Health Disparities among Adult Patients with Familial Hypercholesterolemia in the CASCADE-FH™ Patient Registry

Background

In 2013, the FH Foundation (a patient-led nonprofit organization) launched the CASCADE-FH™ Patient Registry to achieve three main objectives: (1) raise awareness; (2) identify contributors to undertreatment of FH patients in the US; and (3) analyze data from a nationwide database of FH patients to assess for health disparities.

Aims

We hypothesized that health disparities contribute to undertreatment of FH patients in the US. We analyzed data from a nationwide database of FH patients to assess for health disparities.

Methods

The CASCADE-FH™ Patient Registry was initiated in 2013 by the FH Foundation, a non-profit organization that raises awareness and funds research. As of December 2016, 2,537 individuals were enrolled at 26 sites throughout the US.

Outcomes and Variables

Outcomes included: 1. Achieved LDL-C < 300 mg/dL, 2. Treatment with any statin, and 3. Among those on treatment, with a high-intensity statin (i.e., atorvastatin 80 mg/day, or simvastatin 20 or 40 mg daily).

Race/Ethnicity was categorized in a hierarchical fashion by trained research staff.

Statistical Analysis

Multivariable logistic regression was used to evaluate differences in statin therapy and LDL-C goal attainment between new and re-entering FH patients. Variables in the regression models are shown in Table 2.

Results

Patient characteristics are shown in Table 1. Men and women had similar pretreatment LDL-C (women, median 231; IQR 184-289 mg/dL; p = 0.17). Pretreatment LDL-C was higher among women than men (p < 0.001).

Different racial/ethnic groups also had similar pretreatment LDL-C. Though racial/ethnic differences were noted in the age of FH diagnosis.

Table 2. Odds ratios for achievement of LDL-C < 100 mg/dL, and statin utilization, by sex and race/ethnicity.

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>LDL-C &lt; 100 mg/dL</th>
<th>Any Statin</th>
<th>High-Intensity Statin</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>Ref.</td>
<td>Ref.</td>
<td>Ref.</td>
</tr>
<tr>
<td>Asian</td>
<td>0.81 (0.60-1.11)</td>
<td>1.01 (0.80-1.25)</td>
<td>1.33 (0.99-1.78)</td>
</tr>
<tr>
<td>Black</td>
<td>0.67 (0.45-0.99)</td>
<td>1.04 (0.82-1.32)</td>
<td>1.29 (0.97-1.72)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.05 (0.57-1.95)</td>
<td>1.07 (0.67-1.71)</td>
<td>1.04 (0.66-1.64)</td>
</tr>
</tbody>
</table>

** Table 1. Baseline clinical and demostrative characteristics of the FH Foundation (FH) patient registry.**

**Figure 2. Median pretreatment and current LDL-C levels, stratified by sex and race/ethnicity.**

Summary

• Compared with men, women were less likely to be on any statin therapy, less likely to be on a high-intensity statin, less likely to achieve an LDL-C goal of <100 mg/dL.

• Asians and blacks were also less likely than whites to achieve an LDL-C < 100 mg/dL.

• Notably, Asians were more likely to be on statin therapy less likely to be prescribed high-intensity statins. Poor health outcomes and disparities in the utilization of guideline-based statins might have inadvertently led to the undertreatment of Asian FH patients.

• Women were less likely than men to receive treatment more likely to be prescribed high-intensity statins. Healthcare providers who prescribe to blacks might be influenced by current rates of worse cardiovascular outcomes.

• Our results mirror prior findings from non-FH populations in the US: women and minorities receive less guideline-based cardioprotective therapies.

• Few prior studies have evaluated health disparities in FH patients, and none have included multiplet cohorts. In the Spanish Familial Hypercholesterolemia Cohort Study (SAFEHEART) study, women were found to be less likely than men to receive a high-intensity statin and less likely to achieve an LDL-C goal.

• Limitations

• Data are cross-sectional and observational in nature, limiting our ability to detect causal relationships.

• We are unable to detect which patient, social, or healthcare system factors might have led to these associations we report.

• Conclusions

We utilized data from a multicenter US registry of individuals with assigned FH to examine differences in statin therapy and LDL-C lowering. Our findings suggest that health disparities contribute to undertreatment of FH patients in the US. Increased efforts are warranted to raise awareness.