CMEology

HAE – Hereditary Angioedema

Interview with “09”

March 12, 2024

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CMEology

Interview with 09 – Hereditary Angioedema

[START 09 3.12.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: As you know, we're talking about HAE, hereditary angioedema, today.

[IRRELEVANT MATERIAL OMITTED]

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

09: I did some research on HAE during my fellowship, and I also wrote an article for, why don't I find it for you and send it over to you, reviewing some of the medications with a drug company. And I worked with my mentor, my program director who was a big poodle [phonetic] in HAE, so we learned a lot in HAE.

QUESTION: So you learned a lot. Yes, okay.

09: Yes. And we had a lot of patients in research at our center where I trained at [redacted]. We had a lot of HAE patients, too.

QUESTION: All right. So when you're looking at the HAE literature now as a practicing allergy immunologist, what sorts of things are you looking for, and what sorts of questions are you hoping to ask as you approach the literature now?

09: How many acute attacks they have in a week or in a month, and how severe it's debilitating their illness, right? There are so many drug options right now out there, so we want to decide if we want to go prophylactic versus just treat acute attacks.

QUESTION: Okay. So you're using the literature to look at those particular clinical questions?

09: Uh-huh [phonetic].

QUESTION: Okay. Second question is: when you're considering the implications of HAE research for clinical care, is there any particular format in research results that's more influential to you? So I will give you some examples of formats. Example: abstract, a poster, a live conference presentation, academic detailing in your office, UpToDate or a similar point-of-care reference, or journal publications – is there a format that you prefer or is more influential for you when you're looking at the implications of HAE research, or thinking about that?

Commented [1]: Codes (2221-2267) Professional Conferences

09: I think presentations at national conferences. That is one thing that is influential to me, an abstract. Also, poster presentations are easy to navigate through.

QUESTION: Okay. Do you find that you're able to attend conferences, society conferences?

09: Yes. I try to attend one for allergy immunology like the Core-DI [phonetic] every year usually. So I would, yes, I didn't this year, yes, I would have loved to hear a little bit more about the HAE new drugs and new stuff coming in [unintelligible].

(Overlapping Voices)

09: Maybe some posters, yes [phonetic], mm-hmm.

QUESTION: If you're not able to attend the conference, for example, like this year where you just weren't able to go, what would be your—

09: I went this year.

QUESTION: —oh, you did go this year, okay. If you're not able to go, what is your next kind of go-to resource if you have questions about the research and implications for clinical practice?

09: I think drug reps are a good source, too, when you're in a busy clinical practice.

QUESTION: Sure.

09: If they can come and leave some information quick, you know, an abstract or an article, that's really helpful. Or even like email, like a quick abstract something, you know?

QUESTION: Okay.

09: Through the Academy or College, whatever, or if you want to join a society or something, just a quick update just for the week, you know, this is the update. I mean, sometimes in clinical practice, you don't have time to go through articles, so just like a brief summary of it or something.

QUESTION: All right. Third question: what factors are most important to you in the process of interpreting the HAE literature and applying it to clinical care? So are you interested in acquiring skills, knowledge? Does interaction with colleagues or the amount of time that you have, is that a factor in being able to look at the literature and apply it?

09: Yes, the time, obviously, and the interaction with colleagues who are experts, too, would be helpful, right? You don't see that, it's not a common disease, that would be helpful, or easy access on a website or something, too, like ASCO [unintelligible] specialists or something for healthcare people. So that it could be like sometimes the patients are complicated and you don't know, type 3 or are they really, or even acquired angioedema and stuff like that. So it would be nice to see, to have a conversation with somebody.

QUESTION: Okay. Would you say that you have more questions about diagnosis with patients, or is there more of a debate in your mind about how to treat them?

09: Diagnosis not so much. Sometimes they can be [unintelligible] like with type 3, or sometimes when they have normal baseline but then during attacks, they have, right, so I mean, that's easy to diagnose. It's sometimes deciding which medicine to use and which one will get approved or getting it approved through there.

QUESTION: Yes, okay. Through their insurance?

09: And which is the right fit, the right fit because I don't use it a lot, so I don't know which one to select.

QUESTION: Okay. So it sounds like being able to interact with colleagues who may or may not be experts, or being able to approach someone else to give you a hand with that is an important way to gain more information.

09: Mm-hmm.

Commented [2]: Codes (3161-3198)
Pharma rep detailing/MLs

Commented [3]: Codes (4149-4197)
Collegiality

Commented [4]: Codes (4583-4649)
Collegiality

QUESTION: Question four: can you describe any barriers that you found to incorporating research findings in HAE into clinical practice? It sounds like time is a barrier when it comes to—

09: Yes.

QUESTION: —looking at the literature, trying to figure out what to do, yes, I think that, of course, is very understandable especially these days. Are there any other kinds of barriers that you find get in the way of incorporating or applying the research to clinical practice? So for example, patient-related barriers, practice-related barriers—

(Overlapping Voices)

QUESTION: —institutional things that get in the way?

09: The patient-related, yes.

QUESTION: Patient-related?

09: Patient-related if they get an oral versus injectables, right, IV versus sub-Qs. Or it could be also financial, right, both to the patient and to the insurance, and first to get what approved and what financial burden it's going to put to the patient and the time commitment, too, that's going to go into it.

QUESTION: Okay. Tell me a little bit more about what the time commitment piece of it is for patients from your perspective.

09: I mean, if it's an oral pill, it's easy, right, then versus if they have to sit down and think about it and giving them an injection themselves, or to go to a center to do an injection which will require a lot more time, yes.

QUESTION: Right. So the injections would require obviously not only the time that they would have to spend if they're doing the self-administration at home, but then, it sounds like for many people, also, injections involve, of course, having them come into the office and learn how to do that and—

09: Yes.

QUESTION: —watching them.

09: And also to think about it, storage, stuff like that.

QUESTION: Sure.

09: The added [phonetic] steps to it.

QUESTION: Okay. Any practice-related barriers or institutional-related barriers that you find get in the way of translating research findings?

09: Approval.

QUESTION: Approvals? Yes.

09: Getting approvals, yes, or prior authorizations and obviously insurance is big.

Commented [5]: Codes (5667-5728)
Provider time constraints

Commented [6]: Codes (6299-6527)
Cost
Insurance/Prior authorization

Commented [7]: Codes (7530-7610)
Insurance/Prior authorization

QUESTION: Right, okay.

09: Yes, that's the biggest barrier [phonetic] there.

QUESTION: Yes, okay. Do you have somebody in your practice who can help you do those things?

09: Yes. I have a nurse who does all my biologics and everything for asthma and atopic dermatitis and HAE. I don't have a lot of patients with HAE. I have treated one or two, and still, nobody is stable, people move [phonetic].

QUESTION: Sure, okay.

09: [Unintelligible] is more required, which I'm finding out, so yes, I don't have a lot of constant patients.

QUESTION: Okay. But clearly, as biologics and other specialty drugs move into allergy immunology practice, it's not as simple as it used to be.

(Overlapping Voices)

09: Yes, but now we're getting used to it. That's why I would like to see more of HAE drugs being talked, like the biologics for asthma are being talked about, like differences and when to use which one, and which one to give first, which ones for what, like what are the parameters you're looking for? So a little more, a table like an easy form maybe of different medications; or maybe more, little more lectures on it and allergy [phonetic] academy meetings or even local meetings then [inaudible] maybe some dinners, too, around here which maybe we could go to, and I think they do some, but it's more like drug-specific, not general, like comparing all of them.

QUESTION: Yes. Well, it's true. I used to be, in my previous life before I became involved in medical writing and medical research, I took care of a lot of patients with asthma, and clearly, the biologics and the availability of highly-targeted treatments has changed not only the treatment landscape but also just how difficult it is to get patients connected with the medicines that we feel that they need. So having to do prior auths, having to try to find specialty pharmacy if that's necessary can really be quite a process now. It's not as easy as it used to be where you could just write a script for somebody for—

09: Yes.

QUESTION: —a combination inhaler and send them on their way.

09: I know, I know. So that's what I'm saying, and for these drugs, and these are so expensive each, you even think about before writing a prescription, am I doing the right thing, you know, doing it even because they are so expensive, way more than the asthma biologics.

QUESTION: Yes, yes, it's very complicated, I agree. So question five: what do you think introduction of evidence-based practices, or why do you think introduction of evidence-based practices may be delayed in HAE care? So what things get in the way of taking research findings and applying them in clinical practice?

09: Yes, I think it's just because of the rarity of the disease. We don't see it a lot, and then we don't hear about it a lot because [inaudible] right? So we don't see it, and the more patients you see, the more

Commented [8]: Codes (7644-7671)
Insurance/Prior authorization

Commented [9]: Codes (8169-8297)
Excess choices

Commented [10]: Codes (9430-9526)
Pharmacy

Commented [11]: Codes (10309-10347)
Lack of information

experience you get with every drug, everything, every side effect. And I think the hesitancy for primary allergists in the community also to do this is because it's a little more involved, so we try to [unintelligible] these patients even try to go to a big university center themselves. Even when they know they have such a rare disease, they don't want to stay local. [Inaudible] and then, sometimes we don't have the resources even or we don't have all the options or treatment.

(Overlapping Voices)

QUESTION: What options for treatment might you lack?

09: It's just knowing the knowledge or the comfort level because [unintelligible] the comfort level of using them multiple times in multiple patients.

QUESTION: Okay. And that's clearly something that's a little easier to gain with a common condition like allergic rhinitis or even severe asthma, right?

09: Yes.

QUESTION: Where you're probably seeing, I don't know how many patients in a week, right, but you certainly would have more than just one or two people in your practice with that kind of condition, it does make it difficult.

09: Yes. So that's why, just the [inaudible].

QUESTION: Okay. Are there any things that you think would help you get over those barriers? I mean, it is a rare disease, so we really can't change that.

09: I know, [unintelligible].

QUESTION: Is there anything else that would help you feel more confident or would help you gain the experience that you feel that you need to be able to use research findings more confidently in your practice?

09: Yes, just discussing more of it at any conference level, or even journals or even, like I said, emails or even through reps, sometimes it's easier to get things across quickly; or even a fax or something to [phonetic] offices who are interested, or a newsletter, you know? A newsletter might be a good thing, too.

QUESTION: Okay. Does your practice, just out of curiosity, do you have a journal club or maybe a grand rounds or anything that helps you gain knowledge or keep up with it [phonetic]?

09: No. I'm a solo practitioner.

QUESTION: Oh, you are? Okay.

09: I'm in private practice [phonetic], yes.

QUESTION: Okay. And I imagine, do you go to grand rounds, for example, at your hospital, nearby hospital?

09: [Inaudible].

Commented [12]: Codes (10564-10687)
Cases too complex for diagnosing MD

Commented [13]: Codes (12056-12107)
Professional Conferences

QUESTION: Yes, okay. So you're really trying to keep up with these things on your own within the context of—

(Overlapping Voices)

09: That's why I try to go to the Core-DI once a year, which is a resource for me. I would like to listen to more of what's going on there. There were a few ID [phonetic] lectures but not a lot, a lot like the pathologics and—

(Overlapping Voices)

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

09: What's my experience been?

QUESTION: Yes.

09: Well, as a fellow, I've seen, we used to have a lot of [unintelligible] all these available whenever they had an attack, right? I think the biologic was still coming up. I am not sure if I even used it on anybody as a prophylactic. And [unintelligible] wrote an article on what the side effects were on that before, but nobody uses that right now, right?

QUESTION: Yes, that's not preferred practice.

(Overlapping Voices)

09: Yes, but I mean, I've talked to my mentor, obviously it's life-changing for patients, right, who are on once-a-month injection and they don't have to worry about acute attacks and [inaudible].

QUESTION: Yes, okay. So it sounds like you're able to identify patients who would potentially benefit from being on long-term prophylaxis—

09: Yes.

(Overlapping Voices)

QUESTION: —and that you understand what the potential benefits for that person would be in again not having to worry so much about suddenly needing acute therapy.

09: Yes, that's right [phonetic]. Yes, and I think I had one patient, I also tried to get her on an oral biologic, but I don't think we were able to, and I think I lost to follow-up on her. But yes, we tried to get her approved for these because she was having these attacks that were severe, and we tried to, I don't know if I can say a name of a drug?

QUESTION: Sure.

09: Am I?

QUESTION: Yes, you're allowed, sure.

09: She was using the Ruconest, right?

QUESTION: Uh-huh.

09: And that was helping her. But those were just acute attacks. So I tried to put her on prophylaxis and I'm not sure what happened. I was unable [phonetic] to.

QUESTION: Okay.

09: Or maybe I was able to use some sample and she got some GI side effect with the pill. Then I don't know, I haven't seen her for a long time. I can maybe look in her chart.

QUESTION: Yes, okay. So one of the barriers, it sounds like, is just sometimes with these chronic diseases, is holding onto people long enough in a practice to know what actually happens to them. And clearly—

(Overlapping Voices)

QUESTION: —people move, people change insurance.

09: Yes, I think she went somewhere [unintelligible] yes.

QUESTION: Yes, there's all possible—

09: People change insurance and move, yes.

QUESTION: —all kinds of reasons that [unintelligible].

09: I think I tried for Orladeyo for her last, and I saw her a year ago, so [inaudible].

QUESTION: Okay.

09: [Inaudible] 2022 had to discontinue because of significant diarrhea and nausea.

QUESTION: Oh, I see. And that was with the pill formulation?

09: [Inaudible] yes, Orladeyo, oral.

QUESTION: Yes.

09: And I think I was going to try the lanadelumab [inaudible] but I guess [inaudible].

QUESTION: Okay. So seventh question: how do you gather and assess information about the impact of HAE on patients' work, school, family life?

09: How do I gather?

QUESTION: Mm-hmm.

09: Just by questioning, interview during the visit.

Commented [14]: Codes (16238-16287)
HRQOL self assessment instruments

QUESTION: Okay. Is there anything that makes that a difficult process for you to get the information that you need about the impact of HAE?

09: Well, usually patients, yes, will be open about it. Sometimes you have to dig in. Sometimes they're used to it, right?

QUESTION: Sure. Okay. Are you aware that there are validated tools or questionnaires for assessing HAE in terms of the health-related quality of life issues and their impact?

09: Repeat the question?

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

09: No. Yes, I mean, I think I have done it on research with [redacted] [phonetic], but I don't use it actually.

Commented [15]: Codes (16978-17003)
HRQOL self assessment instruments

QUESTION: Okay. So you're aware there are tools having been used [unintelligible] setting.

09: Yes, but I don't use it. I know, yes [phonetic].

QUESTION: Okay, got it. And you actually, you said you had some experience when you were doing your research as a fellow using a quality of life instrument?

09: Yes.

QUESTION: Yes? Okay. Interesting.

09: [Inaudible].

QUESTION: Okay, next question: how do you engage patients in treatment decision-making regarding long-term prevention or reduction of HAE attacks?

09: [Inaudible].

QUESTION: So how do you engage patients in treatment decision-making regarding long-term prevention or reduction of HAE attacks?

09: I guess just by giving them pros and cons of what are the treatment options, the benefits [inaudible] their input and obviously [inaudible] decision with them [inaudible] centered decision-making.

Commented [16]: Codes (17816-17873)
Patient centered decision making

(Overlapping Voices)

QUESTION: Are there any challenges that you find when you're having those discussions with patients about long-term prophylaxis?

09: Obviously finding the right drug and [inaudible].

QUESTION: So the process of finding the right drug with a patient, can you tell me a little bit more about what that involves for you most of the time?

09: The age of the patient, what method they would want to take [inaudible] how committed they are, right, to do it, [inaudible] week, a month [inaudible] medicine or they're just willing, if their attacks are not that severe, if it happens once in six months, maybe they're not willing to do something [unintelligible]. So just getting the quality of life, like you said, assessing that.

QUESTION: Okay. Next question: how do you choose medications for the long-term prevention or reduction of HAE attacks?

09: Like I said, patient-centered decision based on if they want injectable or oral. I know there are just a few out there; there are probably more out there than I know right now. But yes, I just know about the oral and the biologic. That's what my go-to would be for long-term.

QUESTION: Okay.

09: [Inaudible].

QUESTION: It sounds like if you were given the option of having more information about different treatments, so compare a better, some kind of presentation of how those medicines are similar or how they're different, how they can be used in different kinds of patient scenarios, different patient preferences, et cetera, that that would be helpful to you when it comes down to making decisions about which ones, which medication to treat.

09: [Inaudible].

QUESTION: Okay, we're almost done. Next question: how did participation in this CME activity influence the way you think about translating research evidence into clinical care in HAE?

09: Obviously, it gets you to know more about what's out there, what other options are available. I think it's a moving field. There's always [phonetic] a lot of research going on and there's always new drugs coming up. You wouldn't know if you didn't go to a lecture or a CME that other options are out there for you.

QUESTION: Okay. On the basis of having participated in this CME activity, have you been able to identify any changes that you would like to make in your own practice?

09: Just talk to them more about their quality of life, what the options are, and discuss various other options available and put it on the table and let the patient decide which one they want [inaudible] their insurance decide.

QUESTION: Right, exactly. Next question: clinical guidelines can be one way that research is translated into clinical practice. What effect might HAE clinical guidelines have on your practice?

09: I don't have a lot of patients, so I can't speak for [inaudible].

QUESTION: Yes, of course. And you are aware that there are clinical guidelines on HAE?

09: Yes.

QUESTION: Yes, okay. Is that something that you would consider turning to as a resource if needed, asked?

Commented [17]: Codes (18762-18830)
Patient centered decision making

Commented [18]: Codes (19773-19805)
CME

Commented [19]: Codes (20204-20255)
CME

09: Yes. Always, yes.

QUESTION: Yes.

09: [Inaudible] because then it's all expert guidelines, so it's [inaudible].

QUESTION: Yes. And they've been relatively recently updated in HAE, and I expect that will probably accelerate as more therapies are introduced into the market. I think that always seems to be the impetus for updating clinical guidelines. Of course, then the challenge for clinicians is sort of you're trying to keep up with the new drugs that are out there, and then, you're also trying to keep up with the new guidelines that come out. So it does require some time and effort which many of us don't have on a day-to-day basis, that's for sure.

09: Mm-hmm.

QUESTION: Okay. Is there anything else that comes to mind while we're talking that you think is important that people know about treating HAE?

09: It's a rare disease and sometimes people don't even know what to look for, check, your primary care doctors. People go with abdominal pain for many, many years before they're getting diagnosed, right, with HAE. It takes about—

QUESTION: Yes.

09: —I think average 10-15 years for people to get diagnosed.

QUESTION: Yes.

09: So I think refer early, let the specialist order all the blood work, detailed like C1 [phonetic], sometimes they order one, they miss the other function they miss. So I think just refer early anyone diagnosed with abdominal pain or throat swelling or anaphylaxis or whatever it's called in the ER, angioedema, I think should be referred to an allergist for further evaluation [inaudible].

QUESTION: Yes, as I was reading about this and helping to put together the CME activity on this topic, I did think about all the patients that I have run into over the years with unidentified, unidentifiable abdominal pain.

09: Yes. That's what's common, yes.

QUESTION: Yes, and how many of those people are told, well, you've got irritable bowel, or you've got whatever.

09: Yes, I know.

QUESTION: Right? And just—

09: IBS, and they get appendectomy and so many surgeries, right?

Commented [20]: Codes (21736-21846)
Primary care misdx or no knowledge

QUESTION: —yes, and unfortunately have invasive procedures and other things, and it is a definite sign that all of us need to be thinking about this as something in the differential for some of these unusual presentations. Angioedema, upper airway swelling: I mean, that will get your attention really fast, right?

09: Right.

QUESTION: But some of these things that involve the internal organs and mucosa, it can be really very cryptic.

09: Yes.

QUESTION: Anyway, we are in fact looking for other physicians and healthcare providers who would like to participate in this survey, so if you do run into any colleagues who may be interested in participating, you now know what it's like and we would be absolutely delighted to have them join us. We would, of course, offer them the same compensation appreciation token as we are offering to you. So if you do run into someone, [redacted], who is the person who has been corresponding with you and she is the person who set up the interview, if you would kindly email her or have your colleague email her, we would be delighted to include them in our studies.

09: Do you me to send my [redacted] I wrote? I found it while [inaudible].

QUESTION: Yes. Yes, if you could send that to [redacted]

09: I'll send it [redacted] yes.

QUESTION: Yes, that would be amazing. I would very much appreciate that.

09: All right, wonderful. I sent it right now, okay? She should [inaudible].

QUESTION: Okay, great.

[IRRELEVANT MATERIAL OMITTED]

[END 09 3.12.24.M4A]