CMEology

HAE – Hereditary Angioedema

Interview with “01”

January 16, 2024

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CMEology

Interview with 01 – Hereditary Angioedema

[START 01 1.16.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: So we'll go ahead and get started. This should take about 30 minutes, and our goal is to just get your candid answers to some of these questions about HAE. So we are talking about hereditary angioedema, HAE, and the first question is just simply: could you describe your personal experience evaluating the HAE literature in terms of its implications for clinical practice?

01: So I would say that in my personal practice, we don't get a lot of these patients but they do come by, maybe this past year, maybe one or two patients. And I reviewed the literature with my supervising physician, and essentially, my experience with it, basically if a patient isn't responding, if it's typical angioedema, they're not responding to antihistamines or steroids, we lean more towards the hereditary angioedema and we start ordering blood work, again, because we've only had maybe one or two patients this past year. I don't have a whole lot as far as severe hereditary angioedema patients, but the ones that I do have, they're pretty much stable, so I haven't had to escalate treatment or anything, and I haven't really had any scares this past year as far as any flare-ups. But as far as the literature, I do review it constantly with my supervising physician.

QUESTION: Okay, all right. When you're looking at the literature, are there things that you're particularly, you know, if you're looking at it yourself or you're looking at this with your supervising physician, are there things that you are particularly cluing into?

01: Mainly the clinical symptoms, what to order and how to diagnose and treat essentially, and how to do prophylaxis if we ever have to get to that point.

QUESTION: Okay. So it sounds like the patients that you've seen in the last year or so, the one or two that you've seen, they haven't had to have long-term prophylaxis?

01: That is correct.

QUESTION: Okay, got it. So looking at diagnosis then, the workup labs to order, and then, how to choose a long-term prophylactic strategy if they were to eventually need one. So when you're thinking about HAE research, is there any particular format for looking at research results that's most influential for you? So for example, would you seek out abstracts, posters, live conference presentations, academic detailing? I imagine there may not be much of that. Would you look at UpToDate or would you go pull journal pubs? What's kind of your preferred way of looking at the literature?

01: I would say UpToDate and pulling journal articles.

QUESTION: And journal articles.

01: Yes. If there is, you just said it, I forgot what it was, if there is like updated literature, posters, if a pharmaceutical rep stops by, gives us a poster, I'd definitely use those as well, but right off the bat, I would say UpToDate and journal articles.

QUESTION: Okay, got it. Moving on, what are the factors that are most important to you when it comes to interpreting the HAE literature and applying it to clinical care?

01: I would say the most important thing is how long was the study, if they did like a trial on patients for a specific medication. I like to look at sample sizes; adverse effects; and how many of the patients actually made it through the entire trial; and post-trial, were there any adverse effects post-trial.

QUESTION: Okay. So you're really keyed into, it sounds like, the specifics of how that trial is designed and then—

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Expert opinion/Up To Date/Google/Medscape

Commented [2]: Codes (2794-2803)
Expert opinion/Up To Date/Google/Medscape
Expert opinion/Up To Date/Google/Medscape

Commented [3]: Codes (2807-2832)
Evaluating new data
Pharma rep detailing/MLs

Commented [4]: Codes (2832-2833)
Pharma rep detailing/MLs

Commented [5]: Codes (2947-2955)
Evaluating new data

Commented [6]: Codes (2955-2966)
Evaluating new data
Literature review

Commented [7]: Codes (2966-2975)
Evaluating new data

Commented [8]: Codes (2981-3000)
Pharma rep detailing/MLs

Commented [9]: Codes (3453-3466)
Sample size

Commented [10]: Codes (3468-3483)
Adverse effects

01: Yes.

QUESTION: —you're also looking at something which is important, which is how many people actually finish the entire study period; and then side effects both during the trial and then also if there is a study, as there often are, right, if there are long-term studies done on a particular treatment.

01: Yes, that is correct, yes.

QUESTION: Okay. When you're looking at the literature, are you facing any issues in terms of time, interacting with your colleagues? Sounds like you do look at things with your supervising physician if you need to.

01: Yes. So I would say I do work with my colleagues and my supervising physician. I would say in my case, because I've only had one or two patients, when they do come, we actually have time to review the literature, and very briefly in that moment. Let's say I discharge a patient, they have a regular follow-up: in that time-span from that visit to the next one, my colleagues and I and my supervising physician, we'll review the literature some more and say, okay, maybe put in my documentation, you know, consider this at the next visit based off of this literature. Or if the patient has this symptom more so, then I'll put in my note, let's discuss again at the next visit; that way, we can educate the patient on this and that as well.

[IRRELEVANT MATERIAL OMITTED]

QUESTION: So it sounds like you're really, right in the exam room or around the time of the office visit, digging into what you can find on UpToDate, or you're looking at the literature to try to guide you. And it sounds like one of the things that's maybe motivating you to do that is the fact that you just don't see these people very often, right?

01: Right, yes, correct.

QUESTION: Okay, got it. We'll move on to the next question then. Can you describe any barriers that you find to incorporating research findings in HAE into your clinical practice?

01: The only barrier I would say is that the fact that we don't have a lot of these patients, we don't have a lot of pharmaceutical reps coming to us to talk about the acute treatments and the prophylactic treatments. And so, we're not always, kind of like you stated for the previous question, we don't always have the information ready at hand just because we don't come across them a lot. I would say that is the main barrier, is that because we don't have a lot, it's like a cycle: the pharmaceutical reps don't come to us, we're not constantly up-to-date with any latest findings until the patient comes, and then, the patient doesn't come back or the patient is stable, then less cases we have like those. So I feel like it's a repetitive cycle just because we don't get a lot of these patients.

QUESTION: Okay. So just the fact that this is a relatively rare disease means that you don't necessarily have that information right at your fingertips, and it's not like a condition I imagine you see all the time where you just know this stuff, right? You see five patients every day with probably asthma or whatever, right?

01: Right, yes.

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QUOTE

Commented [12]: Codes (5177-5278)
Expert opinion/Up To Date/Google/Medscape

Commented [13]: Codes (5727-5791)
Lack of information

Commented [14]: Codes (5929-6025)
Lack of information

Commented [15]: Codes (6102-6438)
QUOTE

QUESTION: Yes. And then, you said that you don't see pharma reps or other people dropping by to give you information, so that's motivating you guys to, I'm assuming you're doing like an internet search then using UpToDate or using another platform if you're looking for info?

01: That is correct, yes. We had, I think, one or two reps this past year, they stopped by, but that was only like one or two occasions. Other than that, yes, we do use the internet and UpToDate.

QUESTION: Yes, got it. Sometimes there are delays in introducing evidence-based practice into obviously day-to-day clinical practice, and why do you think that there has been some delays in introducing evidence-based practices into HAE care?

01: For my clinic or in general?

QUESTION: You can say whatever comes to your mind: your clinic, in general. We would love to hear your thoughts.

01: In my experience, I would say there is a delay just because it's just not as common as your typical asthma, eczema, allergies, urticaria with angioedema, we see more of that, but the hereditary angioedema, I can only imagine maybe the other allergy clinics in the area, in the city, I can only imagine that they don't have as many cases just like we don't have as many cases. So I would assume that they come across the same issue: there's a delay just because they don't have that many patients with the specific diagnosis.

QUESTION: Okay. What do you think could be done to overcome those delays either in your clinic or in practices in general?

01: I would say just prepare ahead of time. We subscribe to Medscape, PubMed, things like that, and so, whenever an article comes out with hereditary angioedema and it is something new, we do read up on it and we want to make sure we stay up-to-date. But I would say, let's say we have an off-day, slow day, some patients cancelled, we have time to do administrative work, do some literature review maybe on an off-day, say, hey, we haven't had a hereditary angioedema patient recently, maybe we should just read up on some literature just in case this patient, just so happens, comes in tomorrow perhaps, you know? Maybe on our off-days, we can do that ahead of time.

QUESTION: Okay. And I imagine you can probably, like most clinicians, you can probably look at your schedule ahead of time and kind of get a sense of what the next day is going to look like, or the next week?

01: Right, yes.

QUESTION: You'd be able to identify a particular patient and be able to say, oh, we should probably get prepared ahead of time to see that person. Okay.

01: Right, yes.

QUESTION: Is there anything that your practice does like do you guys have a formal journal club or a lunch-and-learn or anything of that sort where you might look at Medscape or look at an article together?

01: Not necessarily. It's just whenever the providers have a rather slower day, we catch up on some administrative stuff and review some literature. But again, because we mostly see asthma and eczema

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Lack of information

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QUOTE

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QUOTE

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Literature review
QUOTE

and allergies, we kind of focus on that as opposed to the angioedema. But we can definitely implement it in preparation, but we don't have like a journal club or anything like that.

QUESTION: Got it, okay. What's been your experience in identifying patients with HAE who would benefit from having long-term prophylaxis?

01: I would say of the two that we had last year, one of them was stabilized, didn't really have any more episodes. The other one, he had episodes, I would say every 4-5 months, and so, in our case, nothing to really bat an eye about, but we did talk to him about prophylaxis. At the time, because of his insurance, because of just his schedule, we weren't too concerned, all together, patient and provider, but we definitely kind of mentioned it to patients, to this one particular patient, but not a whole lot as far as pursuing it.

QUESTION: I see, okay. For that particular patient that you're recalling right now, it sounds like maybe insurance or cost was a potential barrier for that person?

01: Yes, yes, just doing regular follow-ups, cost of medication, he just had a history of having a very, very tough schedule and having issues at the pharmacy, at the specialty pharmacies, with his pharmaceutical benefits. And so, eventually, we were able to kind of stabilize him. He looked out for any newer symptoms, but he eventually just stabilized. But yes, I would say scheduling for regular follow-ups to monitor him, and cost as far as pharmaceuticals and the prophylactic treatment.

QUESTION: Okay. So this was a person then who was using some sort of an acute treatment when they would get an attack?

01: So he had an EpiPen just in case, but we didn't have any specific hereditary angioedema acute treatment, although that's what the rep came to us [phonetic] to talk about once we had this patient. We never prescribed it, so he didn't really have it just because his episodes were mild, and I wouldn't say really recurrent, just they would come every maybe four, five, maybe six months, honestly.

QUESTION: All right, interesting. So it sounds like you did talk about long-term prophylaxis with him, but you encountered some perceived barriers to going ahead with that; and you also assessed his situation and felt that it was mild and relatively stable. And clearly, patients have their own ideas about what is mild and stable, right? I mean—

01: Yes.

QUESTION: —that's one of the challenges I think that we face a lot [phonetic], right—

01: Yes, definitely.

QUESTION: —is for all diseases, is sort of trying to find out what works with that particular patient's point of view and their situation.

01: Right.

QUESTION: So how do you gather and assess information about the impact of HAE on a person's work, school, social, family life, kind of getting at quality of life issues, how do you guys assess quality of life and the impact that HAE is having on quality of life?

Commented [20]: Codes (10169-10233)
Few episodes/pref episodic tx

Commented [21]: Codes (10418-10491)
Insurance/Prior authorization
Pt time constraints

Commented [22]: Codes (10867-10886)
Cost

Commented [23]: Codes (10951-11044)
Pharmacy

01: I would say number one, we can see it with the amount of working [phonetic] visit or follow-up visits that they have to keep on taking time out of their day, so the more follow-up visits they have, it's typically because they have a flare-up. And so, that's one.

I would say number two, the amount of time they've had to take off from work or school, and just basically with our interaction with the patient, how much is this bothering them? Are they, just like you said, are they not really perceiving their symptoms as severe, they think it's mild so they just blow it off; or is it, it's really bothering them? We see that they're in distress, they come to us as a last resort, they're not crying but they're very emotional in the exam room when they're talking to us, we can kind of gauge emotionally how much is it bothering them. But then, we'll also ask them, hey, are you missing time off of work for this? Have you needed to visit the ER a lot? Are your friends and families concerned, are they worried about you because you're having so many episodes around them and they don't understand? Kind of all that put together.

QUESTION: Okay. Are you aware that there are some validated tools or questionnaires that can be used for assessing health-related quality of life impact for HAE?

01: I was not aware, no.

QUESTION: Okay. It sounds like you haven't used those in your practice at this point?

01: Correct.

QUESTION: Okay, got it. How do you engage patients in treatment decisions regarding long-term prophylaxis?

01: We basically, if they're appropriate for it, we bring it to their attention at the visit. We say, hey, you've had this many episodes, there is this prophylactic treatment, we can send it in, try to get it approved with your insurance, it would entail X, Y and Z; we understand that your schedule may or may not be busy; we want to bring it up to your attention; and essentially, all the providers and the patients, we try to have a healthy relationship with them. So we explain to them what our plan is, what the options are, and kind of get their input on it because we don't want to proceed with something if they're not comfortable with it. So we always want to hear their opinions on it.

QUESTION: Okay. What kinds of challenges have you encountered when you're trying to engage patients in that conversation or treatment decisions about long-term prophylaxis, what are the challenges and things that you've come up against?

01: I would say their understanding of what exactly is going on, so we can try to simplify the mechanism of action or the plan of care for the next six months or so and why we're doing it and how to prevent it. But a lot of times, we'll say that the patient doesn't really fully grasp it as far as the medical side of it, is one challenge. Obviously, the second challenge is the patient's own schedule conflict, work conflict, and financial conflict.

QUESTION: Okay. So when you're talking about schedule conflicts, then if you were to start long-term prophylaxis with a patient, you would need to see them more frequently just to follow up and see how they're doing with that new treatment, is that correct?

01: Yes, yes. If it's going to be a long-term treatment, we like to keep a close eye on patients just because we always want to make sure we're aware of any side effects that may have occurred that the patient may not have even realized.

Commented [24]: Codes (12780-12888)
Patient barriers

Commented [25]: Codes (13020-13084)
Patient barriers

Commented [26]: Codes (13215-13262)
Patient barriers

Commented [27]: Codes (14039-14059)
HRQOL self assessment instruments

Commented [28]: Codes (14853-14921)
Patient anxiety/concerns

Commented [29]: Codes (15234-15370)
Patient education

Commented [30]: Codes (15427-15533)
Patient education

Commented [31]: Codes (15965-16023)
Pt time constraints

QUESTION: Okay, all right. Just out of pure curiosity here, so say you were to start me on a subcutaneous long-term prophylaxis medication, how quickly after, would you actually give them their first dose in the office, I'm assuming?

01: Yes. Depending on insurance, either at an infusion center or at our office, yes, we would monitor them roughly about 30 minutes afterwards and your regular follow-up, and then just keep on going from there.

QUESTION: Okay. And then, would you see them, for example, say you start somebody, they get their first dose, you watch them for 30 minutes, no anaphylaxis, et cetera, no problems, then would you see them again in two weeks or a month or kind of roughly how, when would you next see them?

01: Typically, we'll see them in two- to four-week intervals just because again, we like to keep a close eye; afterwards, typically, maybe just once-a-month kind of deal. But usually, whenever it's a long-term treatment like subcutaneously, I would say two- to four-week intervals.

QUESTION: Two- to four-week intervals, okay, which is more often than you might see that person if they had not started the medication, is that correct?

01: Correct, yes.

QUESTION: Got it, okay. All right, so it really does have an impact then on scheduling for you guys, obviously, but then, maybe even more so for the patient if they've got work or other things that they need to obviously do besides go to medical appointments.

01: Right, right.

QUESTION: Right?

01: Yes.

QUESTION: Okay. Wow.

01: And so, like if a different office does it every-month, two-month, every-three-month follow-up, that's perfectly fine. It's just we like to be very watchful over our patients.

QUESTION: Okay. All right, interesting. And then, have you had to choose a medication for long-term prevention or prophylaxis for HAE in the past?

[IRRELEVANT MATERIAL OMITTED]

QUESTION: Have you had the opportunity to choose a long-term prophylaxis medication with a patient?

01: I have not, not in my clinic.

QUESTION: You have not, okay. But you have talked a little bit about some of the things that would go into making that decision, and that includes obviously what the patient thinks about it and what their lives, you know, you're very upfront, it sounds like, in telling them, well, this would be the follow-up schedule, this is what it would be, this is what it would involve, when you're talking with them?

Commented [32]: Codes (16439-16612)
Pt time constraints

Commented [33]: Codes (16921-16966)
Pt time constraints

01: Correct.

QUESTION: Okay. So shifting gears just a little bit, how did participation in the CME activity influence the way you think about translating evidence into clinical care for your patients with HAE?

01: I'll say it helped me a good bit. It kind of opened my mind a little bit: you know, maybe we should although we don't see as many patients like this as our asthma and allergy patients, and on an off-day, maybe we really should just be reviewing the literature in preparation in case this does happen so that way, we're not trying to find something very last-minute when the patient finally arrives.

QUESTION: Okay. Are there any changes that you would potentially make to your practice at this point as regards to HAE?

01: I would say I would bring it up to my supervising physician and the rest of my colleagues and kind of get their input on it. I don't see why we wouldn't try to get more literature on it like on our slow days, but I would definitely bring it up to them.

QUESTION: Okay, great. So clinical guidelines are one way that research gets translated into clinical practice, and what effect might HAE clinical guidelines have on your own practice?

01: Oh, yes, so we follow, we like to look at the guidelines and see what they say. Typically, we don't stray away too far from the guidelines no matter what the diagnosis is, but I would say 99% of the time, we are very closely in line with whatever the guidelines tell us.

QUESTION: And that would be for HAE in addition to other conditions that you guys treat in your practice?

01: Correct. And obviously, with the severity of a symptom, no matter what the diagnosis is, I mean, we'll maybe stray off from the guidelines a tad bit depending on how severe or not severe the patients are, but we typically try to stay pretty close to the guidelines.

QUESTION: Okay, got it. Do you know if the last time this came up, if you looked at the most recent guidelines for HAE?

01: Oh, I would say probably more than six months ago.

QUESTION: More than six months ago?

01: Yes.

QUESTION: Do you recall if you guys actually pulled guidelines or anything when you were, I mean, obviously, UpToDate usually is fairly guideline-based, right? Do you remember if you guys actually pulled any of the guideline papers?

01: I don't recall. I want to say no, but I can't recall 100%.

QUESTION: Okay, got it. Okay, that's great. Is there anything else that comes to mind while we're talking that you think would be good for me to know or for other docs to know about HAE?

01: Nothing in mind right now.

Commented [34]: Codes (18854-18855)
CME

Commented [35]: Codes (18855-19218)
CME
QUOTE

Commented [36]: Codes (19218-19219)
QUOTE

Commented [37]: Codes (19366-19470)
Collegiality

Commented [38]: Codes (20925-20967)
Guidelines

QUESTION: Okay. All right. Anything that came up during this interview that was surprising to you or challenging?

01: No.

QUESTION: Okay. All right, well, that's actually our last question, and we very much appreciate your taking the time out of your busy day to help us out.

01: Of course, of course, any time.

QUESTION: I am actually a pulmonologist by training, but I trained at a center that did a lot of allergy immunology, and I know just kind of how crazy things can get.

01: Yes, it's such a big world, yes.

QUESTION: All different ages, right?

01: Oh, yes.

QUESTION: You guys see adults, you see kids, you see everybody, right?

01: Yes, we do, yes.

QUESTION: Yes. And then you've got people wandering in for allergy injections and I don't know if you do food challenges, but allergy practices have a lot more going on than people often think.

01: Yes. It's not just for the shots, not just [phonetic] sniffles and the food allergies because like I tell my patients, in every body system, there is always some sort of allergy component; whether it's GI, lungs, ENT, there's always some sort of allergy component in that. We will hear from different specialists every now and then, they make the referrals to the allergy office, I was like, okay, we'll take a look at it, you know?

QUESTION: Yes, yes. There's a lot that ends up, a lot of patients end up seeing you whether they have allergy issues or not, right?

01: Yes.

QUESTION: All right. Well, very much appreciate your time.

[IRRELEVANT MATERIAL OMITTED]

[END 01 1.16.24.M4A]