



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.

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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)



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It takes a village...

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

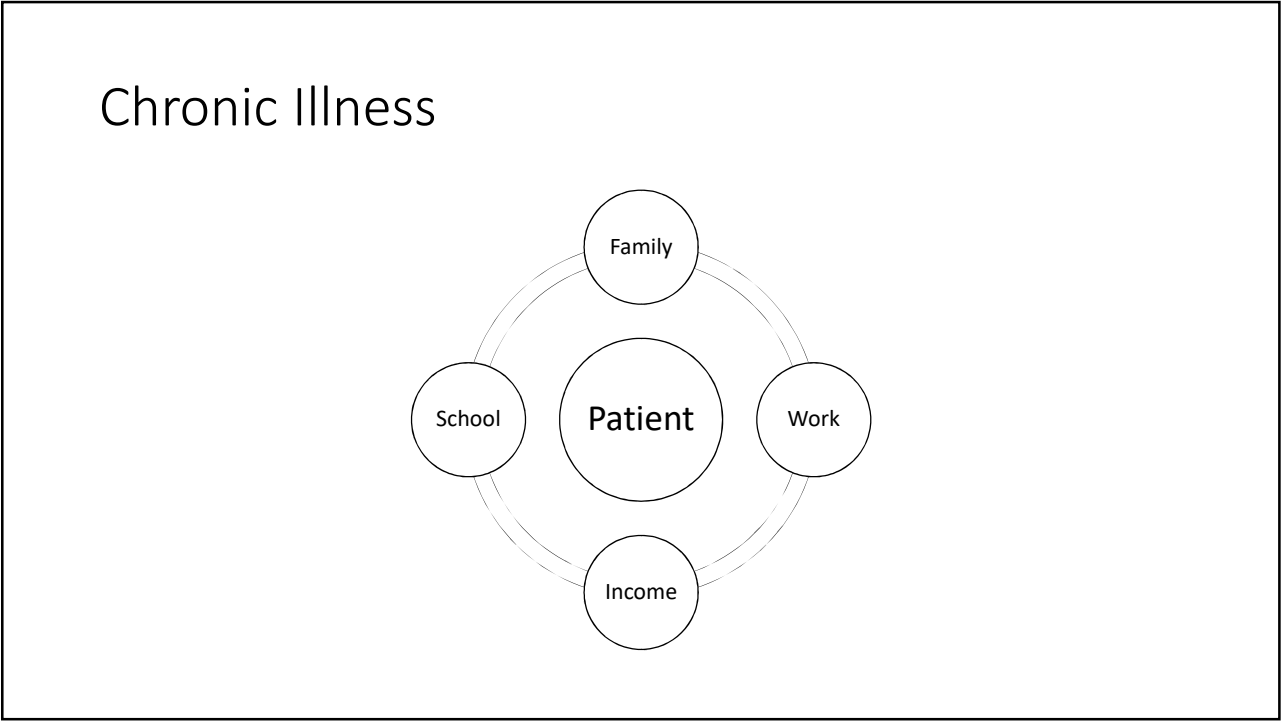


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Psychosocial issues of complex medical needs

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

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It Takes a Village.....

- Social Worker

A black and white photograph of a signpost with multiple directional signs pointing in different directions. The signs read: "LOST", "CONFUSED", "UNSURE", "UNCLEAR", "PERPLEXED", "DISORIENTED", and "BEWILDERED". The signpost is set against a cloudy sky.

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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

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1st Case: KG, Social Issues

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



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Compliance Issues

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

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Social Work Interventions

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



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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

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Legal and Social Implications

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

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Social Worker responsibilities

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



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When the day arrives for transplant.....

- What happens when child is called for transplant???????
- “Tree of legal representation”

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Protective Factors: keys to success

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



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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



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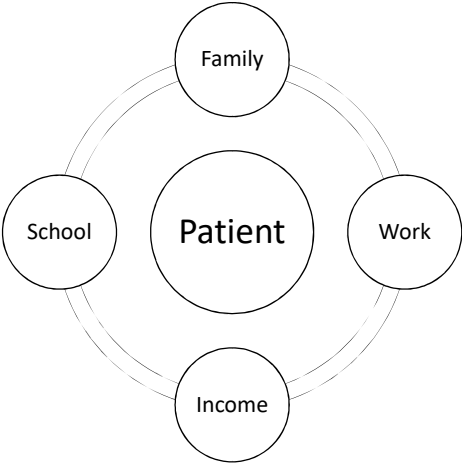
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Chronic Illness



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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



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Labs following transplant:

	3/8/19	3/8/2019	3/8/2019	3/6/2019
Sodium			131mm/L	134mml/L
Potassium			6.4mmol/L	5.5mmol/L
Chloride			109mmol/L	108mmol/L
Carbon Dioxide			20mmol/L	21mmol/l
Glucose L			517 mg/dl	309mg/dL
Blood Glucose (POCT)	518 mg/dL	523 mg/dL		
BUN			27mg/dL	27mg/dL
Creatinine			1.74mg/dL	1.92mg/dL
AST			15 units/L	18 units/L
ALT			23 units/L	17 units/L
Alk Phos			130 units/L	102 units/L
Albumin			3.6g/dl	3.5g/dL

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What is going on???????



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- 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

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Answer.....

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

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All was good????

	3/21/19	3/18/19
Sodium	139mmol/L	139 mmol/L
Potassium	4.5mmol/L	4.9mmol/L
Chloride	108mmol/L	110mmol/L
Carbon Dioxide	23mmol/L	24mmol/L
Glucose L	115 mg/dL	125 mg/dL
BUN	21 mg/dL	33 mg/dL
Creatinine	2.06 mg/dL	2.09 mg/dL
AST	14 units/L	13 units/L
ALT	14 units/L	18 unints/L
Albumin	4.4 g/dL	4.3 g/dL

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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.....

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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

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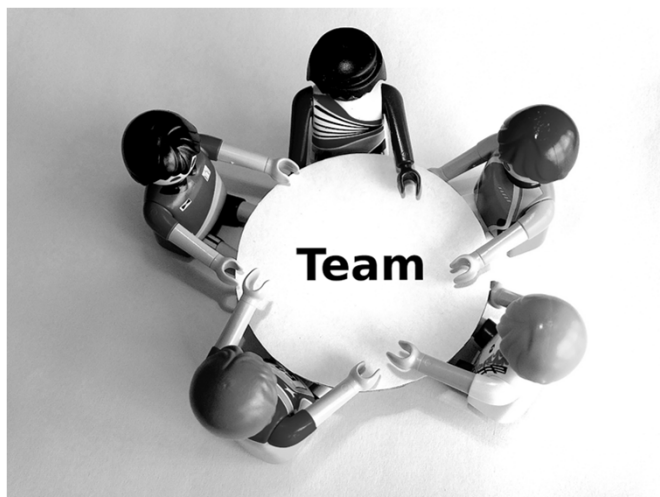
3rd Case: AS, Language barriers

- 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

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Additional Team members

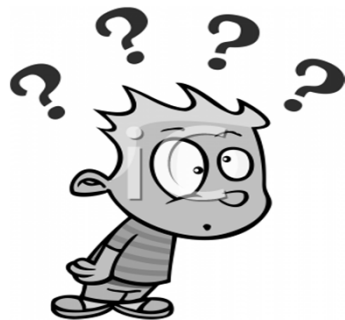
- Interpreter Services



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Challenge:

How to teach post transplant instructions and medications in a different language



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Have all post transplant instructions translated into Spanish

Instrucciones para después del trasplante

- Tome la temperatura dos veces al día. Llámenos 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 Tacro. 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 Tacro 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 pediátrico.

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Lista de medicamentos de trasplante de riñón para

Actualizado el _____ (Horas: 8am 4pm (o después horario oficina))
Fecha del trasplante _____ Su coordinador es Jules/Jan 804-827-4212, 804-827-1761

NOMBRE DEL MEDICAMENTO	Finalidad	Dosis	9am	12 mediodía	5pm	9pm
TACROLIMUS (PROGRAF)	Previene rechazo	1mg caps				
MYCOPHENOLATE (CELLCEPT)	Previene rechazo	250mg tab				
PREDNISOLONE	Previene rechazo	10mg tabs				
FAMOTIDINE (PEPCID)	Protege el estómago	20mg tab				
FLUCONAZOLE	Previene infección de hongos	200mg tab				
VALGANCICLOVIR (VALCYTE)	Previene infecciones víricas	450mg tabs				
STOP _____ SULFAMETHOXAZOLE-TRIMETHOPRIM (BACTRIM) STOP _____	Previene infección	Single strength				
AMLODIPINE	Previene BP	5mg tabs				
NEUTRAPHOS POWDER						
POLYETHYLENE GLYCOL 3350 (MIRALAX)		17G/DOSE				

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Another Challenge.....

- Patient is 4 years old
- She cannot take pills
- Compounding pharmacies are rare
- Insurance issues !!!!!



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- 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?

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• A

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POLYETHYLENE GLYCOL 3350 (MIRALAX)		17G/DOSE				

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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

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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

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In Conclusion:

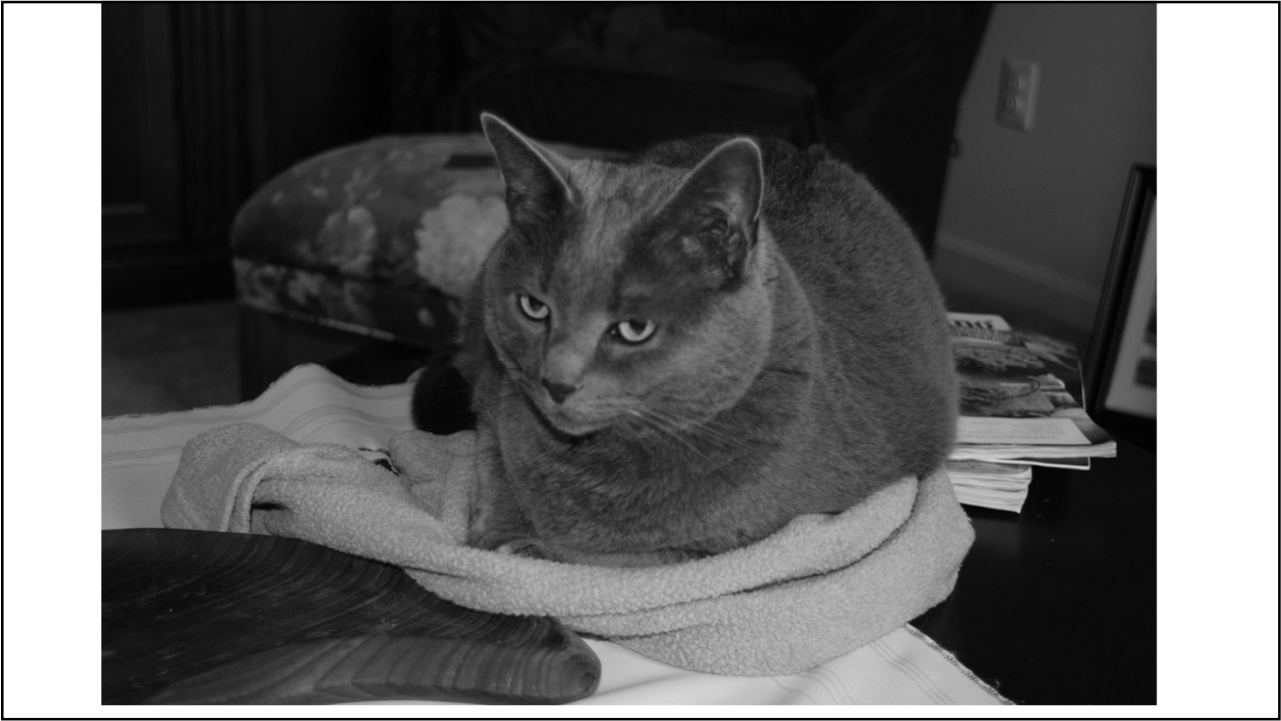
- Renal transplantation is a life-changing experience for the patient and their entire family.
- Many aspects of care must be considered.
- Psychosocial issues can be extremely challenging
- A Team Approach is the most inclusive way to ensure compliance
- Utilize all support services whenever needed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

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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”

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