Exploring the Lag in Migraine Diagnoses using Unstructured Clinical Notes

Samah Fodeh, PhD\textsuperscript{1,2}, Brenda T. Fenton, PhD\textsuperscript{2}, Hamada Al-Talib, MD\textsuperscript{2}, Jason J. Sico, MD\textsuperscript{2}  
\textsuperscript{1}Yale University, New Haven, CT, USA; \textsuperscript{2}VA Connecticut Healthcare System, West Haven, CT, USA

Abstract

Headache is a common medical condition encountered within primary and specialty care clinics and within the emergency room. Despite the clear diagnostic criteria for headache conditions, many patients don’t receive specific diagnoses for their headaches, and hence, may receive guideline discordant care. We explore the lag between patient reported headache and headache symptoms and receiving a formal headache diagnosis using clinical notes.

Introduction

Migraine headache is a common condition encountered by healthcare providers at the Veterans Health Administration (VHA) facilities, however, little literature has been published regarding headache burden and timeliness of diagnoses. Neurologists anecdotally report that veterans suffer migraine headaches for years before the diagnosis is formally coded in their charts, thereby delaying the delivery of guideline-concordant migraine care. While sub-par care seems plausible with a formal diagnosis, the impact of lag and care quality has not been formally studied. We characterized the lag in migraine diagnoses by retrospectively exploring unstructured clinical notes years before the index date.

Methods

Based on structured data, we composed a cohort of patients who were first coded/indexed for migraine in 2017. The index date was defined as the first date with a migraine diagnosis during an outpatient or inpatient visit. We pulled primary care clinical notes in years 2014, 2015, and 2016 for patients that satisfy this condition. We searched for language related to migraine symptoms in the notes in the 2-3 years prior to diagnosis, recognizing that these patients may not be seen annually for their headache. We used a list of terms provided by neurologists including photophobia, nausea, staying in a dark room, sensitivity to light and variant expressions of the same terms.

Results

Using coded structured data, we found that 2,844 patients were indexed for migraine in 2017. As shown in Table 1, the majority are male, white and between 31-50 years old. We retrieved unstructured primary care clinical notes on those patients in 2014, 2015 and 2016. As per Table 2, 14% (396) patients reported migraine symptoms in one year (2014, 2015, or 2016) before their formal diagnoses in 2017. Of those, 22% ((29+22+38)/396) patients had documented migraine symptoms in >1 year before their diagnoses in 2017.

Discussion

Using a sample of notes on outpatient visits and search queries, we established that a lag in migraine diagnoses exists at the VHA. For example, 30% of patients who reported symptoms in 2015 continued to suffer from migraine before their formal diagnoses in 2017. This sample of migraine patients is unique given it is 76% male, whereas the literature is based on predominantly female samples. In future work, this approach will (1.) allow us to determine whether headache care quality differs dependent on the presence and duration of a lag in migraine diagnosis; (2.) be applied to a longer lookback period; and (3.) monitor the impact of an educational initiative to improve proper headache identification.

References

1. Samah Fodeh, Mining Big Biomedical Data, International Journal of Knowledge Discovery in Bioinformatics (IJKDB) 6(1), 2016