The Value of Intensive Outpatient Care for Children with Complex Chronic Conditions

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OBJECTIVE

Children with complex chronic conditions (CCCs) characterized by high medical complexity and fragility, technology dependencies and disabilities have healthcare needs that are not easily met by current systems of care. Novel intensive outpatient care models have been developed in an attempt to achieve optimal outcomes for children with CCCs and their families. Whether the extra time and expertise of these programs deliver high value healthcare, characterized by the best health outcomes at the lowest appropriate costs, has not yet been described.

BACKGROUND

In 2007, the University of Utah’s Department of Pediatrics, Intermountain Healthcare and Primary Children’s Medical Center (PCMC) established the Comprehensive Care Program to better care for children with CCCs. PCMC is the only tertiary pediatric care center in the Intermountain West, serving Utah, Idaho, Wyoming, Nevada and Montana. With 289 beds, it is the base for pediatric training activity for the University of Utah, Department of Pediatrics.

The Comprehensive Care Program delivers intensive outpatient pediatric healthcare in a consultative model for children with CCCs and disabilities characterized by:

1. high medical complexity (>3 organ systems involved and >3 physicians);
2. high medical and fragility (frequent and/or prolonged hospitalizations);
3. technology dependencies;
4. psychosocial complexity.

METHODS

We describe outcomes of the Comprehensive Care Program in terms of health, healthcare satisfaction and costs. Parent perceptions of their child’s physical health, mental health, pain, sleep and community participation were assessed using a modified version of the CDC’s Healthy Days measure. Parent satisfaction with their child’s healthcare was assessed using one question from the How’s Your Health survey; parents indicated their agreement with the statement “I receive exactly what I want and need, exactly when and how I want and need it.” on a 5 point scale. Analysis of administrative data during the three years before and during program participation were used to determine pre-post costs with adjustments for months of enrollment. Costs are adjusted to December 2011 dollars; newborn/NICU costs are excluded.

RESULTS

- 572 children (median age 6.2 years, range 0-33 years) participated in this program (median duration 22 months).
- 34 (6%) of participants died.
- The greatest impacts were seen among the cohort of 85 children with tracheostomies.

ED visits decreased from 7% to 6% for the total population, and from 15% to 11% for those with tracheostomies.

Healthcare Satisfaction: “I receive exactly what I want and need, exactly when and how I want and need it.” (n=315)

<table>
<thead>
<tr>
<th>Question</th>
<th>Average # days (range)</th>
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</thead>
<tbody>
<tr>
<td># of days during the past month that your child’s physical health was only fair or poor</td>
<td>7.2 (0-30)</td>
</tr>
<tr>
<td># of days during the past month that your child’s mental health was only fair or poor</td>
<td>5.1 (0-30)</td>
</tr>
<tr>
<td># of days during the past month that your child did not get enough rest or sleep</td>
<td>5.8 (0-30)</td>
</tr>
<tr>
<td># of days during the past month that your child was uncomfortable or had pain</td>
<td>8.7 (0-30)</td>
</tr>
<tr>
<td># of days during the past month that your child was unable to play or go to school because of his/her health</td>
<td>5.7 (0-30)</td>
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</tbody>
</table>

Total Cost Impact of Comprehensive Care Program

<table>
<thead>
<tr>
<th>Patient Cohort</th>
<th># of Patients</th>
<th>Cost per Month from Pre Clinic to Post Enrollment in Clinic (Range)</th>
<th>Median Duration in Clinic (Range) in Months</th>
<th>Total Cost Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Patients</td>
<td>572</td>
<td>($-84, range: $-20,578 to $572)</td>
<td>22 (0.1 - 65.5)</td>
<td>$-4,089,779</td>
</tr>
<tr>
<td>Trach-Vent</td>
<td>8.5</td>
<td>($-230, range: $-20,578 to $18,198)</td>
<td>26.6 (1.1 - 62.5)</td>
<td>$-3,064,439</td>
</tr>
</tbody>
</table>

IMPLICATIONS

- Novel approaches to the delivery of healthcare for children with CCCs are needed as US healthcare reform progresses.
- We continue to analyze our program as a value driven health care model for children with complex chronic conditions.

LIMITATIONS

- The impact of this clinical program may not generalize to other settings, depending on infrastructure and region.
- The long term implications of this program warrant further study.

ACKNOWLEDGMENTS

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