Familial Hypercholesterolemia in Lewiston/Auburn, ME: Directed Education Towards Improving Community Awareness

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Familial Hypercholesterolemia: A Dangerous Disease in Lewiston/Auburn, Maine

- Autosomal dominant defect in hepatic LDL receptor preventing LDL uptake -> increased serum LDL -> accelerated ASCVD (risk 2.5-10x greater than general population) [1]
- According to a study in the Netherlands, a heterozygous FH-patient of 35 years can reach the cumulative LDL cholesterol of a non-FH 55 y/o [2] -> greater risk for premature ASCVD
- US prevalence: 1 in 250 people [3]
- In Lewiston/Auburn, ME: 1 in 30-50 people (10-fold increase in prevalence) [4]
  - *High prevalence amongst the Franco-American ethnic population* -> improving awareness about the disease and its sequelae amongst this population is an area of need [5]
Relative Risk of Familial Hypercholesterolemia

[Graph showing the cumulative LDL-C (mmol) against age in years for different conditions including homozygous FH, heterozygous FH, and without FH. Key points are noted with ages and thresholds for CHD.]
Public health implications of FH: US and in L/A, Maine

General CVD burden:
- US, 2016: $555 billion in CVD-related costs, estimated $1.1 trillion in 2035 \[^6\]
- FH pts factor into this cost early in life and frequently

US: Family-based CASCADE Screening \[^1\]
- most FH patients have not been treated to established goals
- Identifies FH pts to help ensure treatment prior to developing ASCVD
- Formal cost-effectiveness has not been evaluated; studies in the Netherlands evaluated cost effectiveness at $8,700/year added to patient’s life \[^7\]

Central Maine Heart and Vascular Institute (CMHVI), Lewiston
- Maine CDC last reported direct costs of Heart Disease in 2003 as $230 million \[^8\]
- Specific estimation of FH burden in ME has not been established - a clear area for future work
- Aforementioned CASCADE screening is being implemented at Central Maine Medical Center
- Weekly lipid clinic at CMHVI: Specialty clinic for patients with all dyslipidemias
- Outreach work by local cardiologist and disease expert Dr. McCann to the Franco Center to create awareness of the disease established through grant work

Local community members aware of the disease, its course, and potential sequelae endorse the need for improved awareness at the local, community level
Community Health Perspectives: Dr. McCann and Dr. Picker

“This is one of the few genetic conditions that can be successfully treated, but cannot be successfully treated by diet and exercise alone. This needs medical treatment”

-Dr. Dervilla McCann, MD, MPH, Cardiology and Population Health
Central Maine Medical Center, Lewiston, ME

“The level of public education on FH is encouraging and better now than it has been 5 years ago. However, the fact that I see patients don’t seem to know the full effects of the disease and its implications is surprising, because this situation requires them to be their own health advocates.”

-Dr. Bethany Picker, MD, Family Medicine
Central Maine Medical Center, Lewiston, ME
Intervention: Focus Group Questions and Directed Educational Materials

1) Gather qualitative data from population of interest at local community center (Gendron Franco Center) through small, directed focus groups

Question A: What are your perceptions of the disease (FH) previously mentioned to you by community cardiologist Dr. McCann? What do you know about it?

Question B: What suggestions can you think of about how primary care providers can better serve these patients?

2) Evaluate and synthesize information to identify areas where awareness is strong and areas of improvement

3) Create and deliver handout to Franco-American Center designed to address areas of need in knowledge of disease
Results and Analysis

Sample: ~ 5 focus groups of 3-5 Franco-American patrons, Gendron Franco Center, Auburn, ME

Question A Takeaways

Areas of strength:

1) Consistent recollection of the disease once reminded of Dr. McCann (who first presented information)
2) Awareness that Franco-Americans are an increased risk group for cardiovascular disease - shows effectiveness of prior outreach work by Dr. McCann directed towards this goal
3) Those who had family members/friends implicated by disease had an increased likelihood to understand details of FH - one woman described the disease process as: “body making bad cholesterol”, then recalled a friend’s son who was diagnosed at 6-7 y/o, managed on Lipitor and Niacin - another woman recalled that her father and uncle passed away in early 30s from CVD

Areas of need:

1) Need for better basic understanding about disease (e.g. a genetic process affecting young age vs. non-familial HLD) - e.g. related to situations like “My dad had a heart attack at old age”
2) Self-admission of need for more knowledge - statements that this information was still “new” and “good to be aware of”
Results and Analysis (continued)

Question B Responses

Areas of strength:

1) Recognizing importance of diet and exercise as reinforced by doctor during healthcare visits
   - “I just don’t follow my diet and exercise like I should”
2) Cultural and socioeconomic respect for authority, especially physicians
   - Emphasis on a need to “just listen to what your doctor tells you”
3) Demonstrating a desire for a sense of control and to be proactive in treating their disease
   - After being reminded about the disease, one woman said: “patients need to be shown how to treat their condition”

Areas of need:

1) A desire to have access to FH-related information through existing healthcare resources
   - Former nurse: “have this information available in the office! Even for people without the disease, so all are informed.”
2) Education regarding role of diet and exercise in treatment of FH
3) Knowledge about how the disease can be controlled (i.e. medications)
Limitations and Proposed Evaluation of Effectiveness

Limitations

• Sample size bias
  – Possible skewed evaluation of strengths and areas of need

• Location
  – Alternative settings could be more conducive to varied patient interviews

• Qualitative data
  – Evaluation of improvement based on data could require either quantitative data or creation of a metric to assess this qualitative data

Evaluation of Effectiveness

• Formal evaluation of effectiveness could be ideally assessed by survey
• Assess knowledge of disease as compared to non-familial HLD, its risk factors, and what measures patients can take to prevent sequelae
Recommendations for future interventions/projects

• Evaluate **barriers to care of FH and other dyslipidemias for patients** at local community centers or at primary care office primary care office

• **Target provider perspective** and produce a survey to elicit providers’ thoughts on areas of need in management of FH and associated sequelae

• Work with **food pantries/food distribution centers** to help inform underprivileged individuals with FH about **healthy eating habits for prevention of ASCVD**

• Develop **intake screening questionnaire** to identify individuals with FH who would be **candidates for providing information to CASCADE** (to improve data and research available on FH)
References


Familial Hypercholesterolemia (FH): A Common Disease of Franco-Americans

What do you already know about this issue?

- Franco-Americans are at an increased risk for heart disease.
- The reason behind this involves genetics (disease being passed on from generations)

This is one of the few genetic diseases that can be treatable. Early treatment can reduce many of the negative effects of this disease (heart attacks, strokes, among others)

What should you remember?

- Diet and exercise alone does not "fix" FH. This is different than high cholesterol from diet and exercise alone.
- Very safe, and well established therapy (including medications called “statins”) for FH are available. All patients with this disease should be treated for it with medication.
- If a family member has heart disease in or earlier than their 40's, let your doctor know. Your family member might have FH, which needs more aggressive therapy.

If you or a family member has FH, please sign up for The CASCADE registry at Central Maine Medical Center

By signing up for free to this registry, you will be directly improving the collection of data for FH, increasing our ability to research the disease and ultimately create better treatments.

Please visit: https://thefhfoundation.org/ [1]

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