David M. Harmon, M.D.
Mayo Clinic
Rochester, MN

July 2020
Visual Aids in Patient Education

Use of patient educational information to increase Familial Hypercholesterolemia Clinic appointments in the Community.

David Harmon, MD, Tyler Schmidt MD, Nadia Akhiyat MD, MS, Erica Kludtke RN, Jeffrey Meeusen PhD, Stephen L. Kopecky, MD
Familial Hypercholesterolemia (FH) is the leading genetic cause of premature death and disability in the U.S., though identification and treatment of FH remains < 10%.

Multifactorial cause for under-treatment:
- Cardiovascular Disease Age Bias
- Public Lack of Awareness
- Intolerance to treatment
Previously, the notification system for a possible FH case at the Mayo Clinic has been an interpretive comment automatically added to the LDL-c values >190 mg/dL.

<table>
<thead>
<tr>
<th>LIPIDS/CARDIAC RISK</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cholesterol, Total, S</td>
<td>260*</td>
</tr>
<tr>
<td>Cholesterol, HDL, S</td>
<td>45*</td>
</tr>
<tr>
<td>Calculated LDL</td>
<td>201*</td>
</tr>
<tr>
<td>Triglycerides</td>
<td>68*</td>
</tr>
<tr>
<td>Non HDL Cholesterol</td>
<td>215*</td>
</tr>
</tbody>
</table>

The markedly elevated LDL level is suggestive of a genetic condition such as familial hypercholesterolemia (FH) or familial defective apolipoprotein B-100 (FDB). Molecular genetic testing for FH and FDB is available through Mayo Clinic Laboratories: FH/ADH Genetic Reflex Panel (test ADM). Acquired (non-genetic) causes of markedly increased LDL cholesterol include cholestatic liver disease due to the presence of LpX. If a genetic form of hypercholesterolemia is suspected, family studies including biochemical testing for lipids (total cholesterol, triglycerides, LDL cholesterol and HDL cholesterol) are recommended. Please contact the laboratory at 1-800-533-1710 or the on-line test catalog at mayoclinicrolaboratories.com for information about how to order these tests or to speak with a genetic counselor. Further interpretation would require clinical information.

---REFERENCE VALUE---
Desirable: <100
Above Desirable: 100-129
Borderline high: 130-159
High: 160-189
Very high: > or =190
Background

• Observing a group of 100 patients with LDL >190 mg/dL, only 12 were appropriately referred for further treatment and genetic evaluation

• Our hypothesis:
  − Direct patient/provider outreach, with permission from lab-ordering provider, would increase referral for FH diagnosis and treatment in high-risk patients
  − Implemented 2 educational interventions with information of FH risk, diagnosis, treatment
    • Print letter
    • Cartoon infographic
Attachment A: Sample PCP letter

Dear

I am a preventive cardiologist here and receive a list of all patients with elevated LDL levels. We recently started a Familial Hypercholesterolemia (FH) Clinic and I see that your patient ___ has an elevated LDL would be an appropriate potential patient for the Familial Hypercholesterolemia Clinic and if you would like to refer please place an order for cardiology consult – choose Lipid/cardiology consult (LHC) for Indication, click Familial Hypercholesterolemia for diagnosis, use “lips” – on Scheduling Instructions type “Dr. Kopecky” and I will see _______ anytime.

We have found that over 90% of patients with FH are not aware of this disorder and often times do not feel they need further evaluation for various reasons – young age, asymptomatic status, or just a general misunderstanding of what the disease could mean to them and their family.

To help them understand the importance of being evaluated for possible FH, enclosed are 3 helpful brochures that should be printed out and given to the patient by either you or your nurse/clinical assistant. (1 & 2 are single sheet brochures that introduce them to FH, and 3 is a 5 page brochure with more explanation and resources). Also included is # 4 - a slide with a graph demonstrating the benefits of early treatment in these patients.

In the Familial Hypercholesterolemia (FH) clinic, patients with a markedly elevated LDL cholesterol are evaluated for a potential genetic basis for their high cholesterol. This evaluation includes taking a medical history, doing a physical exam, and blood testing. If a genetic basis is found, family members may also be screened. Diagnosis and treatment is the most effective way to prevent early heart attack and stroke. Recently, the FDA approved non-Statin medications (PCSK9 inhibitors) that have become available that are the most effective treatment for lowering cholesterol and risk for heart attack or stroke.

We do ask that either you or your nurse/clinical assistant inform the patient about this clinic and see if they would be interested in coming for an appointment. If they are interested in coming for an appointment, please have your office notify Ms. Tem Pitcher at 507-284-4443. After she arranges the appointment, we request that your office notify the patient of the specific time, date, and location.

Thank you for your efforts and please call me anytime if I can help in any way.
Lipid Panels collected at Mayo Clinic Laboratories from 2018-2020

1420 patients identified with LDL cholesterol ≥190 mg/dL

Clinical randomization and distribution of FH education (letter versus cartoon)

271 consecutive charts reviewed regarding response/referral rate
Impact of Educational Intervention

Figure 1: Referral rate of patients with and without educational intervention for probable FH (*=p<0.05)
Who was referred?

• In both intervention groups (print/cartoon) patient’s referred were younger
  – 54±15 vs 60±12; p<0.05

• Subgroup analysis
  – Cartoon cohort: female patients more often referred (31% vs. 15%; p<0.05)

• No significant differences were observed between referral rates in either intervention group with:
  – Previous ASCVD
  – Distance from the clinic sites (excluding outliers >400 miles)
  – Religious affiliation
Conclusions

• Distribution of visual educational materials significantly increased referral for identification and treatment of probable FH patients.

• A clinically significant difference was observed between the referral rates of cartoon infographic recipients compared to standard print letter recipients highlighting the impact of a visual educational tool.
What’s Next?

• Focus Groups
  – Sample of patients who accepted and declined FH clinic referral
  – What was motivating/deterring?
  – Perceived severity of illness?

• Advancement of visual education
  – Development of educational video
  – Availability on the patient EMR portal
Questions?
Harmon.david@mayo.edu

July 2020