Implementation of a Caregiver-Focused Educational Intervention to Improve Knowledge and Competency for Managing Adrenal Crisis in Patients with Duchenne Muscular Dystrophy

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Objectives

• Discuss background and significance of adrenal crisis (AC) education and management in Duchenne Muscular Dystrophy (DMD)
• Discuss project purpose, aims, and methods
• Review project results and implications.
Introduction

• Risk of AC in DMD patients
• Untreated AC can lead to hypoglycemia, hypotension, cardiovascular collapse, and death
• Paucity of literature in DMD population
Background of the Clinical Problem

- The 2018 DMD Care Considerations
  - Specific AC-related recommendations
- Baseline data in clinic
- Implementation requires change in practice
  - Caregiver
  - Providers
1) Evaluate if a caregiver-focused educational intervention improves knowledge of AC management

2) Determine the number of iterations required for caregivers to demonstrate injection competency

3) Determine if there is an increase in prescription rates of emergency hydrocortisone following provider training
Review of the Literature

- Despite prior education, patients had inadequate understanding of preventing AC
- Inadequate knowledge regarding how to administer emergency hydrocortisone injection
- Verbal education alone is insufficient
- Effectiveness of teach-back method
Translation Framework

Pettigrew And Whipp's Model of Strategic Change

Context
- Why?
  - Current Practice
    - Variability of Education
      - Insufficient Knowledge
    - Verbal Education Only

Content
- What?
  - Standardized Education
  - Multimodal Teaching Methods
    - AC Education Folder

Process
- How?
  - Adapt Existing Tools
  - Train Providers
  - Caregiver Education
  - Evaluate Throughout Implementation

Life-Threatening: Preventable with Education
Methods

- **Design:** Quality improvement pre-post study
- **Sample:** caregivers of patients with DMD and neurology providers at an academic medical center in the mid-Atlantic
Methods

• **Intervention**: Education sessions with each caregiver and provider
  – **Caregivers**: AC and Injection training
  – **Providers**: PowerPoint presentation and quick reference

• **Data Collection**
  – Knowledge questionnaire pre and post caregiver education
  – Injection Competency: Checklist
  – Rate of prescriptions by providers via chart review
Statistical Analysis

- Aim 1: Wilcoxon signed-rank test
- Aims 2 & 3: Descriptive statistics
## Results

### Caregiver Demographics

<table>
<thead>
<tr>
<th>Caregiver Demographics</th>
<th>(N=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, n (%)</td>
<td></td>
</tr>
<tr>
<td>21 - 30 years old</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>31 - 40 years old</td>
<td>6 (54.5)</td>
</tr>
<tr>
<td>41 - 50 years old</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (36.4)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (63.6)</td>
</tr>
<tr>
<td>Relationship to patient, n (%)</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>10 (90.9)</td>
</tr>
<tr>
<td>Legal Guardian</td>
<td>1 (9.1)</td>
</tr>
<tr>
<td>Highest level of education, n (%)</td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Associate's degree</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Bachelor's degree</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Master's degree</td>
<td>2 (18.2)</td>
</tr>
</tbody>
</table>
Results

• Aim 1

Comparison of Knowledge Scores

Scores

Participant Number

Pre_Total  Post_Total
Results

- **Aim 2**: All caregivers demonstrated injection competency in one iteration
- **Aim 3**: 

![Rate of Prescriptions](chart.png)
Discussion

• Results were consistent with the existing literature
  – Multimodal education improves knowledge and competency
• Provider presentation and a visual reminder in the clinic space supported increase in emergency Rx rate
• Strengths and Limitations
Conclusions

• Swift implementation will protect from the life-threatening complications of AC

• Future Research
  – A standardized education for DMD
  – Studies that compare the effects of different teaching approaches
  – Frequency of education
  – Barriers to implementation
Translation into Practice

• Dissemination
  – Nursing leadership
  – The Parent Project Muscular Dystrophy
  – Greater DMD community

• Sustainability
  – AC champion in the clinic
  – Share AC education resources to department
References


- Department of Endocrinology at Children's National Medical Center. Solu-Cortef injection education and training checklist. Children's National Health System, Washington, DC.


References


Thank you!

- Dr. VanGraafeiland and Dr. Rachel Gafni
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