CMEology

HAE – Hereditary Angioedema

Interview with “06”

June 21, 2024

Contents

TOC \o "1-3" \h \z \u Interview with 06 – Hereditary Angioedema PAGEREF _Toc170117956 \h 1

CMEology

Interview with 06 – Hereditary Angioedema

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QUESTION: First, what is your personal experience evaluating the HAE literature in terms of its implications for clinical practice?

06: Well, I think as far as the literature, I don't really review anything on a regular basis. I would say that unless there is an update that I receive from the College or Academy, or something, a practice parameter update, to be honest with you, I'm not actively reviewing guidelines or treatment decisions.

QUESTION: Okay. If you do interface with the literature, what tends to be, how do you usually get there? In other words, is it an email that you might receive from somebody, or do you use UpToDate in your practice or some other tool that directs you to the literature?

06: Yes. We do have, people do have UpToDate in our practice. Like I said, I do try to stick with more of like the Academy or the College's guidelines, or really the practice parameters, and as far as updates with those or how I receive it, I am a member, so I do get some sort of newsletter from the College and they do have a sort of summarized review of literature that they have extracted from annals. And so, periodically, I do try to read that; actually once a month, I look, just kind of peruse through. But I don't see that much for HAE, to be honest.

QUESTION: Yes, of course. It's a relatively rare condition, right? So things tend not to pop up that much maybe compared to something like asthma or—

06: Right.

QUESTION: —well, especially asthma these days, right?

06: Yes.

QUESTION: Not so much allergy. Okay, 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 for you? So for example, formats might be an abstract; poster; live conference presentation; academic detailing; UpToDate or some other similar tool; or journal publications: is there a format that tends to be more influential for you when it comes to translating research into clinical care?

06: Yes. I think having a poster that is in PDF form, or even its abstract of whatever clinical data that is being reported. Whether that's published by the sponsoring pharmaceutical company or otherwise is probably the most easily accessible for me.

QUESTION: It sounds like you are a member of at least one national professional organization. Do you have a chance to get to conferences?

06: Yes. So I did attend the AAAAI in February, and I actually did get a chance to go do some poster sessions and also on the topic of HAE as I have patients with HAE; and I'm kind of following drugs, various drugs in development that are different, novel.

QUESTION: What factors are most important to you when you're interpreting the HAE literature and how to apply it in clinical care? So for example, are interactions with colleagues most important to you; or using particular skills that you might have, data analysis, other kinds of skills: what are the factors that are most important when you're trying to figure out how to translate research into clinical care?

06: Well, I think if I ever have questions about a clinical trial, I actually like to go to the Medical Science Liaisons for companies that are making the product, if possible. I find them to be very helpful in

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Expert opinion/Up To Date/Google/Medscape

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Prof society updates or tests

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Pharma rep detailing/MLs

extracting whatever, so taking the question that I might have and looking at the literature and being able to kind of summarize it or whatever. So that's usually the most frequently used resource that I have (Overlap).

QUESTION: Do you have access to grand rounds or any other institutional kinds of arenas for answering questions like that?

06: Well, I'm part of a private practice, so we're not really, you know, currently no. Perhaps that changes with [phonetic] a potential hostile affiliation, but even then, no.

QUESTION: Yes, okay. How big is your practice? How many allergy-immunology folks do you have in there?

06: So we have, I believe, [redacted], yes.

QUESTION: How about interactions with colleagues when it comes to something like HAE?

06: Yes, I mean, I definitely chat with my colleagues, my physician colleagues, not just within my practice but friends of mine, allergy friends. So I think if I have a clinical question, management question, then I certainly utilize that.

QUESTION: Okay. Moving on, can you describe any barriers to incorporating research findings in HAE into clinical practice that you've encountered?

06: No.

QUESTION: Okay. Some of the barriers that people find are patient-related issues, healthcare provider-related barriers, practice-related barriers, or institutional barriers. Has there been any problem from your perspective in terms of applying what's the latest evidence to clinical practice?

06: Honestly, no.

QUESTION: Okay. Some people have mentioned that they've had issues with insurance approvals. That varies a lot, honestly, by practice, but has that been a barrier for you that you've found?

06: It wouldn't be any more of a barrier than like any other medication, you know? So it doesn't distinguish itself. If that's a problem, then prescribing any medicine, unfortunately, in today's day and age where lack-of-care support is a problem, so no.

QUESTION: Okay. I assume you are probably prescribing a variety of asthma biologicals at this point.

06: Yes.

QUESTION: And of course, you have to have approval for all of those as well. So do you have someone in your practice who kind of helps with insurance approvals?

06: Yes. So we have a [redacted]

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Collegiality

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Insurance/Prior authorization

QUESTION: What do you think about the introduction of evidence-based practices into HAE? Sometimes there is a delay between publication of research results and incorporation into practice. Anything that you feel causes those kinds of delays?

06: I mean, nothing is coming to mind except just time and patient volume and this being a rare disease, so perhaps that's the only thing I can think of.

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Lack of information

QUESTION: So just not seeing that many patients necessarily with the condition.

06: Right.

QUESTION: Just out of curiosity, if you were to estimate how many people you have in your panel right now with HAE, can you give me an estimate of how many people you might have?

06: Yes. I would say a max of ten. And I say max because maybe a couple have, you know, maybe a little bit less because a couple might not, they have been lost to follow-up, unfortunately.

QUESTION: Okay. Are most of these people people that you have diagnosed yourself or did they come to you with the specific diagnosis of HAE?

06: About half and half, so half were already diagnosed and there are allergists who either retired or perhaps changed practices, et cetera, went on leave; and then, the other half are patients that I myself have diagnosed. But in the patients who I have acquired from one way or the other, I still have experience, of course, reauthorizing meds or having conversations about keeping them on a med or switching, so yes.

QUESTION: Yes, okay. What's been your experience identifying patients who have HAE who would benefit from long-term prophylaxis?

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06: Well, all of my patients, I have on long-term prophylaxis, so 100% of my patients are on both LTP and acute on-demand therapy. It's always been my approach, and I probably am more conservative than others, but I don't want to put them at risk for having a potentially life-threatening laryngeal attack. So I put 100% of my patients on some kind of prophy. And now, with there being oral options and less-frequent dosing for sub-Q, I don't get any pushback from patients, either.

QUESTION: So you don't have people say, well, I'm doing just fine with my on-demand therapy, and I really don't need to be taking something for long-term prophylaxis? Or maybe you do encounter that. Is there a way that you work with patients who are somewhat reluctant to go on a long-term agent?

06: You know, to be honest with you, for this condition, they're never reluctant, and the five that I have diagnosed myself are like, they're terrified of having another attack.

QUESTION: Oh, no. Yes.

06: So it could be that I have a very, I don't know what the word is, faithful or dedicated population, but they follow through and there's not that pushback, I think because they don't ever want to experience this again. So I haven't had that issue, and like I said, I have a lot of patients on things like Takhzyro, which is, if you're okay after six months of being attack-free, we can talk about going from every 2- to 4-week dosing.

QUESTION: Okay. How do you gather and assess information about the impact of HAE on patient work, school, social and family life?

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HRQOL self assessment instruments

06: So I don't use any kind of standardized or validated assessment tools. I am sure there are some out there; we don't have patients enrolled in any clinical trials where that might be something to assess or tick off. But I do ask those questions. I do ask them, I ask open-ended and close-ended questions for each of those domains, and I do try to give the patients an opportunity to bring up any concerns that they have. So no, we don't have like a standardized, but that's really the point of those visits is to make sure that their quality of life is not being impacted.

QUESTION: Okay. So you're not using any standardized tools in your practice at this particular point in time?

06: Correct, yes.

QUESTION: Okay. But it sounds like you are prioritizing a look at quality of life and is it fair to say that, I don't want to put words in your mouth, is it fair to say that you're thinking about quality of life, not just how frequent, how severe the attacks are?

06: Correct.

QUESTION: Yes, okay. How do you engage patients in treatment decisions regarding long-term prophylaxis?

06: Well, I mean, I let them know what the standard, what the options are and what, if there is something that is approved; and I do utilize shared decision-making. So I kind of give them, we have a conversation and they are allowed [phonetic] to make as much of a decision as I am.

QUESTION: Any challenges that you've found in terms of engaging patients in that process?

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Patient barriers

06: For this patient population with HAE, like I said earlier and I'm still kind of struggling to find the exact word to describe it, but I think they're really faithful and they're very trusting of me that I'm going to do what's in their best interest. And so, yes, I'll just leave it at that.

QUESTION: Okay. So it sounds like they do trust your opinion and the recommendations that you're giving them when it comes to long-term prevention. It sounds like also for your particular practice, your usual strategy is actually to have someone on prophylaxis and have an on-demand treatment available for them as well.

06: Yes.

QUESTION: Okay. How do you yourself go about choosing medications for long-term prophylaxis for HAE? Take me through what your thought process is when you're thinking about what therapy is the most appropriate or best for this particular patient.

06: Well, a couple things: I ask if they're needlephobic. If they are, then we talk about an oral option, which is Orladeyo; that's the only one as of right now. And then, if they're not needlephobic, I mention Takhzyro, there's Haegarda. I don't really do Cinryze; I don't usually prescribe it to anyone. The difference with Takhzyro and Haegarda, especially with the dosing frequency, the majority of my patients are on Takhzyro, and I have two patients on Orladeyo. So I would say that dosing frequency, oral options if they do have GI, a history of significant GI problems, I might caution them regarding Orladeyo, at least in the beginning.

If they are concerned about, you know, I think efficacy, there is stop [phonetic]: the most efficacious medicine is the one that they're going to take consistently. So I think the difference is I know for Takhzyro, I think that's Takeda, they've argued they're more efficacious than Orladeyo. My two patients on Orladeyo have done very well, so in my experience, I don't know that I agree with that, but I'm just kind of throwing that out there since you mentioned (Overlap).

QUESTION: Yes, okay. And clearly, patient comfort with route of administration and whether or not they will actually use it are huge issues, especially when it comes to taking a long-term prophylactic medicine. It doesn't work if you don't have an adequate level of it in your body, obviously. You did not participate in a CME activity on HAE, is that correct?

06: Correct.

QUESTION: Okay. Regarding clinical guidelines for HAE, those are one way that research gets translated into clinical practice. What effect might HAE clinical guidelines have on your practice?

06: I mean, unless something dramatically changes where it's like patients don't need to be on both long-term prophylaxis and acute on-demand therapy, they don't really change. I mean, they don't. I don't feel like I've made many decisions based on any of the clinical practice guidelines.

QUESTION: Okay. Is that because you feel like essentially the recommendations have not really changed?

06: I mean, yes, I feel like the recommendations haven't really changed, and I don't know that I'm ever going to be faulted for being extra-conservative to some people for putting everyone on prophylaxis and on-demand.

QUESTION: Okay. Is there anything else that comes to mind while we're talking that you think it would be important for me to know?

06: No, I think we've kind of gone through it all.

QUESTION: Yes, okay, all right. Well, I appreciate your time and your help very much, and your insights into what can be a really difficult disease to manage. I've now interviewed about 14 people, I guess, about HAE, and it's interesting just to hear the wide variety of experiences that clinicians have; and also, to hear a little bit about what their personal strategies are in terms of treatment.

You are actually the first person, I mean, this is a very small N, right, so we need to keep that in mind, but you're the first person who has said to me, I just have everybody on prophylaxis and everyone on an on-demand therapy. And that's very interesting to me because I think it sounds like there are many people who, as clinicians, have not really made up their minds necessarily about having people on prophylaxis, or they meet significant resistance from patients who will just say, no, no, I'm fine just having an on-demand; I don't need to do, I don't want to do or I don't need to do—

06: Right.

QUESTION: —something [phonetic] with long-term prophylaxis. So it's very interesting to hear kind of the variation in different people's experiences, not only with their patients but just sort of how they size up the entire kind of landscape for things as well. At any rate, thank you again.

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Guidelines

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