to success

- Parental/Caregiver support
- Higher SES
  - Education level
  - Employment
- Marital status
- Social–emotional coping skills
- Mental well-being

Second Case: WH Teenager with Insulin-dependent Diabetes

- 14 year old African American male hospitalized for new onset Nephrotic Syndrome
- Already had Type 1 Diabetes Mellitus
- Low income family
- Lower education level
It takes a village...

• Key Players
• Doctors
• Nurses
• Dialysis Nurses
• Social Worker
• Dieticians
• Pharmacists

Chronic Illness
Challenges when family member is on dialysis

- Missing school 3 times a week
- Transportation costs and availability
- Loss of income/job for caregiver
- Stress on siblings and other family members

### Labs following transplant:

<table>
<thead>
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<td>134mm/L</td>
<td></td>
</tr>
<tr>
<td>Potassium</td>
<td>6.4mmol/L</td>
<td>5.5mmol/L</td>
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</tr>
<tr>
<td>Chloride</td>
<td>109mmol/L</td>
<td>108mmol/L</td>
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<tr>
<td>Carbon Dioxide</td>
<td>20mmol/L</td>
<td>21mmol/L</td>
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<tr>
<td>Glucose L</td>
<td>517 mg/dL</td>
<td>309mg/dL</td>
<td></td>
</tr>
<tr>
<td>Blood Glucose (POCT)</td>
<td>518 mg/dL</td>
<td>523 mg/dL</td>
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<tr>
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<td>27mg/dL</td>
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<tr>
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<td>1.92mg/dL</td>
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<tr>
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<td>15 units/L</td>
<td>18 units/L</td>
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<tr>
<td>ALT</td>
<td>23 units/L</td>
<td>17 units/L</td>
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<tr>
<td>Alk Phos</td>
<td>130 units/L</td>
<td>102 units/L</td>
<td></td>
</tr>
<tr>
<td>Albumin</td>
<td>3.6g/dl</td>
<td>3.5g/dL</td>
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</table>
What is going on????????

- Before and after transplant our Nephrology nurses teach the patient and family all about their medications
- Many different teaching methods are used
- Up to 9 different medications are used initially, with up to 20 doses of meds per day
- This patient was very compliant and willing to learn
Answer

• He was so focused on his transplant medications he had forgotten to take his Insulin.

All was good?

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<td>Potassium</td>
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<tr>
<td>Chloride</td>
<td>108 mmol/L</td>
<td>110 mmol/L</td>
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<tr>
<td>Carbon Dioxide</td>
<td>23 mmol/L</td>
<td>24 mmol/L</td>
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<tr>
<td>Glucose L</td>
<td>115 mg/dL</td>
<td>125 mg/dL</td>
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<td>2.06 mg/dL</td>
<td>2.09 mg/dL</td>
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<tr>
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<tr>
<td>ALT</td>
<td>14 units/L</td>
<td>18 units/L</td>
</tr>
<tr>
<td>Albumin</td>
<td>4.4 g/dL</td>
<td>4.3 g/dL</td>
</tr>
</tbody>
</table>
Interventions

• Nursing checked medication list with patient and family

• Social worker talked with patient and family to make sure medication were being given correctly

• Physician performed outpatient kidney biopsy to check for rejection

• Nursing called pharmacy..........

The reveal..........

• Pharmacy had given incorrect strength of Tacrolimus capsules to family

• Patient had been taking too much Tacrolimus which causes toxicity

• Thankfully no rejection was found on biopsy and error was rectified
3\textsuperscript{rd} Case: AS, Language barriers

- 4 year old Hispanic female with Nephrotic Syndrome
- Neither parent speaks English, patient does speak English
- Transplanted after 2 years on Hemodialysis
- Many communication and cultural challenges

It takes a village...

- Key Players
- Doctors
- Nurses
- Dialysis Nurses
- Social Worker
- Dieticians
- Pharmacists
Additional Team members

- Interpreter Services

Challenge:

How to teach post transplant instructions and medications in a different language
Have all post transplant instructions translated into Spanish

**Instrucciones para después del trasplante**

- Tome la temperatura dos veces al día. Llámeme si es más de 38.5.
- Las citas en la clínica serán los lunes, miércoles y viernes a las 9am. Por favor, esa mañana, dé todos los medicamentos EXCEPTO Tacrol. Llegue a las 8:30 am al Pabellón Infantil laboratorio, piso 1º, para hacer los análisis. Cuando termine, vaya al piso 3 Pod A para su visita. Puede dar Tacrol cuando se haya hecho los análisis.
- En horas de oficina, llame a Jules al 804-827-4212 o Jan al 804-827-1761. Después de esas horas, llame a Telepage al 804-828-0951 y pida que llamen al nefrólogo pediatrático.

### Lista de medicamentos de trasplante de riñón para

<table>
<thead>
<tr>
<th>NOMBRE DEL MEDICAMENTO</th>
<th>Finalidad</th>
<th>Dosis</th>
<th>9am</th>
<th>12 mediodía</th>
<th>5pm</th>
<th>9pm</th>
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</thead>
<tbody>
<tr>
<td>Tacrolimus (Prograf)</td>
<td>Prevenir rechazo</td>
<td>1mg caps</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Mycophenolate (CellCept)</td>
<td>Prevenir rechazo</td>
<td>250mg tabs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prednisolone</td>
<td>Prevenir rechazo</td>
<td>10mg tabs</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Famotidine (Pepcid)</td>
<td>Prevenir el almidone</td>
<td>20mg tabs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fluconazole</td>
<td>Prevenir infección de hongos</td>
<td>200mg tabs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valganciclovir (Valcyte)</td>
<td>Prevenir infecciones víricas</td>
<td>600mg tabs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Erythromycin (Bactrim)</td>
<td>Prevenir infección de las vías</td>
<td>Single strength</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amilodipine</td>
<td>Prevenir BP</td>
<td>5mg tabs</td>
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<td></td>
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<tr>
<td>Neuraphes Powder</td>
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<tr>
<td>Polietilenglicol (PEG)</td>
<td></td>
<td>370/700</td>
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</tbody>
</table>
Another Challenge........

• Patient is 4 years old

• She cannot take pills

• Compounding pharmacies are rare

• Insurance issues !!!!!!

• Once a pharmacy is identified and liquid medications ordered, how do you teach parents of a small child the names, doses and frequency of these medications.... In a different language to yours?

• Ideas? Experiences?
<table>
<thead>
<tr>
<th>NOMBRE DEL MEDICAMENTO</th>
<th>Finalidad</th>
<th>Dosis</th>
<th>9am</th>
<th>12 mediodía</th>
<th>5pm</th>
<th>9pm</th>
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</thead>
<tbody>
<tr>
<td>TACROLIMUS (PROgraf)</td>
<td>Prevenir rechazo</td>
<td>1mg caps</td>
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<tr>
<td>MYCOPHENOLATE (Cellcept)</td>
<td>Prevenir rechazo</td>
<td>250mg tabs</td>
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<td>PREDNISOLONE</td>
<td>Prevenir rechazo</td>
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<tr>
<td>FAMOTIDINE</td>
<td>Proteger al estómago</td>
<td>30mg tabs</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>FLUCONAZOLE</td>
<td>Prevenir infección de sangre</td>
<td>200mg tabs</td>
<td></td>
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<td></td>
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<tr>
<td>VALGANCICLOVIR (LOspinovir)</td>
<td>Prevenir infección</td>
<td>400mg tabs</td>
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<tr>
<td>SULFAMETHOXAZOLE-TRIAMPHROM (BACTRIM) STOP</td>
<td>Single strength</td>
<td></td>
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</tr>
<tr>
<td>AMLODIPINE</td>
<td>Prevenir BP</td>
<td>5mg tabs</td>
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<tr>
<td>NEUTROPHILS POWDER</td>
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<tr>
<td>POLYETHYLENE GLUCOL 2350 (MRALAN)</td>
<td>175/DOSAGE</td>
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Outcome in this case:

- The patient’s mom was the Primary Caregiver so I taught her colors and the associated medications
- She learned quickly and we made a game out of it
- By the time of discharge she knew all the medications and colors perfectly

Lessons we learned: One size does NOT fit all

- Explore age and developmentally appropriate interventions
- Assess learning styles
- Start with a plan and revise based on the patient’s needs
- Focus on patient and family strengths
  - Explore thoughts and feelings
  - Encourage support
  - Empower patients and families
In Conclusion:

• Renal transplantation is a life-changing experience for the patient and their entire family.
• Many aspects of care must be considered.
• Psychosocial issues can be extremely challenging
• A Team Approach is the most inclusive way to ensure compliance
• Utilize all support services whenever needed
• It truly does take a village!

Quotes from our patients and families:

• “As soon as I met the different members of my team in the hospital I felt as if I was going to be OK”.

• “I was scared at first as there were so many medications to learn, but even though she bugged me every day Jules made it fun with the colors and I knew I could do this”