CMEology

HAE – Hereditary Angioedema

Interview with “07”

May 8, 2024

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CMEology

Interview with 07 – Hereditary Angioedema

[START 07 5.8.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: This is an interview about hereditary angioedema, HAE, and I'll ask you a series of questions. Please just give me your honest opinion. We're interested in hearing your thoughts on a number of issues, so first question is: what is your personal experience evaluating the HAE literature in terms of implications for clinical practice?

07: I would say once every three months, I try to make a point to kind of stay up-to-date and actually take time to read stuff on relevant things. But I use UpToDate pretty regularly, and honestly, these days, UpToDate is pretty up-to-date as the name suggests [phonetic]. So I do get a lot of information from there probably more on a daily or weekly basis, too.

Commented [1]: Codes (785-876)
Expert opinion/Up To Date/Google/Medscape

QUESTION: All right. Yes, UpToDate can be an excellent, excellent source, and I think they have done a very good job of trying to make critical updates to it on a regular basis, so that definitely helps. What are you looking for if you are reading articles in the literature related to HAE? What kinds of questions are you bringing to your reading?

07: Mostly to see if there are any changes as far as like what's considered first line, newer medicines, mostly just changes to what's already been established, I would say.

Commented [2]: Codes (1422-1508)
New therapies

QUESTION: Okay. When you're considering the implications of the 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: abstracts, posters, live conference presentations, academic detailing, UpToDate, journal pubs?

Commented [3]: Codes (1838-1864)
Literature review

07: Mostly journals and publications but kind of open to it all, but mostly journals and publications.

QUESTION: Okay. Do you have a chance to get to annual meetings where there might be a live presentation on HAE?

07: Almost never.

QUESTION: Almost never? Okay. Can you tell me a little bit about your practice environment?

07: It's a group practice. There is [redacted]. It's in like a[redacted]ea mostly. I see kids, adults, everything. It's all outpatient.

QUESTION: Okay. And it's an allergy immunology practice?

07: Yes.

QUESTION: Okay, got it. So it sounds like you don't make it to the big meetings necessarily, but journals and publications are sort of your first choice for looking at research?

07: Yes, absolutely.

QUESTION: Okay. What factors are most important to you in interpreting the HAE literature and applying it to critical care? For example, interactions with colleagues, any other things that are influential, skills, knowledge, when you're interpreting the literature?

Commented [4]: Codes (2842-2917)
Safety

07: I think I'm always just looking for something that has safety as one as far as like, is there a newer essence [phonetic]? So I think that's the first kind of benchmark, see clearly [phonetic] that the safety of it is either even better or just as good as what's kind of established. And then from there, it's got to be

Commented [5]: Codes (3025-3116)
Safety

something that clearly has some type of advantage, whether it be in clinical efficacy or sometimes whether it be like dosing or something like that.

QUESTION: Okay. So you're looking at what the potential advantages of newer treatments might be compared to what has sort of historically been considered the standard of care?

07: Yes.

QUESTION: Okay. Do you have much opportunity to interact with your colleagues when it comes to topics like HAE?

07: Yes. I mean, we all work in a very close environment, so we regularly discuss cases with each other.

QUESTION: Do you guys have access to in-person or virtual grand rounds through your health system or a nearby hospital, anything like that?

07: We do, but rarely is there a focus on allergy, I would say.

QUESTION: That's true, right; unfortunate but true.

07: Yes.

QUESTION: Okay, all right. So grand rounds probably don't, they just don't cover, you have access but they just don't cover AI topics particularly often?

07: Yes, very rarely, and if it does, it's more on things like asthma, and even that, it's not as relevant, I would say.

QUESTION: Okay. Yes, HAE is a fairly rare condition.

07: Yes.

QUESTION: Most of your other colleagues in other professions, honestly, they probably should know about it, but it's not something that's top-of-mind for them in day-to-day practice.

07: Right [phonetic].

QUESTION: Okay. Can you describe any barriers to incorporating research findings in HAE into clinical practice that you have experienced? And I'll give you some examples of barriers, but if you think of other ones, let me know. But some of the barriers that might get in the way of incorporating research findings into practice could be things that are patient-related, they could be healthcare provider-related barriers, practice-related barriers, institutional barriers.

07: Yes, I think for me, one of, even if whether it be like a newer treatment or some of the newer stuff that I would like to try, like cost and insurance is always a barrier, just everybody's insurance is very different these days and it's almost, I don't want to say arbitrary but sometimes things are covered and not covered under the same, what I think is the same health plan, that kind of thing. And then, other barriers are like we all have a little bit of a status quo, what we're used to doing as far as what we were trained on and things like that, and so, it's hard to sometimes get away from what you're just comfortable doing.

Commented [6]: Codes (3203-3301)
Superiority of efficacy

Commented [7]: Codes (3660-3703)
Collegiality

Commented [8]: Codes (5114-5159)
Cost
Insurance/Prior authorization

Commented [9]: Codes (5395-5623)
Clinical inertia

QUESTION: Okay. It sounds like if you're trying to try something new, a new therapy, for example, then especially with some of the drugs that we're looking at for HAE that are newer, you are encountering issues of cost and insurance approval. Any patient-related issues that you've found when it comes to maybe trying a new therapy?

07: There's always some concern about certain side effects, I suppose, but HAE, it's kind of the patients that experience it, it's not common, and so it's not something that people think they just regularly know about like things like asthma. I would say patients often don't know what they're talking about, but there are a lot of people with asthma, so people kind of have their own opinions, often strong sometimes. But with HAE, I feel that it's relatively a niche [phonetic] where people just don't understand what it is, and so, they're more [phonetic] willing to just do whatever it is that I recommend, I would say most of the time.

Commented [10]: Codes (6375-6597)
Patient education

QUESTION: I see, okay. So patients don't necessarily have enough maybe baseline knowledge about the condition to have an opinion about it?

07: Yes, that's right [phonetic].

QUESTION: Okay. So it sounds like there is an opportunity for patient education there.

07: Mm-hmm.

QUESTION: Okay. Hmm, interesting. Is that different, do you think, from asthma?

07: Yes, like asthma, I always get a lot of patients who say like, oh, my brother needs this inhaler or that inhaler. Even some of the biologics for asthma, they're widely advertised now, so people already come in with a little bit of knowledge or preconceived notions, I guess, of what it is that they want or what they want to do. Some of it often is misled, but at least there is some opinion there, I would say.

QUESTION: Okay. All right, yes, that's true, you don't see the evening news blanketed with HAE advertisements.

07: Yes, yes.

QUESTION: And we probably never will, right? I mean, that would be—

07: Right.

QUESTION: —perhaps not the best use of advertising money. Okay. What do you think about the introduction of evidence-based practices in HAE, and why do you think they might be delayed when it comes from taking evidence-based practices and moving those into actual patient care? What do you think causes delays there?

07: Some of the same stuff we talked about, like I think at least when I was in training, there wasn't actually a lot of options as far as prophylaxis and things like that. There were some but I never really used them first line; it was always, I always used things like Cinryze and androgens before. And so, I think there is always this kind of like, this is what I'm used to doing and you know how to do it, even from the little things like how to order it in the EMR or whatever that you're using. Sometimes if you type things enough, it comes up as the first choice, you know? All these little things make it, there is very little barrier and you know you're not going to have a lot of pushback with insurance, you know the cost is going to be

relatively acceptable for most people. So I think there is a lot of, yes, you know what the evidence is, but there is a lot of other nonmedical barriers that get in the way of trying to do stuff.

QUESTION: Okay. And anything that you found that's been helpful in terms of getting over some of those barriers?

07: Helpful? I mean, it's always nice when it doesn't require some type of lengthy prior authorization from the insurance side to use some of this stuff.

QUESTION: So some of these issues around insurance and authorization contribute to delays in translating evidence-based practices in—

(Overlapping Voices)

07: Oh yes, absolutely [phonetic].

QUESTION: —healthcare, yes. Then it's, I think, pretty natural as human beings, right, you kind of want to take the path of least resistance sometimes?

07: Mm-hmm, right.

QUESTION: Especially in a very busy practice where you've got many, many people to see?

07: Yes.

QUESTION: And yes, it certainly can be more work to get started with something that's new in terms of educating patients, and then like you said, getting approvals and things like that.

07: Mm-hmm.

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

07: What do you mean?

QUESTION: So for example, if you're thinking about patient selection from prophylaxis, what has been your experience in determining whether a patient should have a long-term prophylactic therapy or not, or maybe they should be on a different long-term prophylactic therapy than the one that they're currently on? Any [unintelligible] that you found there?

07: Yes, I don't have a specific criteria necessarily for putting someone on long-term. It just depends on the number of attacks. But sometimes the number is relatively low, but then it could be the severity of the attack, like what organ was involved. And then, some of it is also the perception of the patient that you pick up on, like how, I guess for lack of a better term, traumatized they were by that event.

And then, as far as switching people that are already on long-term, usually, I don't initiate a switch unless there is an issue with a side effect like for some of the androgens, like their LFTs go long here or something; or like if the prophylaxis for whatever reason is not working, then that would be the main thing that initiates a switch on my end.

Commented [11]: Codes (8669-8673)
QUOTE

Commented [12]: Codes (8673-8830)
QUOTE
Barriers to translation

Commented [13]: Codes (10380-10665)
Fear of episodes

QUESTION: Okay. So when thinking about doing a switch for prophylactic therapy if there was a side effect issue or an efficacy issue, that would tip you towards putting them on something different. Have you had patients who have pushed back on the idea of starting on a prophylactic therapy?

07: Yes. I would say, I don't know percentage, but there's a good chunk of people that do not like the idea of it, and then a good chunk of people that are open to it, I would say, because like I said, whatever they went through, it was just so bad for them, they're like, anything to not ever experience that again. They're open to it [phonetic].

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

07: How do I evaluate it?

QUESTION: Yes, how do you kind of get a sense for that in your practice?

07: I do try to kind of quantitate as far as if they tell me things, like if they're a student, how many days of school they've missed; or if they're like a working person, what impacts it has on [phonetic] work, you know?

QUESTION: Mm-hmm.

07: Those are the main ways I try to objectify the impacts on their life, but also I think in my notes, I write something like, symptoms are very burdensome or something like that to give me a sense of this is really bothering them.

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

07: Yes, yes.

QUESTION: Do you guys use those in your practice or have you considered that?

07: Not regularly, no.

QUESTION: Okay. Just out of total curiosity, I'm a former pulmonary and critical care physician who took care of a lot of patients with asthma, do you use like ACT, ACQ, those types of measures with your patients with asthma?

07: Yes.

QUESTION: Okay. And I guess that really isn't so much quality of life, right? Those aren't really quality of life instruments; those are more looking at elements of what we consider to be asthma control, right?

07: Right.

QUESTION: Little different [phonetic].

07: Mm-hmm.

QUESTION: But you guys are using those as kind of a regular assessment tool?

Commented [14]: Codes (11914-12133)
Quality of life

Commented [15]: Codes (12541-12632)
HRQOL self assessment instruments

07: Yes. For like our asthmatic patients, it's kind of part of their pre-check-in paperwork usually, yes.

QUESTION: Interesting, okay. How do you engage patients in treatment decisions about long-term prevention or reduction of HAE attacks?

07: Mostly it's like anything: it just starts with a discussion of why I think they should be on something, and I just try to kind of walk them through the pros and the cons of being on something versus not, and side effects and that kind of thing.

QUESTION: Okay. Any challenges that you have encountered in trying to get patients engaged in that decision with you?

07: For the most part, no. I would say my threshold for recommending someone be on long-term prophylaxis is, you could say it's high. So by the time I'm recommending stuff, this kind of thing, the long-term prophylaxis with somebody, I mean, they have already been hospitalized, even intubated, or they've had a significant burden of symptoms like if it's someone with a lot of GI symptoms, I mean, we're talking a few times a month for stretches of time, they're in pain or whatnot. And so, I don't usually get a lot of resistance, I would say. I will say sometimes they want to, and then cost becomes an issue, so that's a different type of resistance. From the patient themselves, I don't get a lot of resistance because I'm kind of, I don't want to say late but I'm a little bit, I have a higher threshold before I initiate that conversation.

Commented [16]: Codes (13853-13959)
Barriers to prophylaxis
QUOTE

Commented [17]: Codes (14059-14309)
Promoters of translation/ prophylaxis

QUESTION: Okay. How do you go about choosing medications for long-term prevention or reduction of HAE attacks?

07: What I'm trained on is, like when I was in training, Cinryze was, I don't want to say the standard of care but what we used, and so, it's kind of what I'm used to and what I know and very familiar with. I used a lot of androgens, too, in training, and so, as long as they're not a female and they want an oral option, androgens are very open to me. Otherwise, everything else is kind of a case-by-case basis of just [phonetic] to use this other stuff out there.

QUESTION: Have you used some of the newer therapies that are available, the more targeted treatments that have come out in the past several years?

07: Yes, I've used some, but like I said, it's still I'm a little hesitant here and there still with some of this newer stuff, I would say.

QUESTION: Okay. Can you tell me a little more about what kind of makes you feel a little bit hesitant about the newer treatments?

07: It's the track record is just not as long, I guess. So I remember someone being like, you never want to be the first kid on the block to use something, so that kind of mentality. And then, I remember, what's that oral one, Orladeyo or whatever it's called, I remember trying to use it, and trying to get it approved was a very long process. And so, it's just a lot of pain to go through to get something approved.

Commented [18]: Codes (15756-15822)
Hesitance with new products

QUESTION: Okay. So kind of discouraging then from trying to go through that, okay. Clinical guidelines as you know are one way that research gets translated into clinical practice. What effect do HAE clinical guidelines have on your practice?

Commented [19]: Codes (16332-16668)
Guidelines

07: I still try to follow evidence-based medicine and try to follow standards of care, which I think are often established by clinical guidelines that seem to come from like reputable sources. And so, I do try to follow them as much as I can within reason, but as the name says, they're guidelines; they're not rules or mandates, I suppose.

QUESTION: Okay. Is there anything else that comes to mind while we're talking that you think would be good for me to know? This is actually the last question for this afternoon, but anything else, any other thoughts that you have about HAE that might have come up during the interview?

07: I mean, it would be nice, I don't know how it's possible, but I think one of the barriers to care is not the physician, not the patient, but it's always cost, insurance, that kind of thing. And so, if there was a way for this stuff to be a little bit more streamlined, I think it would make it easier, hence better for everybody involved. But I know that's not always easy.

QUESTION: No, it's not always easy, but I also think it's important for people to recognize that that is a factor, and it's certainly beyond my personal level of expertise as a former academician and clinician. I don't know how to solve those problems.

07: Right.

QUESTION: But on the other hand, it really does, as you've described today, there are some very practical and fundamental things that flow from that, right? So hesitancy to use something that's new, difficulty arranging a treatment that a patient may actually want to try or be on.

07: Right, yes.

QUESTION: And therefore, sort of a subconscious and sometimes conscious preference to use what's older and what's already out there instead.

07: Oh, yes.

QUESTION: And those are things that I think do impact clinicians on a daily basis. And people are very busy. You don't necessarily have time in your practice, I imagine, to go and solve all, I mean, you've got practice issues, right? You've got to have somebody on the phone trying to help you do this.

07: Right.

QUESTION: So there are many, many practical issues, I think, that definitely impact trying to get some of these newer treatments out and used. So at any rate, thank you so much for your time. We very much appreciate your taking a moment out of your day to chat with us.

07: Yes. [Unintelligible].

[redacted]

07: Okay.

[IRRELEVANT MATERIAL OMITTED]

[END 07 5.8.24.M4A]