Demographics and Language Needs of Guardians Caring for Patients with Hemoglobinopathies in Nebraska

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What are hemoglobinopathies?

Hemoglobinopathies are disorders where there is abnormal production or structure of the hemoglobin molecule.¹

- Quantity → thalassemia
- Quality → sickle cell disease; Hemoglobins C, D, E, O, etc.
- Passed down through families, typically in autosomal recessive manner
- Variable clinical course

It is estimated that 7% of the world’s population is a carrier for a hemoglobinopathy.
BIRTHS WITH A PATHOLOGICAL HEMOGLOBIN DISORDER PER 1,000 LIVE BIRTHS

- <0.1
- 0.1–0.99
- 1–9.9
- 10–19
- 10–19

2 https://caringcross.org/scd-bt-cure-project/
Background

- National surveillance for hemoglobinopathies does not exist in the United States
- Previous attempts to characterize populations with hemoglobinopathies has not included data from Nebraska
- Nebraska population is changing over time
  - NE welcomed the highest number of refugees per capita of any state in 2016
  - In 2018, 1 in 14 Nebraskans were born outside the US
Background

• No national surveillance for hemoglobinopathies
• Hemoglobinopathy registries to date have no NE data
• Nebraska is changing
  • Welcomed the highest per capita rate of refugees in 2016
  • In 2018, 1 in 14 NE residents born outside the US
# Hemoglobinopathies in NE

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of births</th>
<th>Number of hemoglobinopathies identified</th>
<th>Rate per 10,000 births</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>26283</td>
<td>408</td>
<td>155</td>
</tr>
<tr>
<td>2013</td>
<td>26419</td>
<td>394</td>
<td>149</td>
</tr>
<tr>
<td>2014</td>
<td>27115</td>
<td>444</td>
<td>164</td>
</tr>
<tr>
<td>2015</td>
<td>27120</td>
<td>481</td>
<td>177</td>
</tr>
<tr>
<td>2016</td>
<td>27109</td>
<td>451</td>
<td>166</td>
</tr>
<tr>
<td>2017</td>
<td>26246</td>
<td>489</td>
<td>186</td>
</tr>
<tr>
<td>2018</td>
<td>25900</td>
<td>427</td>
<td>165</td>
</tr>
<tr>
<td>2019</td>
<td>25150</td>
<td>465</td>
<td>185</td>
</tr>
<tr>
<td>2020</td>
<td>24663</td>
<td>444</td>
<td>180</td>
</tr>
<tr>
<td>2021</td>
<td>24882</td>
<td>458</td>
<td>184</td>
</tr>
<tr>
<td>2022</td>
<td>24559</td>
<td>496</td>
<td>202</td>
</tr>
</tbody>
</table>

Courtesy of the Nebraska Newborn Screening Program and the Nebraska Department of Health and Human Services.
Top Five Refugee Arrivals in Nebraska

From 2002-2016, Nebraska welcomed 10,418 refugees from 48 countries.

6.7 Courtesy of the Nebraska Department of Health and Human Services
Research Questions

What are the demographics of infants with hemoglobinopathies in NE?

What are the preferred languages of the guardians of these infants?

How often are interpreter services used in a clinical setting for patients with hemoglobinopathies?
## Methods

### Medical record reviews at Children’s Hospital and Medical Center (CHMC) and the University of Nebraska Medical Center (UNMC)

### Inclusion criteria
- Infants aged 1 or younger
- ICD-10-code corresponding with hemoglobinopathy
- Seen between 2012 and 2020

### Data extracted from patient chart
- Birth year
- Sex
- Race
- Ethnicity
- Caregiver preferred language
- Use of interpreter services
## Results

### 2012 – 2020 Data for Patients with Hemoglobinopathies

<table>
<thead>
<tr>
<th>Record data</th>
<th>UNMC (%)</th>
<th>CHMC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total records</td>
<td>251 (18.8)</td>
<td>1081 (81.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>UNMC (%)</th>
<th>CHMC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic</td>
<td>14 (5.6)</td>
<td>109 (10.1)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>221 (81.0)</td>
<td>954 (88.3)</td>
</tr>
<tr>
<td>Did Not Indicate</td>
<td>16 (6.4)</td>
<td>18 (1.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>UNMC (%)</th>
<th>CHMC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black or African American</td>
<td>170 (67.7)</td>
<td>610 (56.4)</td>
</tr>
<tr>
<td>White</td>
<td>35 (13.9)</td>
<td>152 (14.1)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>--</td>
<td>86 (8.0)</td>
</tr>
<tr>
<td>Asian</td>
<td>9 (3.6)</td>
<td>77 (7.1)</td>
</tr>
<tr>
<td>Other</td>
<td>19 (7.6)</td>
<td>15 (1.3)</td>
</tr>
<tr>
<td>Two or More Races</td>
<td>--</td>
<td>120 (11.1)</td>
</tr>
<tr>
<td>Did Not Indicate</td>
<td>18 (7.2)</td>
<td>21 (1.9)</td>
</tr>
</tbody>
</table>

 Interpreter Services Requested  | 15 (6.0) | 99 (9.2) |
Takeaways

• 16 unique languages identified across both hospitals
• Most patients were Black/African American and English-speaking. White, English-speaking people comprised the second largest group.
• Spanish, French, Karen, and Burmese comprised the largest non-English speaking groups
• Continuing analysis of NE population changes and hemoglobinopathy incidence are important for providing culturally competent care.
Limitations

- Does not include all infants with hemoglobinopathies
- State vital records unavailable to investigators
- Demographics and language were self-reported
- Differences in data captured
Future Directions

- Development of patient-facing materials
- Sustainable population surveillance at state or national level
- Patient experience
- Provider experience
- Hemoglobinopathy incidence
Capstone Committee

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Acknowledgements

Kaeli Samson of UNMC CCORDA for statistical analysis consultation.

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References

2. CaringCross [Internet]. Sickle Cell Disease (SCD) and Beta-Thalassemia (BT) Cure Project. 2023. Available from: https://caringcross.org/scd-bt-cure-project/