Accuracy of self-reported risk factors for hydroxychloroquine retinopathy

Hydroxychloroquine (HCQ) is an effective and typically well-tolerated anti-inflammatory medication, but retinal toxicity is a potential side effect.[1] Current screening guidelines recommend baseline ophthalmic examination to rule out maculopathy and then yearly examination with visual field and optical coherence tomography after 5 years of HCQ use.[1] The presence of HCQ retinopathy risk factors,[2] such as HCQ duration ≥5 years, HCQ daily dose >5 mg/kg real body weight, tamoxifen use, or renal disease, should increase suspicion for retinopathy and may modify the retinopathy screening timeline.

Identifying these risk factors requires taking a patient history or reviewing the electronic health record (EHR). With ever-increasing time demands, providers may rely solely on patient self-report of HCQ retinopathy risk factors. The primary goal of this study is to evaluate whether the patient interview accurately identifies HCQ retinopathy risk factors, and the secondary goal is to evaluate whether eye care providers accurately identify these risk factors.

The study protocol was approved by the Minneapolis Veterans Affairs Health Care System Institutional Review Board (IRB)/Ethics Committee and adhered to the tenets of the Declaration of Helsinki. We utilized the Veterans Affairs Informatics and Computing Infrastructure (VINCI)[3] to query Corporate Data Warehouse[4] data to identify patients currently taking HCQ and presenting for routine examinations in the Minneapolis Veterans Affairs Eye Clinic. After informed consent, all study subjects completed an in-person interview survey regarding HCQ retinopathy risk factors (Supplementary Table 1, available online). We reviewed the eye care provider note at the study visit and queried the EHR for HCQ retinopathy risk factors, cognitive diagnoses, and psychiatric diagnoses.

A demographic and clinical summary of the 93 study participants appears in Table 1. After identifying subjects with HCQ retinopathy risk factors by EHR review, we determined whether the subject interview and eye care provider note identified these risk factors (Table 2). The presence of a cognitive or psychiatric diagnosis did not reduce self-reporting accuracy: 5/9 (56%) subjects with a cognitive disorder, 20/28 (71%) subjects with a psychiatric diagnosis, and 23/42 (55%) subjects with neither cognitive nor psychiatric diagnoses correctly reported all HCQ risk factors.

The patient interview identified HCQ duration ≥5 years in 75% of cases but was less successful at identifying HCQ daily dose >5 mg/kg and renal disease. Similarly, the eye care provider note identified HCQ duration ≥5 years but not HCQ daily dose >5 mg/kg or renal disease in most cases. Inconsistent self-report of HCQ retinopathy risk factors corresponds with previous studies showing variable accuracy in patient self-reported medication use.[5]

Improving HCQ retinopathy screening by manual EHR review of risk factors can be time-consuming, but EHR templates may improve efficiency. Alternatively, if EHR confirmation is not feasible, we recommend communicating with the patient's HCQ prescribing provider, communicating with the patient's prescribing pharmacy, or requesting that the patient bring the medication bottle to the eye clinic to verify HCQ duration and dose. Other methods such as monitoring blood HCQ levels may improve HCQ retinopathy screening in the future,[6] but at present accurately assessing established HCQ retinopathy risk factors remains central in providing good patient care.

One study limitation is that the older and more predominantly male population may affect generalizability. Although prior HCQ studies have predominantly female populations, male patients also take HCQ and develop HCQ retinopathy.[2] Additionally, with the potential for expanded clinical indications for HCQ treatment,[7] the sex ratio of patients taking HCQ may change. The study is also limited by a small sample size.

In conclusion, solely using the patient interview or prior eye care provider notes may not consistently identify HCQ retinopathy risk factors. Optimizing EHR use, with either manual review carried forward or automated templates, would improve quality of care in HCQ retinopathy screening.

Table 1—Demographic and clinical characteristics of the study population

Characteristic	Result (n = 93)
Age, mean (range), years	69 (33–88)
Height, mean (range), cm	172 (152–193)
Real weight, mean (range), kg	89 (44–146)
BMI, mean (range), kg/m^2	30 (21–37)
Sex	
Female	13 (14%)
Male	80 (86%)
Cognitive diagnosis	15 (16%)
Psychiatric diagnosis	28 (30%)
No psychiatric or cognitive diagnosis	56 (60%)
HCQ duration based on EHR, mean (range), years	5.6 (0.1–20.5)
>6 month interruption in HCQ	6 (6.5%)
HCQ daily dose, mean (range), mg/kg/day	3.9 (0.4–9.0)
eGFR <60 mL/min/1.73m^2	19 (20%)
Tamoxifen use	0

BMI, body mass index; HCQ, hydroxychloroquine; EHR, electronic health record; eGFR, estimated glomerular filtration rate.

Table 2—Accuracy of hydroxychloroquine retinopathy risk factor reporting

Situation	n	Risk factor(s) correctly reported by subject (%)	Risk factor(s) correctly reported by provider (%)
Any HCQ retinopathy risk factor	69	40 (58)	33 (48)
HCQ duration ≥5 years	47	35 (75)	39 (83)
HCQ dose >5 mg/kg/day	10	5 (50)	3 (30)
Renal disease	29	11 (38)	3 (10)

HCQ, hydroxychloroquine.

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Supplementary Materials

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