CMEology

HAE – Hereditary Angioedema

Interview with “10”

May 31, 2024

Contents

TOC \o "1-3" \h \z \u Interview with 10 – Hereditary Angioedema PAGEREF _Toc169296921 \h 1

CMEology

Interview with 10 – Hereditary Angioedema

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

10: I haven't seen recently any latest guidelines from professional organizations that I associate with, primarily the allergy community, College of Allergy and Immunology. I pretty much get my information from some conferences and also from the representatives of drug companies that produce some of the products that are used for treatment.

QUESTION: Are you using any tools in your practice, point-of-care tools, for example, like UpToDate or other—

10: Yes. Well, I will use UpToDate in various clinical situations, not specifically recently for HAE; I don't know what they have to say most recently.

QUESTION: If you do pull a paper or something, what kinds of questions are you trying to answer when you go to those information sources?

10: I'm trying to get some information primarily about the efficacy of, and comparison between, products that are out. I'm interested in the newer developments, of course, but they're not as important to me because they are not available yet for use. But I'm trying to really primarily, of course, review side effect profiles of some of the products, and mostly the efficacy, what to expect, and any comparisons between the products regarding efficacy and side effects; and also get some idea as to patient, what the general consensus is on patient preferences of patients at this point.

QUESTION: When you're thinking about the implications of HAE research on clinical care, is there any particular format of research results that is more influential to you? So I'll give you some examples. Different formats might be an abstract; poster presentation; live conference presentation; academic detailing; UpToDate, something similar like that; or a journal publication. Of those different formats, what tends to be more influential for you?

10: I think live conferences, ones that I have started to attend again since Covid; and also what I see on again the American College and Academy websites, and their presentations on the topic.

QUESTION: Just out of curiosity, what are the conferences that you like to go to?

10: Well, directed to allergy and clinical immunology—

QUESTION: Yes.

10: —the conferences are either, mostly state, regional, and also national conferences.

QUESTION: Like [redacted]

10: [redacted] Allergy and Immunology.

QUESTION: All right. You said you also get some information off of websites. Are you getting emails sent to you that direct you to the American College, for example, the American College website? How are they reaching you?

Commented [1]: Codes (421-522)
Guidelines

Commented [2]: Codes (590-645)
Professional Conferences

Commented [3]: Codes (649-698)
Pharma rep detailing/MLs

Commented [4]: Codes (885-938)
Expert opinion/Up To Date/Google/Medscape

Commented [5]: Codes (1219-1277)
Superiority of efficacy

Commented [6]: Codes (1279-1320)
New patient practices

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New patient practices

Commented [8]: Codes (2203-2229)
Professional Conferences

10: Yes, usually, it's a lot of, yes, advertising to me. It's more of some of them, I forget the exact ones, but like WebMD or so, pretty much almost every day, I'm seeing something on it that if I had the time to do it, I could, some educational presentation from one of the medical websites.

QUESTION: All right. If you're at a conference then, are you mostly going to a plenary session or a podium presentation?

10: Yes, most of them are plenary sessions that I attend. Most of the state and international, well, most of the conferences I go to, they usually do have, they're sponsored in part and they have areas where there are, of course, some representatives of the various pharmaceutical companies. And so, I roam around there, talk to the reps there about their products and any new information they have about their products and extensions of indications and extensions on ages for their products.

QUESTION: What factors are most important to you in interpreting the HAE information or literature that you get and applying it to clinical care?

10: I'm sorry, what was the question again?

QUESTION: What's most important to you in the process of interpreting the literature: interacting with colleagues; interacting with a pharma rep, for example; skills; knowledge; anything else that comes to mind?

10: Other than the formal presentations, I may speak to colleagues, but I don't make an effort to talk to them necessarily about their experience with the various products. So there will be still a lot of, you know, of course, I take it with a grain of salt regarding what the reps have to say, they're marketing their own product, but they usually are pretty well-informed and, at least on their product, they have fairly reliable information on their products regarding HAE, regarding a lot of the reduction of attacks and severity of attacks and pretty much what they're seeing. Also, they can give me some information as to, I spoke to one the other day, that can give me information about what other physicians are finding, are discovering about their product and their experience. So it is a lot, I get a lot of information from the pharmaceutical reps.

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Collegiality

Commented [10]: Codes (4766-4870)
Pharma rep detailing/MLs

QUESTION: Just out of curiosity, are they actually giving you printed literature?

10: Yes.

QUESTION: Papers [unintelligible]?

10: Yes, I'll get some printed literature usually. My contacts with them are, in the HAE area, most of my contacts are actually direct contacts; they come into the office and we spend time together usually over a lunch. And they'll leave me information both about their product and also about the general topic of HAE diagnosis and some insights on HAE in general.

QUESTION: All right. Just out of curiosity, what type of practice are you in: academic, private practice, health system?

10: It's a private practice; it's a multispecialty group. Most of my time, I share time, it's a combination, but most of my time is with a multispecialty group. [redacted] well, it's a nonprofit but private medical group associated with a couple hospitals. [redacted] with them, and so, I work out of a medical office that's just across the parking lot from the associated

hospital where a lot of medical specialists for the group practice. And I share an office with a couple, actually ENT doctors which as [phonetic] an allergist, we see a lot of the same patients regarding upper respiratory conditions.

QUESTION: Roughly how many patients would you estimate that you've got in your panel right now who have HAE in one form or another?

10: It's six right now.

QUESTION: Were those patients referred to you with the diagnosis of HAE, or were you kind of the person who sorted it all out and determined that they had HAE?

10: It's been a combination. Just thinking offhand, I think out of those six, most of them have been long-term patients of mine. I think I've diagnosed personally, who came to me without the previous diagnosis, about half of them, I made the diagnosis after referral from, I don't recall if it was from their primary physician or from the emergency room. And then, the other half were maybe already prediagnosed and were changing medical groups and I took over the care, and we may or may not have switched their therapies over the years.

QUESTION: All right. Can you describe any barriers that you've encountered when it comes to incorporating HAE research findings into clinical practice? So some of the examples would be: patient-related barriers, health care provider-related barriers, practice-related barriers, or institutional barriers, things that keep you from taking what is current in the literature and applying it in the exam room.

Commented [11]: Codes (7944-7991)
Patient barriers

10: Well, most of the barriers are really with patients. I've tried to talk to them more about present new treatments that I think they should look into that I think are better therapies than what they're on, some of the patients. I think it's patient education about newer therapies and they have concerns about changing therapies that are working for them fairly well right now; they sort of resist a change even though it may be, I would think, more convenient for them. So some of the problems have been actually directly with patients in education and, I mean, of course, it's a shared decision-making and they have the final decision, but sometimes it's maybe I'm not persuasive enough.

Commented [12]: Codes (8629-8718)
Patient education

We try to get them information; I find that the pharmaceutical companies are pretty good. There isn't a barrier with them: they send out information to patients, and when I ask them to send information about a particular product to the patient, they're pretty good on that.

I haven't had much problem with the insurance companies or the medical groups or whoever approves, authorizes the therapies; they have been pretty good for the most part. I haven't had to spend a whole lot of time with getting prior authorizations for therapies.

QUESTION: You said that one of the things that is a barrier that comes up with patients is related to switching—

10: Yes.

QUESTION: —medications. Are there specific concerns that you think patients have related to switching?

Commented [13]: Codes (9400-9584)
Patient anxiety/concerns

10: Yes. I think they are having few attacks and they are concerned about if they switch to another therapy that either during the switch or after the switch, they will run into more problems. I think that's

primarily their concern. I find it difficult to see how some patients still prefer frequent subcutaneous or intravenous therapy every three or four days.

QUESTION: You actually have people who are still getting intravenous?

10: Yes I do.

QUESTION: Oh, my goodness.

10: I've got patients who get C1 esterase inhibitor infusions every 3-4 days IV.

QUESTION: Wow.

10: Cinryze being the product. And patients are concerned they've had family members who have passed away from angioedema, and they're doing so well with intravenous, they continue on that, and both their health plan and we [phonetic] would like them to switch. Finally, they would have visiting nurse come in twice a week: I think it becomes more of a social thing for them of somebody coming by to talk, to be with them also, but finally had the patient taught how to give her own infusions if that's what she wants to continue. But yes, I have patients receiving that or subcutaneous replacement, which is still a couple times a week. So it's surprising how patients respond to their disease and their decisions on treatment.

QUESTION: Sure. I can certainly empathize with people who feel like what they're on is working and why rock the boat and having to go through, right, learning how to use a new medicine, monitoring for side effects, all that stuff. It certainly can be a challenge for people who are used to one particular treatment or another. What do you think delays the introduction of evidence-based practice into HAE care? So it sounds like one of the barriers you've encountered is patients just not really wanting to switch. Are there other things that you think delay the use of evidence-based treatments that are new or approaches to the disease that are new?

10: I don't see it for a condition like HAE because it's patients, either for the confirmation of their diagnosis or for initiation of treatment or continuation of treatment, my experience has been, I have seen primary care doctors continue the therapies, but most of the time, the patient is under the care of an allergist for this condition. I think the allergy community, other allergists that I'm in contact with, they're familiar with the newer monoclonal antibody therapies and oral therapies for the condition.

And so, again, you're probably aware there are so many, half-a-dozen or so, new products that are around the corner for the condition that still are not there yet; they're not available. But it's going to be a hard decision to really make as to starting patients on new therapies and which one to choose, and any reasons, I think they're still going to mostly have to do with taking the side that probably they'll all be pretty efficacious; and if they all are similar in effectiveness, it's going to be more of a convenience and the frequency of dosing and, of course, any preference for oral versus systemic parenteral therapies.

QUESTION: So those patient-related factors will become, you think—

10: Yes.

QUESTION: —more of an issue as the therapeutic landscape—

10: Yes.

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Primary care misdx or no knowledge

Commented [15]: Codes (11917-12492)
Excess choices

QUESTION: —expands for that, okay. What's been your experience in identifying patients with HAE who would benefit from long-term prophylaxis? Were there any challenges that you encountered? What helped you identify those patients who should be on prophylaxis?

10: Well, I do have a couple of patients who are just still on on-demand therapy. Basically, it's because of the infrequent attacks and the lower severity of their attacks that they're comfortable and I'm comfortable allowing them to treat on-demand. But at some point with the prophylactic therapy, I think with the less frequent dosing for prophylactic therapy, it's going to rival the number of treatments that a patient has with on-demand. So there really wouldn't be any reason to continue just on-demand only if a prophylactic can be given two or three times a year or so, and it prevents patients from experiencing attacks.

QUESTION: Just prevents the attack all together rather than having to respond to something that's acute?

10: Right, yes.

QUESTION: Okay. I'm just curious: I have heard a couple of clinicians that I've talked to say that they have had patients on androgens still.

10: Yes.

QUESTION: Is that something you run into?

10: I don't have patients on androgens for long-term prophylaxis; I still use it for short-term prophylaxis. For patients who are on just on-demand therapy, some of them will go on a couple weeks of Danazol prior to dental procedures and rather than getting intravenous C1 esterase prior, short-term prophylaxis with C1 esterase inhibitor, they go on androgen therapy. Yes, I remember, I have been in practice for a while, where that was the only therapy available for prophylaxis. It works very well. You'd run into some side effects in female patients that are concerns, but I think it's very effective.

But these days for long-term prophylaxis, I certainly don't know of any reason really why to do that. I can't imagine that it's a financial issue these days; there is some support somewhere to cover these patients, but maybe not. I don't know, in other parts of the country, there may be some issues with cost of therapy or not getting the pharmaceutical companies to cover the cost for those patients.

QUESTION: Okay, interesting. When you're assessing a patient, how do you gather information about the impact of HAE on their work, school, social, family life?

10: Yes, I don't take any surveys from them; it's pretty much just during the visit. A lot of times, these HAE patients, I guess it could be for some other conditions, it's hard to get them into the office for follow-ups when they're doing pretty well. I try to see them at least every six months but a lot of times, it goes a year or so, a year or longer, and it's only when we call them and tell them we need to get reauthorization for their therapy, they need to come in so I can really assess them in person, that I get them to come in. Otherwise, they're just getting delivery of their medications and they're just pretty much on their own and doing their own thing. I'm trying to think now of the question: what prompted that answer of mine? What were you asking me about?

QUESTION: Yes, so just kind of your general strategy for assessing the impact of HAE on quality of life.

10: Yes. Well, again, it's pretty much, whether it's over the phone or actually in a visit when they do come in to see me, it's basically just talking to them person-to-person and finding out what's going on in their life and how comfortable they are with their therapy. Is it consuming a lot of their time thinking

Commented [16]: Codes (12988-13067)
Few episodes/pref episodic tx

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HRQOL self assessment instruments

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Insurance/Prior authorization

about, worrying about attacks; or obviously finding out about any attacks they've had and use of on-demand therapies. And it's just recording those kind of things in the medical record as to frequency of any attacks that have occurred, any on-demand therapy, and pretty much how their therapy is going, whether it's keeping them from traveling or any physical, other situations at work, whether it's affecting their social life or recreational activities. If they have problems traveling with their medications, is that an issue for them or not? Yes, so it's just basically seeing how they're doing and asking them if they are comfortable with their present treatment, and if I think that something else would be good for them, I would bring it up at those visits.

Commented [19]: Codes (16985-17109)
HRQOL self assessment instruments

QUESTION: Are you aware that there are validated questionnaires for assessing health-related quality of life in HAE?

10: No, I'm not.

QUESTION: Okay. I think they have really been used primarily, and no surprise, right, in a research context.

10: Okay.

QUESTION: So sometimes, I'm actually a pulmonologist by training and asthma was my area of expertise, I guess you could say; I don't practice any longer. But some of us, I think because of the relationship to asthma, we're kind of comfortable using some of these tools in the exam room. But of course, you have to know about them, you have to know where to find them, it's a whole process, right, of being able to use even a short questionnaire to assess someone. When you're talking with patients about treatment decision-making, specifically about long-term prophylaxis, what kinds of challenges do you find when you're talking to them about potential options, and what do you find makes that process easier?

10: Well, I think it does make it easier, these little booklets or pamphlets, they're usually product-orientated, but I like to give them one of those for any particular product that I'm thinking would be something that they would be interested in. I like to have those; that goes along with any discussion on the treatment because it may prompt questions for them that at the following discussion, we can address. I think a lot of times, yes, the patients don't have, the questions and concerns come up later when they go home, and so, with a booklet, they can get a better idea as to various options.

QUESTION: Are you giving those to patients in advance of a visit with them, or how do you work the timing out on that?

10: Well, I discuss the product, one or two products perhaps, and shortly give them just an overview as to what it would entail for them as far as how it's given and what to expect. And then, I'll also give them the booklet on their way out, and then either, it depends when the follow-up is going to be, with these patients, I'll usually say if you have any interest in this product for either starting prophylaxis or changing their prophylactic therapy, let me know and we can discuss it more perhaps over the phone, or if they prefer on a visit.

QUESTION: Yes, okay. How do you choose between medications for long-term prevention and prophylaxis for HAE attacks? How do you think about that?

10: Well, these days, I really prefer one particular product and because I've had good experience with it and it seems to be a preferred product for the condition; and I don't see any other products being any more efficacious. I do mention, the big question is whether they want a therapy that is an injection or if

they want to try, well, there's only one oral therapy right now which I don't have any patients on right now, no takers for it yet, but I think that's an option for them. But I'd find patients who would prefer something that doesn't require daily treatment even though it's an oral, and I also feel that with oral therapy, patients are going to fall out of being adherent to their therapy. They're doing well and then they'll miss a day here or there, then nothing will happen, they'll miss more, another few days and then they just stop taking it.

QUESTION: Yes, which would set them up to having more frequent or more severe attacks, sure.

10: Yes.

QUESTION: Okay. You did not participate in the CME activity related to HAE, is that correct?

10: Which one? Are you talking about a specific one?

QUESTION: Well, specifically, you did not participate in a CME activity that prompted us to contact you to do this interview?

10: No.

QUESTION: Correct? Okay, all right, that's fine, no problem. Clinical guidelines are one way that research gets translated from the literature into clinical practice. What effect might HAE clinical guidelines have on your practice?

10: I would take it very seriously. I think it would, for the majority of patients, it's the starting point I think for me, would be a starting point of what's the consensus now of initial therapy or therapies and starting there, but then moving on based on my own personal experience and other options, just knowing, I think, that you're not going way out of line of guidelines is helpful. I think it would keep me more focused on treatment that is the best for the majority of patients.

QUESTION: Yes, there is clearly lots of different, clinicians have very different feelings about guidelines, and I think everyone uses them in a different way somewhat depending on their level of experience. It sounds like you've seen many patients over the years with the condition; you've seen therapies evolve over time.

10: Yes. You bring up asthma and, of course, that's the big one right now.

QUESTION: Yes.

10: That's one with all the biologics that I use for it now. It's usually which one to use for different patients is becoming more confusing and maybe not even as important anymore; and the use of inhaled steroid or short-acting bronchodilators as primary therapy for a lot of patients instead of daily controller medicine.

QUESTION: Yes, the landscape has really changed. I actually left clinical medicine around 2016, 2015, so I think the only biologic I ever prescribed—

10: Omalizumab.

QUESTION: —was omalizumab, right? Xolair.

10: Yes, yes.

QUESTION: And then, it seemed like within the year or so after I was out of practice, we just started to see like a new biologic every year. And the treatment landscape has become pretty difficult and it seems like there is no one, of course, is ever going to do any head-to-head studies—

10: Yes.

QUESTION: —so it becomes more difficult, I think, for clinicians to pick and choose. HAE is, of course, a much more rare condition, but I think your point about the fact that there are going to be, there are new agents in the pipeline, there are going to be new things that people are going to have to consider and choose from.

10: Yes, I'm just surprised that there is so much interest. Like you say, it's not the most common condition, but there are so many therapies vying for use for these patients, I'm just surprised that there's that much interest from the pharmaceutical companies. And of course, the most interesting one, I think, is going to be the gene therapy, one-time injection to eliminate kallikrein production.

QUESTION: That's just incredible to think that we're at a point where we casually can say, you know, gene therapy, right?

10: Yes.

QUESTION: That's pretty remarkable that we're at that juncture, for sure. One more quick question for you: anything else that you feel is important for me to know about HAE from the standpoint of someone like yourself who is an experienced clinician, anything that you feel that people in the field are doing research or whatever, are they missing anything? Is there something that they should know about what it's like to care for these patients in clinical practice?

10: Well, I think it's pretty rewarding to be able to treat these patients who were previously very frightened, and with good reason for a lot of them, and just that, even though they're a small community, we are able to really impact their life and other family members that they have, both who have the condition and who care for their family members who have the condition. So I do appreciate that these other therapies have come on the market, the ones that we have already which are good, which are great advances compared to, like you say, the androgens and the thrombotic therapies that we used to use sometimes.

QUESTION: Mm-hmm, sure.

10: So yes, I think it's going to be sort of like a model for other genetic and difficult conditions.

QUESTION: Okay. Well, that wraps up the questions that I have for today. Very much appreciate your time.

[IRRELEVANT MATERIAL OMITTED]

10: Thank you very much, I appreciate it.

[IRRELEVANT MATERIAL OMITTED]

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