CMEology

HAE – Hereditary Angioedema

Interview with “03”

February 9, 2024

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CMEology

Interview with 03 – Hereditary Angioedema

[START 03 2.9.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: Today's interview is about HAE, so hereditary angioedema. The first question is: what is your personal experience evaluating the literature on HAE and its implications for clinical practice?

03: I think overall, I've had a good experience. I think there are a lot of resources out there that clearly define what symptoms, signs, lab results we need to look for. That way, we can correctly diagnose these patients and find them, and especially with angioedema, there are a lot of patients that can come in as a referral for angioedema, but we need to be able to differentiate between, is this being triggered by an allergy, is it acquired or hereditary angioedema? So I do feel like there is good data out there that you can follow good guidelines.

QUESTION: What are you looking for when you look at all those different resources? What are you looking for as you're seeing these patients and having to answer these questions in your practice?

03: Usually, what I'm looking for is up-to-date things, so things that are recent; that way, I can kind of just keep myself, refresh my memory. And so, I'm usually looking at articles, journals. I tend to look through a lot of data with the American Academy of Allergy, Asthma, and Immunology and see what information that they have that seems to be more current and recent. That way, I'm able to refresh my memory when I do have patients coming in with disease symptoms.

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Literature review

Commented [2]: Codes (1500-1552)
Guidelines

QUESTION: You mentioned the American Academy of Allergy, Asthma, and Immunology. Is that something that you would look at, you would go to their website, for example?

03: I usually will go through their website. I use the computer a lot. I use UpToDate a lot as well, and I usually will look through articles that they've published that I can find online.

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Expert opinion/Up To Date/Google/Medscape

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Expert opinion/Up To Date/Google/Medscape
Expert opinion/Up To Date/Google/Medscape

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Expert opinion/Up To Date/Google/Medscape

QUESTION: Okay, so you're looking for published articles. Are you using PubMed then to find those?

03: Sometimes I use, yes, PubMed or just really the internet.

QUESTION: All right. Do you have access to a medical library where you can get articles that are behind a pay wall?

03: No, unfortunately no. I do have a paid subscription with the American Academy of Allergy, Asthma, and Immunology, so they'll send me things in the mail, but it's not very often, unfortunately [unintelligible].

QUESTION: The paid subscription with Quad AI [phonetic], I'm just not familiar with that. Can you tell me a little more about that?

03: It's something that I believe my job subscribed us for, and so, every now and then, they will send me magazines. Well, it is a magazine, it's *Allergy and Asthma Proceedings*, and so, they send me things that will usually come with different topics, guideline articles as well.

Commented [6]: Codes (2914-3007)
Guidelines

QUESTION: Is that magazine online or is it something that you receive in print?

03: It's received in print.

QUESTION: In print, okay, interesting, all right.

03: Yes.

QUESTION: I'm vaguely familiar with that publication. I've seen it before. And obviously, Quad AI is a very reputable organization. So when you're looking at the literature, what kinds of questions do you find yourself most often asking?

03: When I'm looking through articles, I think it's probably how to classify these patients, how to diagnose them, and then treatment recommendations.

Commented [7]: Codes (3482-3513)
Testing

QUESTION: Okay. 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 for example, actual journal publication versus an abstract or a poster that's been presented at a conference: is there any particular format that you tend to favor when you're looking for information?

03: I don't think so. I think what I do tend to [inaudible] something that's going to be maybe easy to read and go through. But I think I tend to favor more if there's maybe like an article or abstract table; I think I'm kind of a visual learner. I do have a binder that I keep in my office, so anything that I find like, oh, this can be useful, or maybe a quick reference, I will print it out and then have it in my binder where I can refer back to, and different things like that.

Commented [8]: Codes (4015-4079)
Evaluating new data

QUESTION: Okay. You mentioned also that you are able to use UpToDate. Is that something that your practice has a subscription to?

03: Yes, ma'am.

QUESTION: Yes? Okay, because usually it's pretty expensive, so most people don't have their own.

03: It is.

QUESTION: Yes, but your practice has the subscription to UpToDate.

03: Yes.

QUESTION: Okay, got it. When you're looking at and interpreting the HAE literature, and you're applying it to clinical care, what are the factors that are most important to you in that process? So for example, are you looking at aspects of your skills or knowledge base that you want to improve? Are you thinking about interactions with colleagues?

03: I think more so how I can improve my skills and better help patients.

Commented [9]: Codes (5153-5181)
Improve skills

QUESTION: Okay. What types of interactions would you have maybe with a colleague about HAE?

03: Well, at our workplace, we actually have a chat room where we can touch base with different providers. And so, if we have a patient maybe with HAE come in, maybe we are questioning the labs or treatment, we can go into the chat room and touch base, and then that way, we can get different opinions, recommendations. And so, I feel like that helps.

Commented [10]: Codes (5342-5408)
Chat room

QUESTION: And the providers that you're interacting with in the chat room, are those people in your practice or your network or your hospital?

03: Yes.

QUESTION: How does that work?

03: Yes. They're in the practice.

QUESTION: They're in the practice, okay.

03: Yes.

QUESTION: Are you working in a subspecialty practice, allergy-immunology type practice then?

03: Yes, ma'am.

QUESTION: Okay. And you guys see both adults and kids?

03: Yes.

QUESTION: Okay. Are you able to see patients and prescribe independently, or how does that work in your practice?

03: I am, but I do have a supervising physician that does sign off on all of my charts.

QUESTION: I see, okay. Would that person be somebody who you might interact with when you're looking at the HAE literature?

03: Yes and no. I feel like my supervising physician specializes more in ENT and sinuses, and so, when it comes to HAE, I will interact more so with maybe some of the physicians that have more experience with allergies and immunology.

Commented [11]: Codes (6560-6675)
Collegiality

QUESTION: Okay. Yes, it totally makes sense that you would go to someone in the practice who has that maybe as more of an area of interest, or maybe an area of just even experience who's seen patients with that condition. Okay, next question: can you describe any barriers to incorporating research findings in HAE into clinical practice that you've experienced?

03: Well, I think [redacted] and I think sometimes they are maybe dead-set in practicing the way that they have always practiced. And so, I think anytime that maybe there are new recommendations or changes, they might be a little bit hesitant. That might be the only barrier that I maybe see.

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Clinical inertia

QUESTION: So maybe in working with older clinicians, there may be some hesitation then in incorporating some of the new recommendations or research findings?

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Clinical inertia

03: Yes.

QUESTION: Okay. Do you encounter any barriers to incorporating research findings with HAE when it comes to patients?

03: I think because [redacted] I don't think that we've really, I've really experienced that, no.

QUESTION: Okay. Have you had patients, for example, push back on recommendations regarding their HAE care?

03: No, but I also don't know it because the patients that we currently treated for that condition are maybe on the younger side. So I think that yes, they are interested in the newer treatment recommendations. We had one patient that had switched over to our practice because they were being treated by somebody, and they had watched maybe something or seen something on TV about the newer treatment recommendations with the prophylactic treatment and were interested in maybe trying that out versus more of the on-demand treatment, you know, trying to prevent it versus waiting for something to happen. So no, I haven't really had any pushback [inaudible] encountered that as of yet.

QUESTION: Okay. So it sounds like you've had patients come in and talk to you about perhaps a newer treatment option.

03: Mm-hmm.

QUESTION: And perhaps some of your older physician colleagues haven't necessarily seen some of those new recommendations or aren't as aware—

03: Right.

QUESTION: —of what those new options might be. Any barriers related to insurance or institutional issues? Sometimes people who are on IV therapy obviously have to interact with an infusion center. Any issues, barriers that you've encountered with insurance or institutions?

03: I want to say that our practice is very lucky because we have a whole department that handles all of that. And so, our job more is just on finding the patients, making sure documentation and labs and everything have been done to try to make that process easier.

QUESTION: Okay. So you're not as involved upfront with the insurance, handling the insurance or questions about insurance?

03: No. Luckily no.

QUESTION: Luckily no: oh yes, that is so much the case, right? Well, that's great.

03: Yes.

QUESTION: It sounds like you have a little bit more freedom and then you can talk to patients more and—

03: Right.

QUESTION: —diagnose and treat them, which is great.

03: Yes.

QUESTION: So why do you think that the introduction of evidence-based practices, so maybe some of those newer practices and approaches that we've been talking about, why do you think those are delayed when it comes to HAE care?

03: Well, I think some providers might see it, you know, if they've been prescribing certain medications that have been working, they might be kind of like, well, why start doing something different? And I think maybe there is also, especially being like an advanced provider, if you're under the supervision of a

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QUOTE

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QUOTE

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Clinical inertia
QUOTE

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QUOTE

physician that has been doing it that way, you might just adapt those practices just because you're being told, or it's more by going off of their experience, almost like an experience-based knowledge versus, hey, let me see UpToDate, find out what is evidence-based, what's changed, what's more recent. And I think anytime that new things come out, there is a little bit of hesitancy or fear just with the unknown, so it's kind of just about jumping in and trying something different, especially if it's going to improve the quality of life of patients.

QUESTION: Okay. Is there anything that you can do personally to overcome some of those barriers?

03: I think it's going to be really probably just doing a lot of research, reading, asking questions, and attending maybe classes, doing the continuing education hours, but really trying to, instead of just getting the certificate at the end, really trying to focus on, okay, well, what have I learned and what can I really use to try to improve things?

QUESTION: So it sounds like you've taken advantage then of CE or online CME-type courses?

03: Yes.

QUESTION: Do you ever go to in-person conferences or anything where something like HAE would be discussed?

03: I try to every couple of years to attend something in practice [phonetic]. We do have our own annual provider meeting with our practice where we're able to choose from certain topics that maybe we are not as comfortable with treating. And then, they will hold classes and extra education that we can do some type of hands-on, but we've discussed HAE there.

QUESTION: You have, okay.

03: Yes.

QUESTION: Okay. Just out of curiosity, how many providers including APPs do you guys have in your practice?

03: Oh, gosh. [redacted], but it is a good amount.

QUESTION: Okay, wow. In the office that you work in, just out of curiosity, how many people are in there that are providers, so APPs plus MDs?

03: [redacted].

QUESTION: Okay. So you guys have got a pretty, if you've got patients coming in and out, it's a pretty busy place it sounds like.

03: Yes.

QUESTION: Okay. Next question: what has been your experience identifying patients with HAE who would benefit from long-term prophylaxis?

03: It's very uncommon, so I've only been able to diagnose one. The other patient had actually come from another practice looking for different treatment options. I think what I've struggled more with is

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Expert opinion/Up To Date/Google/Medscape

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QUOTE

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QUOTE

Commented [21]: Codes (12716-12776)
Few episodes/pref episodic tx

when they're having angioedema and they haven't started any new medications and the blood work is all normal, so it almost [inaudible] the question comes with, is it a mutation or what is going on?

QUESTION: Okay. So it sounds like you don't see a lot, I mean, this makes sense, right, it's a rare condition, and some of the challenges, it sounds like, have been when they have had an episode of angioedema but you're looking at them now and their blood work looks normal?

03: Blood work looks normal; it's angioedema without urticaria and no itching. I [redacted]

QUESTION: It sounds [phonetic] like you've had a situation where maybe the blood work did not support the diagnosis of HAE.

03: Right.

QUESTION: In a classic way.

03: Yes. There is idiopathic, but I think you kind of want the blood work to show something; that way, you feel more comfortable prescribing medication.

QUESTION: Of course, right. So it sounds like you're relying quite a bit then on your laboratory workup to identify patients who have HAE.

03: Mm-hmm.

QUESTION: And then, you occasionally will find someone, like you were saying, who maybe has a classic angioedema without urticaria, but their blood work doesn't support that, and then, you're kind of, I mean, if they have something that's easily identifiable like a cancer, well, then that can be treated. But there are other times where it's just more ambiguous and you don't know whether to start something—

03: Right.

QUESTION: —or not, yes, and that can be really—

03: Yes.

QUESTION: —really, really challenging because obviously, starting new meds is a significant step for you guys and for the patient as well.

03: Right.

QUESTION: Next question: how do you gather and assess information about the impact of HAE on a patient's work, school, social, family life?

03: Well, that was one of the important, I think, things that I had learned with the CME that I had done was that we currently, there has been no recommendation really on maybe having patients fill out any type of quality of life questionnaire for patients. And so, I did find that that might be helpful and something that we might want to start implementing.

Commented [22]: Codes (14969-15166)
HRQOL self assessment instruments

QUESTION: Okay. If you were going to do that, would you know where to go to find that questionnaire instrument?

03: I had looked at some. I know that there is one specifically for HAE, and then, I had found another one that was the H80 [phonetic] quality of life that goes over asking questions about functioning, and it's like fatigue, mood, nutrition, and I think it was, there was another area that it asked about, like being embarrassed, fearful, anything like that.

QUESTION: So it sounds like something that you might consider then using in your own practice would be sort of an assessment of quality of life.

03: Yes.

QUESTION: Like a validated tool of some sort, okay.

03: Mm-hmm.

QUESTION: But you haven't been able to do that yet, haven't found an opportunity to do that quite yet?

03: Well, we have, when patients come in for a follow-up, I had brought it up as a tool that we have printed out, so it's something that we were going to start doing.

QUESTION: Oh, okay.

03: Having the patient fill out just to keep track of, yes, ma'am.

QUESTION: Okay. So it sounds like you actually have printed it out and you plan to actually start using it?

03: Yes.

QUESTION: Okay. Can you tell me the name of the specific instrument or questionnaire again that you've printed out that you're going to use?

03: Let me see [phonetic]. I do have it saved on my desktop. It's Angioedema Quality of Life Questionnaire.

QUESTION: Okay. And is that one that you found out about specifically from the CME activity?

03: I don't know if this specific one, but they did go over quality of life, assessing that while treating patients and kind of going through that, and since it wasn't something that we were doing, I thought, well, especially hearing the stories of the two patients and what was going on in their personal life and how it impacted their life, I thought, well, it's not something that we really maybe addressed too much in the visit. And so, I thought that that was a better way of maybe being able to identify any depression or anxiety or fears or maybe something that the patient just wasn't comfortable, maybe offering reassurance and finding areas that we could maybe help during the follow-up.

QUESTION: Okay. So being able to use that instrument then to just be able to dig a little deeper into how the condition is affecting somebody's life?

03: Yes [phonetic].

QUESTION: And yes, I agree, patients aren't always, I mean, we think we're doing a fantastic job interviewing them, but they often don't tell us, they can't tell us, right?

03: Yes.

QUESTION: Time, other things prevent them from telling us—

03: Yes.

QUESTION: —how a condition might affect them. So it sounds like you think that the questionnaire would be useful in that regard.

03: Yes.

QUESTION: Next question: how do you engage patients in treatment decision-making when it comes to long-term prevention or reduction of HAE attacks? So we're really talking long-term recurrences.

03: Right. I think as a provider, I always tell patients that it's my job to go over their options with them and then for us to make the decision on what they think would be best. We did have a patient that was having quite recurrent attacks and it was really affecting work, personal life, all of that. And so, when we discussed prophylactic treatment options, he jumped onboard right away.

QUESTION: So that person was very receptive, it sounds like—

03: Yes.

QUESTION: —to doing a long-term prophylaxis type treatment.

03: Mm-hmm.

QUESTION: Okay. Just out of curiosity, what type of treatment did that patient decide to opt for?

03: Haegarda.

QUESTION: Okay.

03: It's the C1 inhibitor.

QUESTION: Is that the sub-Q?

03: Yes.

QUESTION: Injection? Okay. Some people get IV infusions, but that's become less common. But it was the sub-Q administered.

03: Yes.

QUESTION: And was that patient going to self-administer that?

03: [redacted] that they were able to do at home.

QUESTION: I see, okay. In your practice, do you guys give them their first sub-Q injection?

03: Yes.

QUESTION: In the clinic then and monitor them?

03: Yes, we do.

QUESTION: Okay. Most allergy clinics are set up pretty well for watching people.

03: Yes.

QUESTION: Right?

03: Exactly.

QUESTION: If you're doing allergy injections and—

03: Yes.

QUESTION: —food challenges, right, so you're familiar [phonetic] with that kind of thing.

03: Oh, yes.

QUESTION: All right. So it sounds like that person decided to go ahead and go on a prophylactic therapy. Have you had the opportunity to discuss long-term prevention or prophylaxis with any of your other patients?

03: I think that's the big, that's the one that really sticks out with me.

QUESTION: Okay.

03: Yes, not so much with any other patient. I think with him, that's the one that really sticks out.

QUESTION: By any chance, was that the person who came from a different practice—

03: Yes.

QUESTION: —because they were interested in some of the newer options?

03: Mm-hmm.

QUESTION: Okay.

03: Yes. And I think maybe with his wife being in the medical field, she was the one that was like, hey, there are other treatment options out there; maybe we can try a different practice.

QUESTION: And prior to that time, was that person just relying on an on-demand treatment?

03: Yes.

QUESTION: Okay.

03: And if my memory serves me well, I think it might have been like an androgen. It was something that he wasn't tolerating. Something was going on.

QUESTION: Okay.

03: Or that was what was recommended after he was diagnosed.

QUESTION: I see, okay. And he wasn't satisfied obviously with that.

03: No.

QUESTION: And I think current treatment guidelines right now would probably put androgen therapy lower than some of the other long-term prophylaxis precisely for that reason, because of the difficulty tolerating a hormone treatment.

03: Right.

QUESTION: It can be tough for people. How do you choose medications for long-term prevention or a reduction of HAE attacks? How are you kind of prioritizing those things in your mind when you're thinking about it?

03: I think a lot of it is based off of what the patient is reporting, their history and what would work best for them in safety, preventing anything, a severe reaction where they might end up in the hospital.

QUESTION: Okay. So those factors might push you in one direction or another when it comes to differentiating between—

03: Mm-hmm. How frequently are they having their reactions. For that gentleman, he was having them quite frequently, so I remember with him, kind of just preventing them sounded like a better fit.

QUESTION: Okay. So it sounds like you're also taking into account patient preference—

03: Yes.

QUESTION: —as well when you're making a treatment decision about long-term prophylaxis. Okay. We're coming to the end here.

03: [Unintelligible].

QUESTION: We just have three more questions. How did participating in the CME activity influence the way that you think about translating evidence into clinical care when it comes to HAE?

03: Well, like I was mentioning with the quality of life questionnaire, that was something that when you're going through the CME, going through the information and recommendations, and then, when you're able to identify something that isn't being done in your practice that might be beneficial, then you can go ahead and start researching, looking into things, and then finding a way to implement that.

QUESTION: Okay. Are you aware of whether anyone else in your practice, your other APP colleagues or the MDs, do you know if any of them plan to start using the quality of life questionnaire for HAE?

03: Everyone, when I brought it up here at our local practice, it was something that they were open to and thought it was a good idea.

QUESTION: Okay. Is there anything that your practice has done to make that easier for you guys? So for example, it's very common for allergy-immunology practices to have an asthma action plan printed off and sitting in the room somewhere, right?

03: Right.

QUESTION: Are there other forms or things that you guys would have in the room? Would you consider or have plans to actually just put forms in the room so that they're right there when you're seeing the patient?

03: Typically, we don't have anything in the room. But I mean, that would probably be a good idea to have maybe when a patient comes in with that as a diagnosis, maybe like a packet that can already be ready to go.

QUESTION: So you're not scrambling around.

03: Exactly, yes.

QUESTION: I do know very well what that's like. Unfortunately, it's all clinicians do, right?

03: Yes.

QUESTION: You're rushed [phonetic] in time and you need to have something and you don't want to take the time to go find it, print it, bring it into the room—

03: Exactly.

QUESTION: —[unintelligible] obligated, okay.

03: Yes.

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

03: Hmm. Can you repeat the question?

QUESTION: Sure. Clinical guidelines can be one way that research gets translated into clinical practice, and what effect might HAE clinical guidelines have on your practice?

03: I think it's going to be how the recent guidelines, how we're going to go about treating patients and maybe when going over treatment guidelines, how we're going to be presenting those options to patients, and then also, during the workup, if there are any changes, anything else that we should be ordering to try to diagnose the patients.

QUESTION: Okay. Are you aware of HAE clinical guidelines, and do you use anything like that currently in your practice or maybe have that in your binder, for example?

03: I have a table and I'm not really sure if I even have the complete article, but it was the U.S. HAE, a Medical Advisory Board 2020 Guidelines for Management of Hereditary Angioedema. So they did have a table that I did put aside that goes through the classification of HAE, diagnosis, the different on-demand treatments, what would be the prophylactic treatment, and then, it had additional considerations for children, also management plans. And so, I held onto that because I thought it would just be a good thing to have. Yes, to be able to refer back to.

QUESTION: Okay. Last question: is there anything else that comes to mind while we're talking today that you think would be good for me to know?

03: I don't think so.

QUESTION: Okay. Well, I very much appreciate your time today and your dedication in completing the CME activity, and then volunteering to speak with me about HAE and some of the factors that affect you and your practice, very much. Please reach out to us if you have any questions. Please reach out to [redacted]
Otherwise, this concludes the call.

[IRRELEVANT MATERIAL OMITTED]

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