Caring for a Multi-Cultural Population: Providing the Best Care Possible with Available Resources

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Total DMD/BMD patients: 211

- Denver Metro / Colorado Springs area patients: 168 patients; 82% of DMD patients
- Rural Colorado patients: 19 patients; 9% of DMD patients
- Patients from outside of Colorado: 20 patients: 9% of DMD patients (OK, WY, KS, NV, NM, TX, NE, IA)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Number of Patients</th>
<th>Percentage of Patient Population</th>
<th>Number of Clinic Staff</th>
<th>Percentage of Clinic Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>12</td>
<td>5.6%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>White</td>
<td>127</td>
<td>60%</td>
<td>14</td>
<td>93%</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>0.9%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Unknown or Not reported</td>
<td>4</td>
<td>20%</td>
<td>1</td>
<td>6.7%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>49</td>
<td>23%</td>
<td>1</td>
<td>6.7%</td>
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</tbody>
</table>
Considerations For Providing Care Across our Multi-Cultural Population

**Social and economic factors.**

**Psychological and emotional factors.**
Social and Economic Factors

In general, regarding child and youth with special healthcare needs, “social determinants such as poverty, substandard housing, poor nutrition, and undesirable social and environmental conditions are strongly influential factors in many minority communities and may heavily contribute to poor outcomes”

- uncoordinated government social systems;
- inadequate medical education and training;
- family and cultural norms;
- a lack of community understanding of special needs;
- and fragmented and biased social, educational, and health systems in communities. (4)
• Children’s Colorado serves many patients from rural areas, which tend to have fewer resources in their communities:
  – Fewer school-based specialty services.
  – Less access to knowledgeable therapists, PCPs.
  – Fewer home health support options.
  – Travel to the hospital is more difficult for logistic and financial reasons.
  – Did You Know? *Rural communities constitute 20% of America’s population, but less than 10% of physicians practice rurally.* (3)

• Our undocumented patients face particular challenges:
  – Lack of insurance
  – Difficulty obtaining equipment, or the right equipment
  – Lack of access to wrap-around supports
  – Often these same families are lower income, and may have monolingual parent(s).
Social and Economic Factors: Providing the Best Care

Are we maximizing our available resources to provide the best care?

- Children’s Colorado’s Governmental Affairs team.
- Financial support
  - Charity Care for uninsured
  - Use of Medicaid and/or hospital-based restricted funds for gas, lodging, and transportation).
- Improved care coordination and communication
- Culturally competent care – we are always striving to improve.
Psychological and Emotional Factors

**Anticipatory Grief** – the grief process that a person undergoes before a loss actually occurs. (1)

“although cultural differences are perceived to exist in mourning rituals, traditions and behavioral expressions of grief, there are no particular differences in the individual, intrapersonal experience of grief that can be attributed to cultural heritage or ethnicity alone” (2)

Anecdotally, we have noticed that anticipatory grief may be a contributing factor to how a family engages in care – avoidant behavior versus hypervigilance.
Psychological and Emotional Factors: Providing the Best Care

• Children’s Colorado clinic staff show interest in learning more about the patient and family’s individual needs, so that we are able to cater to those needs as much as possible.
  – Morning meeting prior to clinic is used to review those needs and provide updates.

• We refer patients and families to individual and family psychotherapies for additional support, as desired/available.
  – Internal therapy resources as well as community-based resources.

• Counsel parents and provide additional psychoeducation about why certain resources may or may not actually be beneficial for their child.
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References


