CMEology

HAE – Hereditary Angioedema

Interview with “14”

May 10, 2024

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Interview with 14 – Hereditary Angioedema

[START 14 5.10.24.M4A]

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QUESTION: The first question is: what is your personal experience evaluating the HAE literature and its implications for clinical practice?

14: I mean, there's not a vast amount of knowledge or stuff that I see in the literature about it. It's like what I consider one of these orphan diseases in the world because a lot of patients don't even know about it, or even the primary care doctors aren't aware of it. So a lot of the times when we diagnose patients with this, a lot of times, we have to educate the PCP about what it is. And then, if we're diagnosing someone with type I, which I haven't done in a while because I'm near an academic center and it's kind of like a referral center for HAE, so prior to these drugs coming out, I had picked up a couple people and their family members but sent them to the tertiary center; they have better, had the protocols and the studies for these drugs when they were first being put out. So nowadays, most of my patients are more type III or whatever you want to call them nowadays because they keep changing that term.

QUESTION: Okay.

14: So I don't know if there's a lot out there. I mean, you see these charts about trying to diagnose people and seeing what their levels are and where they fit in, but a lot of times, people who have those type I's and type II's are kind of easier to diagnose, and then, the type III's kind of go to the wayside.

QUESTION: Okay. When you're looking at the literature for HAE, I know that there isn't a plan [phonetic] out there because it is a rare, very rare condition, but what kinds of questions are you trying to answer when you go to the literature?

14: I'm trying to look at ways to kind of, I guess, diagnose it or predict it earlier or get people to think about it in an earlier stage. Obviously, finding treatments that are simple and not as involved and that are pretty well-tolerated.

QUESTION: Okay. So it sounds like you have had people referred to you maybe by a PCP where the diagnosis of HAE wasn't really considered?

14: Yes. The person they diagnosed with type I, she got referred because they thought she had like a tuna fish allergy. It was a hospital consult.

QUESTION: Oh wow, okay.

14: And they thought she anaphylaxed from that, and when I evaluated her, you found out, you know, typical dental work a couple days before, had some episodes in the past, her Mom has similar; I mean, it was almost like she read the textbook. And I never saw a medical resident get so scared because the girl was sitting on the floor, and like I said, this was before anything, all you had to give them was FFP [phonetic] or whatever. So they were trying to treat her as an allergy patient and then we just kind of had to transfer her upstairs so she could be monitored a little bit more aggressively and then give her some FFP to kind of get her through. And then, like I said, I referred her to the tertiary center; the rest of her family who have it didn't realize it.

QUESTION: Wow, okay, interesting. So I think that also speaks to the fact that even though you are in an academic center, this is an illness where people end up being referred on to even more rarified levels of care, right? Tertiary centers, quaternary care kind of settings

14: Mm-hmm.

QUESTION: Were you referring particularly for participation in a clinical trial then or just—

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Primary care misdx or no knowledge

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Primary care misdx or no knowledge

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Literature review

(Overlapping Voices)

14: Yes, exactly, because all it was was back then, it was like danazol and stanozolol, which weren't your best options. I mean, they were your only options but at that point, this is when some of the newer drugs were coming out. So the academic center had the ability to plug people into studies.

QUESTION: Okay, got it.

14: Nowadays, I mean, those patients we manage, and most of them are mild, most of my patients are mild because if they had more severe issues, they've kind of been funneled to the other area.

QUESTION: Okay, got it. So when you're considering the implications of HAE research on clinical care, is there any particular format of research results that is more influential for you? So formats, I'll give you some examples: abstracts, poster presentations, live conference presentations, academic detailing, UpToDate or something similar, or journal publications. Is there a format that's more influential for you when it comes to looking at results?

14: I don't know if there's a particular format. I mean, I read a lot of the abstracts when I go to like the academy or college meetings. I go through the poster presentations, like everything else, kind of see what their design was and see if it was well-thought, not well-thought out, but you know what I mean, like more of a larger study as compared to like two or three people; and going to conferences and kind of simulating my interest in reading what they're kind of going for with the abstracts, if it's a new therapy, or a modification of a therapy, or a different way of looking at these patients.

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Professional Conferences

QUESTION: Okay. So you're actually able to make it to national conferences?

14: Yes, I usually try and make it to, I mean, between me and my partners, we kind of pick which one we want to go to. I usually go to one or the other, the academy or college, once a year, and there are some local meetings that I try and go to as well.

QUESTION: Okay, all right. What factors are more important to you in the process of interpreting the HAE literature and applying it to clinical care? So some factors that might be important to people again in this process of translating literature into clinical care are skills, knowledge, interaction with colleagues, time limits.

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QUOTE

14: I think, yes, interaction with colleagues is probably the most important in anything because since this is a more rare issue, and like I said, I'm more in clinical practice, I am not privy to a lot of the things in the pipeline unless I do marketing and things like this. You don't get to see, and like I said, I don't have the 50 patients with it to have my personal experience where I'll have like a dozen patients who are, like I said, more mild in complexity. So it's nice to get input from patients, people that are actually seeing patients with these conditions in real-world experiences because sometimes these studies are very, like I said, very small or the exclusion criteria kind of cherry-pick the patients. So it's nice to see what the real-world experience is.

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Collegiality

QUESTION: Okay. So would those colleagues then be maybe somebody at a tertiary center that you might call up and chat with, or someone within your own practice that you end up talking to?

14: It would be someone at a different center, the academic center.

QUESTION: Okay. Moving on, can you describe any barriers to incorporating research findings in HAE into clinical practice that you have experienced? So examples of some potential barriers would be patient-related barriers, healthcare provider-related barriers, practice-related barriers, or institutional barriers: anything that poses a challenge or a barrier to translating research findings into clinical practice?

14: I think the research finding issue is getting your patient to understand, and a lot of times, they won't understand regardless of their education level because, like I said, most people have never heard of this, and you have to explain to them what the situation is. I don't have any kind of institutional or practice issues. The only issues you end up getting is sometimes like if you want to try some of these newer products or newer therapies, like I said, the insurance companies sometimes will create barriers that don't go along with guidelines or things that have been recommended by thought leaders or places that are seeing patients, a larger quantity.

QUESTION: Okay. So insurance barriers as regards to getting prior authorization?

14: Yes, like the prior authorizations or like the clinical history or laboratory findings, they make these hoops to jump through that you have to end up doing peer reviews and so forth, which can be quite frustrating because a lot of times if you do a peer review, it's not someone of our specialty. It's somebody, one time it was an OB which was hilarious because they don't even know what the condition is. And you find out with a lot of the peer reviews that it's not specialty-related with these unusual issues.

QUESTION: Yes, although you could make the case honestly that someone like an OB who does procedures really ought to know, right?

14: You would think; you would think.

QUESTION: You would think that that should, and surgeries and other abdominal things, gosh, you would hope that maybe they had at some point maybe at least heard of the condition in their training. But maybe not, right?

14: Not at all. But it was interesting because she got very well-educated and, like you said, considering that in patients who present with different things, that she could probably say, well, maybe that person had this and not many realize it [phonetic].

QUESTION: Yes. Just as part of working in content area of HAE, learning more about it to help create a CME activity on this, [redacted] so I did a lot of asthma-related stuff, but I did find myself going back and thinking, gosh, that person who kept coming back to the emergency room when I was a [redacted], right, with acute abdominal pain that nobody could figure out, boy, I'm sure this wasn't on my differential, and it really does make you think about how HAE manifests as common symptoms of other common conditions, and maybe we really are missing this a lot, especially inflammation and swelling of internal organs, right? It's so obvious if someone's got mouth swelling, upper airway stuff; you would hope that you would immediately start to think about that. But some of these less obvious presentations, I can see how patients go undiagnosed for a long period of time and suffer because of that, unfortunately. What do you think delays the introduction of evidence-based practices into HAE care?

14: I think like you said, patients don't consider, or their providers don't consider it and aren't aware of it. So it's kind of like they don't know what they don't know. A lot of these patients might present to their PCP or the ER and giving, I mean, we see a lot of times giving epi, giving steroids thinking it's an allergic reaction, then if they're lucky enough, they pop into our office, and then we consider it early on

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Patient education

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Lack of information

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Lack of information
QUOTE

and institute therapy if need be, or trial therapy just to kind of rule out the diagnosis as well, especially those mild patients who don't have, like you said, those obvious ones.

QUESTION: Yes, okay. Is there anything that you feel could help some of those delays in implementing evidence-based practice into clinical care, anything that you feel could help overcome those problems?

14: I think if you had, like the Immunodeficiency Foundation has out a list of ten things to consider someone for immunodeficiency, if you had like a simple thing that you could present to someone and say, if you have blah blah blah, then you could, you should really think about this; and put it in simple terms that could come to their mind, and in this way, they might, like I said, get plugged in earlier or evaluated earlier for therapy.

QUESTION: So ten things you could consider aimed at patient education or at physician education?

14: You could do both because like the IVF people have it for providers and for patients, so you could dummy it down to like the patient level, and then have something more clinical for the providers or medical personnel.

QUESTION: Okay. So it sounds like education could be a part of having this be identified earlier. How about translating evidence-based practices as regards to treatment into HAE?

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Lack of HAE commun. resources

14: That's presenting it to the people who treat these patients and having them, since it is a more uncommon issue, is maybe getting these patients to enroll or involved with the HAE community so that they can increase reporting their outcomes and better guide the treatment guidelines that if somebody is doing something good in a particular area, a lot of times, you're not knowing that in a different area, especially if you're in the private practice world.

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

14: Like I said, once you kind of explain the condition to them, which some of them get it and some don't, then you have to explain the treatment options and a lot of them are like, how long do I have to take this for, because they think it's a finite condition. But you have to explain that, no, that it's probably a life-term problem. And a lot of times, since I've been doing this for a longer period, I can explain that I've had patients with similar situations that have this condition, and this is how they've done.

And I have had some patients who are willing to talk to other patients about their situation, and that makes it a lot easier because then it's patient-to-patient because a lot of times, they won't ask us some questions. They feel uncomfortable to sometimes ask something they think is a stupid question or something they don't think is important, whereas when they talk to someone along their own level, or somebody can say, I've been there, bring things up, a lot of times, that makes it more appealing to them and easier.

QUESTION: Okay. So it sounds like stories about people who have decided to go on long-term prophylaxis and what their experience has been, and then, finding an opportunity for a patient to connect with someone else who's kind of lived through this and maybe face the same decisions that they have has been helpful. Any challenges that you found in finding people who would benefit from HAE prophylaxis and identifying those patients?

14: Some people are just not interested in doing certain things. Nowadays, the options are a little bit better because you have an oral version and an injectable version. Back in the day when you only had like the

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IV route

IV infusions, that was a lot harder to sell. But nowadays, it's a lot easier: people are more comfortable with, and used to, injections for other conditions, so they're familiar with the concept. So I think patients are a little bit more accepting, but still, they all want to know long-term safety. And especially if you have a woman of childbearing age, then you're worried about what's the teratogenic effects, and those kind of things you have to worry about.

QUESTION: Of course, okay. How do you gather information about the impact of HAE on a patient's work, school, social life, family life?

14: I ask. I don't do a formal quality of life scale, but I kind of ask them pointed questions about how it's affecting those things: sleep, interactions with family, travel, because a lot of those patients have underlying psychosocial issues because of it. Or the fear of having an attack, being in certain places, being away from home, unfamiliarity, it's kind of like the patients with food allergy who don't want to go places; they stick to their own normalcy.

QUESTION: Yes. I wish my son who has food allergies would be a little bit more like that, quite honestly. But anyway, he's an adult now, so he's got to live and learn on his own.

14: You can give him Xolair now so that might help [phonetic].

QUESTION: Yes, yes, I guess we could do that. I guess that actually would be an option. So it sounds like you're not using a formal quality of life validated instrument in your practice to look at that issue with patients?

14: I haven't. I mean, I guess I could look one up and do it, but the only time, a lot of patients fill out those things and for different conditions, we do them because the insurance company makes you do it to qualify for certain things. But a lot of times, you can get those same answers without coming up with a particular number. You know how much it's affecting them; you can tell.

QUESTION: Okay. So you can get the same kind of information, you feel, from just a good interview in the exam room. Have you actually had an insurance company ask you for a quality of life metric for someone?

14: Not for HAE.

QUESTION: Not for HAE.

14: I've had it for other conditions.

QUESTION: Okay, interesting. How do you engage patients in treatment decision-making when it comes to long-term prevention for HAE?

14: I believe in shared decision-making in any condition in my office. It's kind of like long-term be it asthma, food allergy, urticaria, because I think, or immunodeficiency, you're asking these patients to do something the rest of their life most of the time, so it's got to be something they feel comfortable with; it's got to be user-friendly; it's got to be safe; like I said, tolerable. So I present the different options and then I could tell them, because then they're going to ask, well, how do you feel about this or that, and I'll tell them this, it might be something more like if I could say, if my family member had this issue, this is what I would consider; or I can say, I have X amount or number of patients who do this and do fairly well. So I kind of give them that, my experience.

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Long-term safety concerns

Commented [13]: Codes (14661-14807)
Long-term safety concerns

Commented [14]: Codes (14853-15201)
HRQOL self assessment instruments

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HRQOL self assessment instruments

Commented [16]: Codes (17077-17353)
Shared decision making

QUESTION: Okay. Any issues that you feel you tend to get pushback from patients about just the general issue of prophylaxis? Any areas where it just seems like patients are more likely to say no because I feel this way or that way?

Commented [17]: Codes (17698-17887)
Few episodes/pref episodic tx

14: Someone who has mild issues with episodic episodes, then they're like, well, I don't feel like taking something all the time if it's going to possibly cause this problem; or I can't afford it and those kind of things; or I'm not interested; or a family member took something or something, and they have a jaded view on medicine in general that they're afraid that it's going to cause something. So you have to kind of reeducate them and kind of get them off the internet and present them with the medical data or direct them to the people, like I said, somebody who has the condition or the HAE Foundation, those kind of things, that they can get some information that's true.

QUESTION: Okay. So it sounds like referring patients, having them talk to other patients, pulling them away from erroneous sources on the internet are strategies that might make that process a little bit easier. How do you go about choosing medications for long-term prevention of HAE attacks?

14: I usually present the options to the patients about what they could use, so if they want, you know, there's an oral preparation, there's an injectable preparation, you have an IV preparation. Most of the patients are more in tune to either the oral or the single injection, and obviously, those patients also have some acute treatment as well. So that's kind of how I explain to them; that's pretty much it. And then, depending upon the injection, if they want to do one versus another, that's up to them; I just present my experience with the different ones and let them, like I said, decide what they want to do.

QUESTION: How do you view the current treatments for HAE prevention and prophylaxis at this point? How do you think about them in your head in terms of safety, efficacy?

14: Well, I think they work fairly well in my patient population. I think with the injectable ones, I haven't seen really much side effects or tolerability issues, and I think they've been fairly effective and once you get the patients, most of my patients are on once-a-month injections after the earliest parts and they're doing well. I do have some patients who take orals; the issue with the oral is the GI side effects that sometimes gets better after being on it a little bit longer. So that's pretty much how I kind of deal with it with them.

QUESTION: Okay, all right. You probably don't have anybody who's getting IV therapy in your practice [phonetic]?

14: No.

QUESTION: So it really comes down to a question of sub-Q medication versus oral, and have you had a chance to explore using the newer formulations that are out there?

14: [Unintelligible].

QUESTION: So you have used oral.

14: Yes, I like Takhzyro; I use predominantly Takhzyro. I don't really have anyone on Haegarda just because I don't really have any kind of support in the office from that institution or that company. So the Takhzyro people have been a little bit more present in our office, helpful in getting patients approved for the medications, and re-approvals if need be.

QUESTION: Okay. All right, we're coming to the end here. It sounds like you did participate in the CME activity on HAE. Did that activity influence the way you think about translating evidence into clinical care for these patients?

14: I think it highlighted some things that need to be considered and brought up some things that I don't always, I'll say think of at first. So it did reinforce some things that I learned that, like I said, it's not a big part of my practice or it's not an everyday experience, so sometimes, you have to be reminded of some things. So I think it was good in reinforcing that.

QUESTION: Can you tell me a little bit more about what sorts of things the activity may have reinforced for you?

14: I think just considering the total effect on the patient, the condition, just remembering, like I said, the psychological aspects of it and the social issues that have to be considered. The types of medications and their concerns about being on them, preventing, possibly somebody who's having not as many episodes but severity of episodes really should be considering prophy.

QUESTION: Okay, all right. Clinical guidelines are one way that research gets translated into clinical practice, of course. What effect might the HAE clinical guidelines have on your practice?

14: I think they'd support our continued use of the products and maybe allow for more streamlined prior authorization processes, especially for, like you said, the type III type patients who the insurance companies try and say they don't have it because there's no good way of really proving it unless you try them on the medications and it improves. So clinical guidelines are good because then the insurance companies can't deny things if it's a respectable institution that develops these guidelines or endorses it.

QUESTION: Okay. Are there any particular questions that you might go to the guidelines to help you with in terms of your making a treatment decision or a diagnostic decision?

14: I don't think so. I think that's more of trying to fight with them to get approval or a trial of prophy to show clinical benefit. Or even, I had somebody recently, they wouldn't pay for [unintelligible] even though they were on a prophy when I'm like, this is ridiculous. So those kinds of nonlogical thinkings of insurance companies.

QUESTION: Yes, okay. Yes, that makes really very little sense. Is there anything else that comes to mind while we're talking about HAE that you think would be important for me to know, or for other people who are seeing these patients to know?

14: Not that I can think of. I think, like I said, just understanding that this affects the patient globally [phonetic], so you have to consider that.

QUESTION: Okay. All right, well, I appreciate your time very much. I know you probably have a busy day ahead of you. If you don't, fantastic, enjoy it.

[IRRELEVANT MATERIAL OMITTED]

QUESTION: Again, thank you so much for your time. You will be receiving your Amazon gift certificate shortly. If you have any issues or questions or things that come up, please do reach out to [redacted], she is the person that arranged the interview this morning, and let her know what you think.

Commented [18]: Codes (20975-21152)
QUOTE

Commented [19]: Codes (21470-21643)
QUOTE

Commented [20]: Codes (21643-21834)
QUOTE
Severity/frequency of attack

Commented [21]: Codes (22378-22379)
Guidelines

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Guidelines
Insurance/Prior authorization

I think I also need to, you made one comment about this being a marketing intervention of sorts, and I just want to make sure that I let you know that this is actually a study that we'll be putting together for publication, looking at clinician views about HAE specifically, and you've probably gathered this, but specifically about how do we translate literature into best practices, clinical guidelines, and ultimately better care for our patients.

So at some point, I doubt it will be in 2024 because the publication process moves so slowly, and at some point, this will be, your feedback and your views and those of about 14 other clinicians will be kind of coalesced into a manuscript. We use a process of, actually a machine learning algorithm analyzes the content of all of the different interviews, and then we pull common themes from that. Naturally, everything is anonymous, confidential; your name, anything particular about you will never appear in the manuscript. But we really do appreciate your time, giving us the thoughtful responses today, and wish you the best for the weekend.

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