CMEology

HAE – Hereditary Angioedema

Interview with “02”

January 29, 2024

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CMEology

Interview with 02 – Hereditary Angioedema

[START 02 1.29.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: First question: these follow a pretty logical sort of flow, but first question is what is your personal experience evaluating the HAE literature in terms of its implications for clinical practice?

02 As far as HAE literature goes, I've done maybe, other than like basic reading outside of an allergy handbook or something, I have maybe done one or two CME courses regarding this. And it's not something that I've had a lot of experience with clinically, so as far as its implication on my clinical practice, it hasn't had too much of an impact yet, other than keeping it as, and I don't know if this is the question or if you're just wondering what kind of literature I've encountered, but keeping it as like a differential certainly, but yes.

Commented [1]: Codes (632-673)
CME

QUESTION: Okay. Have you read papers, pulled any papers on HAE, for example?

02 I've read, like I have perused, I suppose, like when I've looked up papers just on like the National Institutes of Health or something if I was looking for an answer to a question that I had thought of maybe as I was doing a CME course, but yes, that's pretty much that.

QUESTION: Okay. When you're looking, for example, when you say NIH, do you mean you were like searching on PubMed?

02 Just honestly searching on Google and looking for more scholarly sources.

QUESTION: Okay, got it. If you're looking at Google or whatever for a scholarly paper, what is usually in your mind when you're doing that?

02 You mean what kind of, what am I looking for as far as like finding a reputable source or something?

QUESTION: Sure, absolutely. Or are you looking for a clinical review, or are you looking for a primary research clinical trial pub, or what is it that you find yourself searching for the most?

02 That's a good question. Because there hasn't been necessarily a particular case or a particular question, I guess, per se when I'm looking this up, I don't necessarily have a type of research or findings that I am looking for as it may benefit me from seeing something more clinical or anecdotal or even something that's more of like a meta analysis. But I haven't been very stringent in looking at my resources because of the fact that I haven't necessarily had a case to apply it to; it's been more so just looking for general information, I guess, if that makes sense.

QUESTION: Yes, absolutely. So when you're considering the implications of HAE research on clinical care, is there any particular format of research results that's more influential to you? So this could be something that you've done a search on, or maybe that you haven't, but for example, would you be looking for research that's presented as an abstract or a poster, or a live conference presentation? I don't know if your office has academic detailing so people who come in from a pharma company and present you with data, or if you prefer to look at research in UpToDate or a journal pub?

02 Oh, yes, that's a great question. I think certainly all of those different resources are beneficial for different reasons. But I think that in general, I tend to gravitate towards something that's maybe more visual or easy to present the information so that I don't have to spend quite so much time digging around for the information I'm looking for. So typically, something that's like an abstract, or I do find sometimes more of the live conferences or CME can be beneficial because they're kind of straight-to-the-point typically. And I haven't had the representatives come in and do any kind of education at our office, it's a smaller office, but I have had that experience with other, not for HAE but with other companies, and I have found that pretty educational and useful as well.

QUESTION: Okay, all right. So you have had reps come in for other disease states, for example?

02 Mm-hmm.

[IRRELEVANT MATERIAL OMITTED]

QUESTION: What factors are most important to you when you're interpreting the HAE literature and applying it to clinical care?

02 What do you mean by that?

QUESTION: So for example, are you constrained by time or constrained by your ability to interact with your colleagues around a particular topic? Anything that you find either helps you interpret the HAE literature, or maybe gets in the way of interpreting the literature and applying it to what you're doing clinically?

02 Yes, I think probably the main constraint is just time. Like I alluded to previously, when you have to read through literature and try to figure out what the outcome is, and having the time to research or read through the different research is probably one constraint.

Something that I have found helpful because I don't have a lot of experience with HAE clinically, is when the research does some kind of summary reminding me of important factors within, I mean, this goes for any disease state, but for HAE, reminding me of some of the key things that are important to know within HAE, like different terminology or different, you know, the C1 inhibitor, for example, just reminding me of what are things that are important to consider. So if it's clear, like maybe a clear demonstration or a reminder of what HAE is, and clinical findings and whatnot, that helps me to understand the research a little bit better as well, as far as [phonetic] treatments or diagnosis and things like that.

QUESTION: Okay, fantastic. Can you describe any barriers to incorporating research findings in HAE into your clinical practice? Sounds like you haven't had a lot of patients with HAE; that would be one barrier.

02 Yes, that's one barrier is we just really haven't necessarily seen it. We've considered it in our patients with angioedema but haven't really had, maybe one or two that I worked with a doctor on that we had suspected that. But I think another barrier, I guess one barrier, too, is taking the findings of the research as to which medication or treatment may be recommended either as like a treatment or prophylaxis; and trying to apply that to the patient I think is difficult when you have to keep in mind insurance and getting approved and fighting for coverage. And at the end of the day, the recommendation maybe for that patient is not always what we can get insurance to cover, so that's a barrier that we run into.

QUESTION: Yes, okay. And certainly one that we all run into with all disease states these days except the most basic things for which there are six [phonetic] drugs.

02 Exactly.

QUESTION: Yes, it can definitely be an issue. And it sounds like you have worked then with another provider who you guys have had a patient with angioedema, so you've had to think about HAE and the differential diagnosis of that. How do you see your office or your fellow providers? Are they helpful to you? If so, how are they helpful to you in learning about the condition and how to treat it?

02 Yes, it's me and one other provider. So I'm a PA and she's a doctor at this office that I'm at, and she has been very helpful. She has her own knowledge base. She's been doing this longer than I have, so it's kind of helping me to understand, for example, like what labs to order and how to interpret the results that we get, and considering different types of HAE and whatnot. So I've found her incredibly helpful at helping me to understand this.

QUESTION: Okay. What do you think about the introduction of evidence-based practices in HAE care? Some people have said that it just takes a long time, that there are delays in introducing evidence-based care into HAE. What do you think causes those delays, and how do you think they might be overcome?

02 I guess just time constraints, if it comes down to it, is just understanding what the evidence is and going through that and being able to incorporate that in the practice just takes extra time, I think.

QUESTION: Okay. So knowing the evidence, first of all, and then, being able to take steps in your own practice to use that evidence.

02 Mm-hmm.

QUESTION: Okay. Do you and the physician that you work with, do you have journal club or grand rounds or anything else that facilitates your education on topics like HAE?

02 No, we don't have anything formal like that. We get occasionally like once a month, we'll get the allergy, basically a magazine that has recommended articles or research that whoever the company is that sends us the magazine has decided is pertinent to review and whatnot. So sometimes, we'll review some articles that we see there, or if one of us goes to a conference and we come back and we will share or go over the information that we've learned from that, but we don't have anything formal that we do on a routine basis.

QUESTION: Okay. And have you gone to conferences where HAE has been a topic?

02 I have not attended anything where HAE has been a topic, but she has.

QUESTION: The physician who you collaborate with?

02 Yes, the physician who I collaborate with, yes, she has been to some of those.

QUESTION: All right. And is there anything that you would choose to do on your own as regards to HAE to sort of help you in your ability to use that information in patient care?

02 Yes, I would like to attend something. I find it really useful, I mentioned this earlier, like if some kind of representative came to our office, or if they held some sort of dinner or event or even like a conference where I could see a presentation regarding that, or even a virtual one, I think that would be really beneficial. I think reading sometimes for me, it can be hard when I don't have like a patient in front of me to apply right after I read, so sometimes, if I am just reading on my own, it can be difficult to remember that information months later if a patient arises unless I reference my notes. But I find that if I do more of like a conference where they can provide examples or a CME course or something where they can provide example patients, I find that useful.

QUESTION: Okay. Yes, it can be really hard with rare diseases to keep that information in the top of your head.

Commented [2]: Codes (7951-8142)
Clinician time constraints

02 Yes.

QUESTION: I mean, the common stuff, asthma, allergy, right, all this stuff that you see day in, day out, that's different, and you're right, it seems like we try to read and we try to have a broad base of knowledge, but it helps so much to be able to hang that knowledge around an actual person, or even like a hypothetical case in [unintelligible]—

02 Exactly.

QUESTION: —something like that, okay. So have you actually been able, either by yourself or with your physician colleague, have you been able to identify any patients in your practice that have HAE?

02 We haven't. I don't think, at least me personally, she might be a different story, she probably has, but me personally, we had a patient somewhat recently who we had suspected may have HAE, so we, actually this just happened quite recently, so we ordered labs and haven't seen the results of that yet. But we have kind of discussed next steps and maybe what to try if the labs come back consistent with that.

QUESTION: So it sounds like you're in the process of working up somebody then who may have it.

02 Yes.

QUESTION: Yes, okay. And you've talked a little bit about what the options would be for HAE treatment if that person actually ends up having it. They may not, right?

02 Right, yes.

QUESTION: Did you talk with the patient about any of that?

02 About treatment options or just in general?

QUESTION: Yes.

02 Yes, so we talked with the patient because of the way that she kind of presented with just the angioedema and just the timeline of things. We had thought that she might benefit from, we have a contact who can get us samples of Ruconest, so we talked to her about potentially trying a sample of Ruconest and see if there is any kind of clinical improvement if this were to happen again. So that's what we discussed with the patient.

Commented [3]: Codes (11971-12024)
Avail of samples

Commented [4]: Codes (12025-12221)
Avail of samples

QUESTION: Could you spell Ruconest for me? I'm sorry, I'm not familiar with the trade name.

02 Oh, yes, sure. When I do the CME or read, it's all the generic names and I have only ever [phonetic] really encountered the trade name. So Ruconest is R-u-c-o-n-e-s-t, and I'm not sure what the generic name is of that.

QUESTION: All right. That's not a medication though specifically for HAE, am I correct?

02 I believe that it is. I think it's only for HAE, yes.

QUESTION: Okay. I'll go and check; I'm double-check. But anyway, you actually gave her, found some samples for her to try in the meantime while you were kind of waiting for results of her workup?

Commented [5]: Codes (12782-12833)
Avail of samples

02 Yes.

QUESTION: Okay. Do you know when she's coming back to see you?

02 I imagine within the next, I believe within the next maybe two weeks or so.

QUESTION: Oh, okay. It'd be interesting to see what your results are.

02 So with this Ruconest, we are in contact with the drug rep, I guess, and he gave us a resource of a nurse who could help because this is an IV medication. So the nurse went, could go out with the sample at the time of an angioedema attack, I guess you could say, and we did get an email from them stating that I think over this past weekend, the nurse had gone to help her use one during an attack, and it seemed to provide relief of her symptoms. So I haven't talked to the patient myself, but we did get that feedback.

QUESTION: Interesting, okay. Well, it'll be very interesting to see what all your labs look like and how you guys can put everything together. Okay, so if you're maybe even thinking about the patient who you just saw, how do you gather and assess information about the potential impact of HAE or this angioedema event on the person, so on their work, school, social functioning, family life [unintelligible] et cetera?

02 Yes, and stop me if I'm not answering the question correctly, but factors that I think we discuss or keep in mind are what do they do for work; where are they on a day-to-day basis; what their age is; what their level of education is, with understanding what's going on, and how to use the treatments and access to ERs, for example, or access to us even in our office, things like that we keep in mind.

Commented [6]: Codes (14134-14476)
Patient anxiety/concerns

QUESTION: Okay. Are you aware of any validated tools or questionnaires that you can use to assess the impact of HAE on people's health-related quality of life?

02 No, I don't think so.

QUESTION: Okay. There are some questionnaires that people have developed. They're not long, but they are used to essentially help clinicians put a quantitative score, if you will, on how much of an impact HAE is having on a person. And those have been useful in a research setting, and people have also found those to be useful in clinical settings as well when they're trying to figure out what to do as far as therapy.

So how would you say that you engage patients in treatment decisions? And this particularly pertains to long-term prophylaxis or prevention when it comes to HAE, and I realize it sounds like you haven't had the opportunity to firmly diagnose and then treat someone with this disorder. But could you talk a little bit about how you guys in general, when you're thinking about preventive therapies for something like angioedema, how do you approach that with your patients?

02 Sure. So if we're talking more prophylactic, I've briefly discussed with the doctors some of the options for HAE in particular, and I know there are different routes of administration, different potential side effects, different frequencies of how often these are used, and just like you said with other disease states, too, there are different biologics. There are things that we can offer to patients, and discussing with the patient how often a treatment might be, or if an injection versus an oral tablet might be a better route, or if there are any potential contraindications or adverse reactions that could occur that might be more relevant to some patients than others, those are all things, I think, that we take into account when discussing treatment options with the patient. And insurance coverage, of course.

QUESTION: Of course, right? Exactly. Anything that you found in your experience that makes these conversations difficult when you're trying to, because they can be complex sometimes, but in your experience, what are the things that make those conversations about preventive therapy difficult?

02 I think probably the main thing is the level of education or just the level of understanding of the patient when it comes to this. Sometimes it takes maybe approaching the explanation or the options in different ways, or taking the time to answer questions if a patient is not understanding or isn't sure which route might work best for them. So maybe the patient's level of understanding and education, and also the time that it takes if the patient has a lot of questions or needs a lot of explanations, sometimes that can impact, too, how long it takes to work with a patient.

QUESTION: In your experience, anything that helps those conversations go more easily?

02 Yes. I can't really draw upon like a particular example, but if there is some kind of, well, I guess like handouts or some kind of something to simplify the information for the patient either visually or just with layman's terms, bullet points, sometimes that can be beneficial for the patient to better understand their options, I think.

QUESTION: Okay. Is that something that you would give to somebody before you have a conversation with them about treatment options? Or is it something you end up, because we all know how compressed everything gets, right?

02 Yes.

QUESTION: Or is something that you would end up kind of handing to them at the time that you're explaining things?

02 Yes, I think ideally, the way that it would work which sometimes is the case, is present options and give them things to read about and whatnot. But I find usually what happens is we discuss the options and we kind of go over everything, and if we decide to lean a certain way, then we give them something to take with them to read a little bit more about it.

QUESTION: Okay. It sounds like you have not yet had to choose medications for long-term prevention for HAE. But if you were to imagine, for example, that this gal you recently saw, her labs come back and she does have HAE, and you're standing out there in the hallway, right, with the chart, what are the things, what are the different factors that you imagine you would take into account? You're going to have to have a conversation and choose medications for HAE, for long-term prevention: what are the factors that you think are going to be important when you guys are making that decision?

02 I think some of the factors, I touched on a little bit previously, but understanding what's the age of the patient, for example: are they a pediatric case or an adult? What is the route of administration I think is something that I would take into account: is this a patient who is going to be able to give themselves an injection or is this someone who is going to remember to take a pill every day? Things like that, taking into account, and then if it's someone who has, I don't know necessarily the details offhand of the different medications and what may be contraindicated, but if they have some kind of reason why their scenario with their medical history might not be a good idea to use a certain medication, those are all things I would take into account when choosing a treatment for them.

QUESTION: Okay. You had mentioned insurance obviously earlier.

02 Oh, yes.

Commented [7]: Codes (16696-16828)
Patient education

QUESTION: That could be something that could potentially play a role, is you may have the ideal medication in mind, right?

02 Yes.

QUESTION: Boy, have I had done this a number of times, right?

02 Yes.

QUESTION: You talk to somebody and you get them to agree, and then, you find out four days later that their insurance doesn't want to cover it, and yes, it can be tough, I think, for both the patients and the providers—

02 Absolutely, yes.

QUESTION: —in that regard. Okay. All right, we're getting to the end here. I have a couple more questions for you, three as a matter of fact. So next question is how did participation in the CME activity that you did, how did that influence the way that you think about translating evidence into clinical care for HAE?

02 I'm trying to think because that was like a few months ago I did it, and I think I did a couple, but I believe one of the points that kind of stuck with me after that was keeping in mind continuity of care, I guess, for HAE, and so, making sure that no matter where their location is or as they transition from a kid into an adult, that they have continuity of care for the HAE. So even though I haven't necessarily been able to implement that in practice, it's something that I have kept in mind that I didn't necessarily consider prior to that activity.

QUESTION: Okay. Anything else that came up that you felt might change the way that you approach a patient with HAE or someone that you think might have the condition?

02 Sure. Again, I believe, although I can't entirely recall, that it did talk about the diagnosis or various treatment options of the HAE. And so, I think that kind of sparked in my mind just understanding the different options and how it might be different for different patients as far as treatment goes. But I don't know details off the top my head.

QUESTION: Okay. So just knowing that there are different treatment options?

02 Sure, yes.

QUESTION: For HAE, okay. Next question: clinical guidelines can be one way that research is translated into clinical practice, and what effect might HAE clinical guidelines have on your practice?

02 What do you mean by that, like clinical guidelines for what?

QUESTION: So different allergy-related or asthma-related societies, for example, they might put together a formal paper in the literature that is basically a set of guidelines for the diagnosis or treatment of a condition [phonetic].

02 Sure. I think I find clinical guidelines pretty helpful to base the diagnosis or help guide as we go through the diagnosis and the treatment options. Patients don't always follow the exact guidelines and everything is a little different, but I find them useful.

QUESTION: Okay. And have you had the opportunity to look at guidelines that are related to HAE?

02 Other than with this most recent patient, I think the doctor had kind of guided me through as far as ordering the labwork and whatnot, the doctor I work with, but I haven't looked at any particular guidelines myself.

QUESTION: Okay. Were you aware if your physician colleague actually pulled guidelines out and looked at those as you guys were making your decisions about [unintelligible]?

02 I don't think that she did. I don't think she did for this patient because she seemed knowledgeable as to what the guidelines were without having to look that up.

QUESTION: Okay, got it. Last question: is there anything that comes to mind while you and I are talking, and we very much appreciate your time, anything that comes to mind that you think would be good for me to know or for other people in the field to know?

02 Nothing that's really come to mind right now that I can think of to share.

QUESTION: Okay. Anything that surprised you about reflecting on HAE or HAE care for your patients?

02 I don't know if this is the right answer, but I guess I was kind of surprised that there were so many different treatment options, and different forms of how those treatment options or different mechanisms of action for those different treatment options. But then also, just from talking with my physician colleague, how difficult it can be, as mentioned before, for those treatment options to be accessible to patients, so insurance-wise, basically, and coverage-wise and whatnot. So it kind of surprised me, although it probably shouldn't have, that sometimes access to care can be delayed or more difficult to obtain just because of, simply because of insurance.

QUESTION: Yes, it's clearly an ongoing challenge for all of us in the U.S. I mean, people [unintelligible] have their own challenges, which is that the number of drugs they can give is very limited sometimes, right?

02 Right.

QUESTION: And so, they don't necessarily have to go through approval process issues, but they just have a very limited pharmacy in some ways when it comes to especially kind of rare or complex diseases.

Commented [8]: Codes (24732-24849)
Pharmacy

02 Right.

QUESTION: And that can be difficult and challenging, of course, in its own way.

[IRRELEVANT MATERIAL OMITTED]

[END 02 1.29.24.M4A]