2018 myRESEARCH™

Science Internship Program: Public Health

Civic Education
Office of Government and Community Relations
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An Analysis of Patient Education Literature for Sickle Cell Disease: Quality and Accessibility

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Abstract

• The objective was to analyze currently available patient-aimed informative literature for its readability and accessibility, and to create a new informative coloring book consistent with patient reading levels, using illustrations as comprehension aids.

• The information was analyzed for a variety of readability measures, and compared to the readability measurements of two other chronic genetic diseases.

• We researched how to create effective health education literature, and created an informational coloring book on sickle cell disease.

• The medium of a coloring book was chosen for the new patient-aimed informative literature because it could combine easily readable text at the 5th grade level, while accompanying it with illustrations, which have been proven to increase information recognition.
Sickle cell disease (SCD) is a genetic disorder that leads to a mutation of the hemoglobin. This leads to acute pain episodes and chronic pain.

SCD patients face a lack of accessible, easily readable, patient-aimed informative literature.
Purpose

• Analyze patient-aimed informative literature for readability ease in comparison to realistic patient literacy capabilities

• Compare sickle cell disease patient-aimed informative literature readability to that of other chronic genetic diseases' patient-aimed informative literature
Purpose (cont.)

- Research and implement evidence-based methods for creating better patient-themed informative literature
- Create new patient-themed informative literature through a high-comprehension rate medium and consistent with patient reading capabilities
Hypothesis

- If sickle cell disease patient-aimed informative literature was created through evidence-based methods to improve reader comprehension, it would help patients increase knowledge of their disease and care for themselves better.
Methodology

• Research sickle cell disease
• Identify sickle cell patient-aimed informative literature from a variety of sources
• Separate literature sampled into ‘print information’ and ‘online information’
• Analyze the readability of the literature
Methodology (cont.)

• Compare the readability of the SCD literature to the readability of literature about other genetic diseases
• Research methods for creating patient-aimed informative literature with patient-appropriate readability levels
• Create a patient-aimed informative coloring book
## Data

<table>
<thead>
<tr>
<th>Intended Audience</th>
<th>Mean U.S. Grade</th>
<th>Age Group by Year</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teenage Sickle Cell Disease Patients</td>
<td>7</td>
<td>12 - 13</td>
<td>6.25%</td>
</tr>
<tr>
<td>Sickle Cell Trait Patients</td>
<td>7</td>
<td>12 - 13</td>
<td>6.25%</td>
</tr>
<tr>
<td>Parents of Pediatric Sickle Cell Disease Patients</td>
<td>10</td>
<td>15 - 16</td>
<td>34.38%</td>
</tr>
<tr>
<td>Adults with Sickle Cell Disease</td>
<td>10</td>
<td>15 - 16</td>
<td>53.13%</td>
</tr>
</tbody>
</table>

- The SCD patient-aimed informative literature was above the goal of a 5th grade reading level for all intended audiences.
Data (cont.)

- 5.3% of in-print patient-aimed informative literature was at or below the goal of a 5th or 6th grade reading level
- The mean reading level of patient-aimed informative literature for SCD on the Flesch-Kincaid Reading Level Formula was 9.7, closest to a 10th grade reading level
- A study found that 46% of U.S. adults are estimated to have restricted health literacy skills; of that number, 19% have literacy difficulty with the most basic texts
- A study found that low-literacy adults using the internet to find health information most often found information written at a 10th grade level, and found correct information 1/3 of the time
Results

Mean Flesch Reading Ease Scores for Patient-Aimed Information

- Polycystic Kidney Disease
- Cystic Fibrosis
- Sickle Cell Disease

- Mean Flesch Reading Ease Scores for Patient-Aimed Information
- Average Reading Ability for An American Adult
Results (cont.)

• A study found that, in comparison to three other reading comprehension aids, illustrations lead to the highest scores on information recognition tasks.

• The coloring book combined an average Flesch-Kincaid Reading Level of 5th grade and illustrations as comprehension aids.
Results (cont.)

**What Is Sickle Cell Disease?**
Sickle cell disease is a genetic disorder that affects red blood cells.

Healthy red blood cells are shaped like a donut. Sick cells are crescent-shaped. This change can cause more problems when the red blood cells are moving through the body.

**How Did I Get Sickie Cell Disease?**
Sickle cell disease is passed on from parents to their children. The trait can be passed on to other family members.

- Trait Carrier
- Trait Carrier
- 25% Trait
- 50% Trait Carrier
- 25% Sickle Cell Donor

Sometimes, a person with sickle cell disease can pass the trait on to their children.

**Why Are Sickle Cells Shaped Like That?**

The shape of the cells is due to a mutation in their DNA. They are darker and narrower than healthy cells. This can cause the cells to become more flexible, allowing them to be more efficient at moving through the body.

**Why Am I In Pain?**

When red blood cells are sick, they can stick together and block blood vessels. This can cause pain, particularly in the legs and arms.

**How Can I Stay Healthy?**

- Take water. It helps keep your body healthy.
- Wear sunscreen and use other forms of sun protection, especially when you are in a warm place.
Conclusions

• Most SCD patient-aimed informative literature currently available is above the average patient’s reading capabilities

• An effective way of optimizing patient comprehension of literature is to combine easily readable text with illustrations as comprehension aids

• Sickle cell disease patient-aimed informative literature lags behind that of other similar genetic diseases, showing the need to invest in minority health education
Recommendations

- Take patient reading levels into account when creating patient-aimed informative literature.
- Use comprehension aids such as illustrations to further ensure comprehension.
- Sickle cell disease healthcare providers should continue to develop better patient-aimed informative literature.
References


Special Thanks

- Ira Bragg-Grant, BS, LSW
- Gilberto Pena, BA
- Callie Troung
- Nedra Starling, MA, MPH, DrPH/ABD
- Cleveland Clinic Civic Education Department and Office of Government and Community Relations