Adolescents with Chronic Kidney Disease: A Model for Transition to Adult Care

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Background: It is well known that increasing numbers of children with chronic illness are surviving into adulthood. Transitioning from pediatric to adult care is complex and demanding, thus there is the need to have organized and efficient processes in place for successful healthcare preparation of these youth to adult-focused health care services. Changes in provider aspects and health care system processes may be disorientating for pediatric patients accustomed to intense and involved care (Samuel et al., 2014). Patient risks, along with the increase in survival to adulthood, support the need to have systematic processes in place for health care transition (HCT) preparation to adult health care services.

Details of Innovation: Multi-phase project: Phase 1 included multi-disciplinary meetings to discuss the tools used to develop the transition program and to recruitment based on inclusion criteria. Phase 2, participants received the transition policy and a self-administered transition readiness questionnaire, adapted from the National Alliance to Advance Adolescent Health (NAAAH, 2016). Phase 3 involved establishing a treatment plan based on the readiness questionnaire. The treatment plan established priorities and a course of action to integrate health and personal goals. Finally, phase 4 involved administration of the TRxANSITION Scale™ (2012), which assisted in determining individual young adult’s knowledge and skill to transition, with higher scores relating to better transition potential.

Outcomes: Success designated full transition to adult care. N=19, 74% were Chronic Kidney Disease (CKD); 26% were renal transplant recipients. TRxANSITION Scale (2012) variables with the highest Pearson Correlation coefficients for total scores and strong positive relationships were self-management (N=19, r=0.91, p<0.01, two-tailed), insurance (N=19, r=0.83, p<0.01, two-tailed) and school (N=19, r= 0.82, p<0.01, two-tailed). Four participants successfully transitioned.

Implications: Purposeful HCT preparation provides youth with ongoing access to subspecialist care, promotes competence in disease management, fosters independence, social, and emotional development through teaching self-advocacy and communication skills, and allows for a sense of security for support of long-term health care planning and life goals. This structured HCT offers a model for providers and can be used as a pilot for other services to promote this most difficult task. Successful transition leads to improved quality of care with a decrease in hospital readmissions, decrease in morbidities and decrease in hospital/healthcare costs.

Open Ended Question: What strategies can be used in the pediatric setting to prepare adolescents with Chronic Kidney Disease or Renal Transplant to transition to adult-oriented care?

References:


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Background
- It is well known that increasing numbers of children with chronic illness are surviving into adulthood.
- Transitioning from pediatric to adult care is complex and demanding, thus the need to have systematic processes in place.
- Transition has been described as, “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”
- “Up to 35% lose renal transplants without transition.”
- Lack of a structured healthcare transition (HCT) program leads to increased hospital costs, readmissions and poor healthcare outcomes.

Program Objectives
- Develop a transition policy
- Complete transition readiness assessment questionnaires for CKD/Transplant adolescents ages 16-27
- Complete UNC TRxANSITION Scale to measure healthcare skill maturity and knowledge in a multifaceted mode
- Identify gaps for teaching needs for CKD transition

Best Practice Recommendations
- All adolescents warrant early preparation for transition to maintain trust and assure continued medical care.
- Transition should occur as a step-by-step process, conducting regular readiness assessments, beginning at age 14, to identify needs and goals in self-care.
- The adult medicine culture may have different expectations and may be less attuned to the developmental and behavioral struggles of adolescents; so do experienced pediatric hospitals and services.
- Build ongoing and collaborative partnerships with adult primary and specialty care providers.

Sample
- Inclusion: English-speaking; ages 16-21 with diagnosis of CKD stage ≥3; or renal transplant; established baseline creatinine; no hospitalizations within the last 3 months
- Exclusion: cognitive impairment
- N=19

Time Frame
- This model was developed over the course of 6 months in Pediatric Nephrology Outpatient Clinic of a large academic medical center.

Demographics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N=19</th>
<th>%</th>
<th>Range</th>
<th>Mean (SD)</th>
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<tbody>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>15-18</td>
<td>7</td>
<td>37</td>
<td>15-18</td>
<td>20.15 (2.93)</td>
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<tr>
<td>19-21</td>
<td>6</td>
<td>32</td>
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<tr>
<td>20-27</td>
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<tr>
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<td>Transplant</td>
<td>5</td>
<td>26</td>
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</tbody>
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Measures/ Instruments
- Transition Readiness Assessment: 2 domains - health and using health care
- UNC TRxANSITION Scale: 32 items, 10 domains
  - 1-domain knowledge skill mastery, 0-1 (0-floor knowledge skill attainment), 0-3 (full knowledge skill attainment) for a maximum score of 10.
  - Strong inter-rater reliability (r=0.71)
  - Type of Illness
  - E-mediated
  - Advances
  - Nutritions
  - Self-management
  - Information-expectation
  - Trade/ school
  - Insurance
  - Ongoing support
- Meds & Nutrition
- Lab Values: from record review

Results
- Of the nineteen enrolled, 74% were CKD; 26% were renal transplant recipients.
- TRxANSITION Scale variables with the highest Pearson Correlation coefficients for total scores and strong positive relationships were self-management (N=19, r=0.91, p<0.01, two-tailed); insurance (N=19, r=0.83, p<0.01, two-tailed) and school (N=19, r=0.82, p<0.01, two-tailed).
- Four participants successfully transitioned to adult care, while the other fifteen continued in HCT at a slower pace as determined by their TRxANSITION Scale™ scoring.

Conclusions/ Implications for Practice
- Purposeful, interprofessional HCT preparation provides youth with CKD, ongoing access to subspecialists, promotes self-care and emotional development, while allowing continued support of long-term health care planning through self-advocacy and communication.
- This interprofessional, evidence based project is a beginning step in planning transition of pediatric patients to adult services and adds to the body of knowledge for a topic which has proven to be challenging and often difficult for patients, families and providers.

Acknowledgements
- Much gratitude for the use of TRxANSITION SCALE and tools allowed by Maria Ferris, MD to evaluate this project.