

2016

The Importance of Collecting an Accurate Family Medical History

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Recommended Citation

Leahy, Danielle T., "The Importance of Collecting an Accurate Family Medical History" (2016). *Family Medicine Clerkship Student Projects*. Book 119.

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COLLECTING AN ACCURATE FAMILY MEDICAL HISTORY: WHY IS IT IMPORTANT?

A COMMUNITY PROJECT FOR THE FAMILY MEDICINE ROTATION AT COLCHESTER FAMILY PRACTICE

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Rotation 6
Dec 2015-Jan 2016
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2: PROBLEM IDENTIFICATION AND DESCRIPTION OF NEED

- Family medical history (FMH) has been recognized as an important non-modifiable risk factor for many chronic diseases including cardiovascular disease, diabetes, and even several types of cancer. In general, having a family history of certain chronic diseases can increase one's risk of developing that disease by 2-5 times that of the general population. The number of affected relatives as well as early onset of the disease can greatly increase the risk of a patient developing that specific disease.¹
- However, a number of studies have shown that patients' recall of their family history is often inaccurate and missing important information such as family members' age at onset or diagnosis of a disease.²
- Additionally, there is substantial variation regarding how often family physicians are actually obtaining FMH during visits. In the Direct Observation of Primary Care Study, which included 4,054 outpatient visits for 138 family medicine physicians, it was shown that FMHs were discussed during only 51% of new patient visits and 22% of follow-up visits. Furthermore, the average time spent collecting information about a patient's FMH was less than 3 minutes.³
- Patients' understanding of the importance of obtaining an accurate FMH and even their perception of familial risk of common chronic diseases is also highly variable based on personal experiences and education.⁴
- Therefore, to assist physicians in acquiring a more accurate and detailed FMH from patients it would appear that patients need to be educated on why collecting their FMH is an important part of understanding of their own health and risk for developing diseases. In addition, patients should be given the opportunity and the tools necessary to gather their FMH prior to their scheduled visit with their physician, allowing the patient more time to have a conversation about health history with their family members. In doing so this would allow time for the physician to discuss the information with the patient during their scheduled office visit and work on developing a plan rather than hastily attempting to gather the information when neither party is truly prepared to do so.

3A: PUBLIC HEALTH COST AND UNIQUE COST CONSIDERATIONS IN HOST COMMUNITY

- Obtaining an accurate FMH from a patient allows the physician to assess the patient's risk of developing certain diseases by evaluating the genetic component of disease risk in conjunction with environmental risks based on a patient's social history. Knowing the FMH allows for earlier screening or disease detection and can even help physicians make specific recommendations for lifestyle modifications to help decrease the patient's chance of developing diseases which they are genetically predisposed to.
- A thorough FMH may also decrease total medical costs by helping guide the physician in creating a work-up for an otherwise vague chief complaint. For example, a patient complaining of fatigue and joint pain with FMH of diabetes and liver cirrhosis may be worked up earlier for hereditary hemochromatosis since this would be higher up on the list of differential diagnoses.
- In order to better understand the public health implications of collecting an accurate FMH, it is important to compare the cost of treating a chronic disease with the cost of disease prevention had the patient and physician known to screen for the disease based on the patient's FMH.
- The specific cost considerations for the host community in Vermont can be demonstrated by comparing the cost of treatment for genetically-linked diseases, such as colorectal cancer and type 2 diabetes, to the cost of early disease detection or prevention based on the pattern of disease in a patient's FMH.

3B: PUBLIC HEALTH COST AND UNIQUE COST CONSIDERATIONS IN HOST COMMUNITY

■ Colorectal Cancer (CRC):

- In Vermont, the rate of colorectal cancer is 38.9 per 100k people. It is estimated that 10-30% of CRC cases are associated with a familial risk. Having one first degree relative with CRC increases the risk of development of CRC by 2.3%, but having two or more relatives increases risk by 4.3%.⁵
- However, according to a recent study, 25% of people were unaware that they had even one first degree relative with CRC.⁶
- One study showed that the net cost for treatment of CRC increased based on the stage of the cancer. For Stage 0 (carcinoma in situ) the net cost was ~\$7,002, however, for Stage 4 (distant metastasis) the net cost of treatment was ~\$15,276. According to the Journal of the National Cancer Institute, based on the increasing cost for chemotherapy used in advanced CRC, most CRC screenings have actually become cost saving.⁷
- According to American Cancer Society guidelines, patients with at least one first degree relative with a history of CRC before age 60 should begin having screening colonoscopies at age 40, or 10 years before the youngest case in the immediate family. With this guideline, those patients who have a known and accurate FMH of CRC would benefit greatly by early screening and detection of disease and it would ultimately save money on healthcare costs.

■ Type 2 Diabetes Mellitus (T2DM):

- According to the CDC, it is estimated that 6.7% of the population in Vermont has diagnosed T2DM. More specifically, in Chittenden County the prevalence of T2DM increased from 4.7% to 6.3% from 2009-2012.⁸ It is known that having a family history of T2DM has a significant and independent association with the development of T2DM. Therefore, public health strategies such as assisting patients in collecting an accurate FMH is crucial in helping identify those patients that would benefit from specific lifestyle interventions or early screening and monitoring for this disease.⁹
- The estimated total economic cost of diagnosed diabetes in the US in 2012 was \$245 billion, which was a 41% increase from the previous estimate of \$174 billion in 2007. This estimate highlights the substantial burden that diabetes imposes on society.¹⁰
- On average, people with diagnosed T2DM spend ~\$13,700 per year on medical expenditures, of which about \$7,900 is attributed to costs related to T2DM. While gaining better control of T2DM after diagnosis can decrease one's overall medical expenditures, it would still be cost-saving for patients who have a genetic predisposition to T2DM to make necessary lifestyle changes to ideally prevent or significantly decrease the severity of disease.¹⁰

4A: COMMUNITY PERSPECTIVE ON ISSUE AND SUPPORT FOR PROJECT

■ **[Name withheld] Genetic Counselor, University of Vermont Cancer Center**

- “We are just barely beginning to scratch the surface when it comes to genetics in medicine. In the future we hope to have the capability to sequence a patient’s DNA and use that information to determine their risk for different diseases. At this point, collecting an accurate family medical history continues to be one of the most important tools we have in primary care in regards to evaluating the risk of our patients developing certain diseases. Of course genetics is just one part of the puzzle, but a comprehensive family history includes information about different environmental and lifestyle factors that even the most advanced scientific tests would never be able to pick up. The future of genetics really is in primary care and there would be real benefit to both patients and providers if a geneticist was included as part of the ‘medical home’. Then we could be the ones really spending the time piecing together the family history and suggesting different screening tests or lifestyle changes for the providers to incorporate into the patient’s treatment.”
- “A good family history tool is one that encourages discussion amongst family members and educates them on the importance of gathering this information. You’d be surprised how often a patient lists a family member as having ‘stomach cancer’ and later on you find out they actually had colon cancer.”
- “There is enormous variation in the amount of information patients seem to know about their family’s medical history. Even if a patient can list a number of medical conditions that have affected their family members, they don’t know important factors like age of onset or specific treatments they received.”

■ **[Name withheld] Colchester Family Practice Provider**

- “In order to gather a comprehensive family medical history you really need to give the patient enough time to contact family and ask these questions. When we give them a form to fill out in the waiting room it’s basically like, ‘Here’s your chance to fill out this really important piece of your medical record in 5 minutes’. And then as a provider we glance at the form in the room and fill what we can into the computer, but we don’t have the time to go through each family member, asking additional questions in hopes that it prompts them to share a piece of information they probably didn’t think was important enough to write down.”

4B: COMMUNITY PERSPECTIVE ON ISSUE AND SUPPORT FOR PROJECT

■ [Name withheld] Colchester Family Practice Provider

- “I’m bad at getting patients’ family histories because I’m usually seeing other people’s patients. Especially with older patients I don’t even bother. It would be extremely helpful if patients had access to a system that just auto-populated the family history they entered right into their EHR. This way they could update it on their own when new information became available to them.”

■ [Name withheld] Colchester community member, non-medical professional

- When asked to name the diseases they knew had a genetic component, the following conditions were listed: diabetes, colon cancer, heart disease, and mental health disorders like bipolar and depression.
- When asked about the following diseases, they stated there was no genetic component (even though there is): osteoporosis, breast cancer, ovarian cancer, high cholesterol, rheumatoid arthritis and blood clotting disorders. They were surprised to discover that all of these diseases could have a genetic component to them and some, such as breast, colon, and ovarian cancer could all be linked by the same gene.
- “I think there are a lot of people who really don’t know much about their family’s medical history. I mean I admit that I don’t know much other than some of the major diseases like heart disease and diabetes in my family, but I couldn’t tell you anything about the age they were diagnosed or if they received any treatments. I do know things about their living habits like if they smoked and drank, but that’s the easy stuff to know since you see them doing that and it just sticks in your mind. I do think it would be beneficial for people who aren’t working in the medical field to have a little bit more information explaining why their family’s medical history is helpful for the whole family. Honestly, I’m pretty surprised by some of the diseases you pointed out as being genetic and come to think of it my Mom did have a lump removed from her breast and I have no idea what it even was. I should probably ask her.”

5: INTERVENTION AND METHODOLOGY

- **Identified the necessary elements for adequate documentation of a patient's family medical history**
 - Incorporated the information received through literature reviews as well as from the interview with the UVM Geneticist (i.e. medical condition, age of onset, cause of death, ethnicity, lifestyle factors, and specific treatments received)
- **Created a comprehensive family medical history form**
 - Reviewed the practice's current patient intake form and identified necessary changes to the FMH section based on elements identified from literature review
 - Constructed two different versions of the FMH form and then obtained feedback from patients about which style was preferred
- **Developed an educational handout to accompany the new family medical history form**
 - To educate patients on the importance of collecting a comprehensive FMH, how to go about asking family members for this information, and how this information is used by physicians
- **Incorporated educational handout and new family medical history form into packet which is to be mailed to patients prior to scheduled office visit**
 - In an effort to give patients adequate time to contact family members and collect necessary information, materials should be made available to patients in advance of their appointment

6: RESULTS/RESPONSE

- **Subjective patient feedback regarding their past experiences collecting family medical history:**
 - Many mentioned that they had never taken the time to specifically discuss family medical history with their family members
 - When tasked with filling out a FMH form in the past, many relied solely on their recollection of seeing a family member go through an emergency event or procedure related to a specific medical condition (i.e. Father being hospitalized after having a stroke)
- **Subjective patient feedback regarding the different formats of proposed family medical history form:**
 - Check-box format was viewed as being more direct, easier to fill out, and seemed more user-friendly especially for those with limited medical knowledge
 - Open-response format was thought to be more conducive for initiating conversation between family members, but was also viewed as being more work for the patient, and some felt less confident that they would actually take the time to fill it out
- The decision was made to use a hybrid-style format which included using check-boxes for a number of pertinent genetic diseases often seen in primary care, as well as an area to fill in an open-response about each allocated family member's lifestyle or other pertinent information
- Providers at Colchester Family Practice agreed that educating patients about the importance of FMH is something that is not commonly discussed in a patient visit. They are looking forward to seeing the new FMH form and educational handout being implemented in their practice and hope it encourages patients to further explore and share their FMH

7: EVALUATION OF EFFECTIVENESS AND LIMITATIONS

- **Effectiveness:**

- At this time the newly designed FMH form and educational handout are in the process of being incorporated into the materials being mailed out to patients, so it will take time to be able to assess the effectiveness of this project
- In order to gauge how successful the implementation is, it would be important to track how many patients are bringing the completed FMH form to their office visits
- Over time it would also be of interest to follow patients with a documented family history of a specific disease in order to see whether this information prompts more early screening interventions to slow disease progression and/or even prevent development
- Collecting feedback from patients and providers about the way the form is being filled out and/or utilized is also important so that changes or updates can be made to the forms as needed to promote continued use

- **Limitations:**

- Even with the information about the importance of FMH which is being provided by the educational handout, it is likely that some patients still won't have the time or may not be willing to fill out the FMH form
- Patients who are estranged from their family or have family members who do not wish to discuss their personal medical history will be less successful at obtaining the information necessary to complete the FMH form
- These documents are currently available only in English, so for those patients who do not speak English or do not have access to a translator, it would be difficult to complete the FMH form and it is unlikely that they would benefit from the educational handout provided either

8: RECOMMENDATIONS FOR FUTURE INTERVENTIONS/PROJECTS

- With the creation of the electronic health record (EHR), many primary care offices are moving away from paper forms in an attempt to keep all information stored in one easily accessible format. One recommendation for this project would be to develop an online tool which could interface with the hospital's EHR so that patients could access and make changes to their documented FMH right from home
- Perhaps creating an area in the UVM patient health information portal "MyHealthOnline" would be a good place to start since many patients already have access to this service already and are using it to track other aspects of their care. Patients would even be able to send messages to their healthcare providers when important updates are made to the FMH, which could allow the providers to make note of any future tests or interventions they may want to discuss with the patient at the next visit
- As the field of medical genetics continues to grow, the prospect of hiring a genetic counselor for primary care practices is something that is worth discussing. As previously stated, this could potentially save time for providers if someone else is in charge of entering this information into the patient chart and monitoring for any changes or patterns occurring in the patient's FMH. It would also allow for continued collaboration and educational opportunities for providers to learn more about genetics as medicine continues to trend toward implementing genetic tests as a basic part of patient care.

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