Transition of Young Adults who Receive Healthcare Services at the Renal Unit in the Pediatric Hospital of Puerto Rico

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Background

The International Society of Nephrology (ISN) reported in 2011 that the survival rates of patients with renal disease has progressively increased to 85-90%. Adolescents with renal disease are a particularly vulnerable group that should receive health care services throughout their entire lifetime. In order to achieve a transition process from a child/family-centered care to an adult-oriented healthcare system it becomes necessary to develop a purposeful and planned course of action that makes it possible for young adults with chronic conditions transition fluidly (Wiston, Harden, Ferris, Kerr, Mahan & Ramzy, 2011). A successful transition process helps young adults develop a sense of responsibility and autonomy necessary for assuming the primary role in making healthcare decisions regarding their lives.

Goals & Objectives

The goal of this study was to identify the needs of young adults and their families participating in the Renal Unit at the Pediatric Hospital of Puerto Rico regarding the process of healthcare transition to adulthood. The main objective was to identify the families perception of the readiness of the young adults receiving dialysis treatment.

The specific objectives are:
- Develop a socio-demographic profile of the families of the young adults receiving dialysis treatment at the Renal Unit in the Pediatric Hospital.
- Describe the aspects identified by the families as necessary for the transition process of their young adults from pediatric care to adult care.
- Identify the services needed by the parents in charge of the care of young adults receiving dialysis treatment at the Renal Unit in the Pediatric Hospital.

Methods

Design
- Non-experimental transversal descriptive design.
- Data collection use of a questionnaire with close and open-ended question.

Socio-demographic data (family composition and level of knowledge in diagnosis, treatment and medical condition):
- Scale from the Readiness for transition Questionnaire- RTQ where parents rated the young patient's readiness level in activities related to personal care: 0-88 (Gilleland & Sandra Aamaral, 2012). Adapted and translated to Spanish.

Results

Sample
- 13 parents/caregivers selected upon availability
- The majority of patients received hemodialysis treatment (73%)
- Mean age of the patients was 18 years (± 1.66), when they should be in the final stages of a transition plan
- Most of the respondents were from monoparental families, unemployed and the patients had Medicare, Medicaid or private health coverage

Parent's perception on patients readiness for transition scale

<table>
<thead>
<tr>
<th>Item</th>
<th>Not involved at all</th>
<th>Sometimes involved</th>
<th>Often involved</th>
<th>Almost always involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking medications daily as prescribed</td>
<td>18%</td>
<td>18%</td>
<td>63%</td>
<td>-</td>
</tr>
<tr>
<td>Scheduling primary care appointments</td>
<td>55%</td>
<td>9%</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>Calling in or ordering refills</td>
<td>36%</td>
<td>18%</td>
<td>27%</td>
<td>18%</td>
</tr>
<tr>
<td>Explaining your medical condition to others</td>
<td>9%</td>
<td>55%</td>
<td>-</td>
<td>36%</td>
</tr>
<tr>
<td>Knowing details about your insurance coverage</td>
<td>64%</td>
<td>27%</td>
<td>9%</td>
<td>-</td>
</tr>
<tr>
<td>Attending medical appointments</td>
<td>46%</td>
<td>18%</td>
<td>-</td>
<td>36%</td>
</tr>
</tbody>
</table>

Behaviors related to health care

- Seeking family help: 36% 9% - 55%
- Seeking help from medical providers: 27% 9% 18% 46%
- Establishing relationships with young adults with renal disease: 18% 9% 9% 64%
- Creating friendships: 18% 27% - 55%
- Creating time for personal needs: 9% 9% 27% 55%
- Participating in social events: 27% 9% 36% 27%

Behaviors related to social development

Conclusions & Recommendations

- The majority of the young patients don’t have a transition plan.
- Families perception about the patients readiness to transition reveal that they are less involved in behaviors related to health care. Little involvement in such activities may result as a consequence of not having a formal transition plan.
- Systems of care should develop transition protocols that benefit the population of children with chronic conditions.
- The development of further research about transition with the population of children with chronic conditions in Puerto Rico is recommended.