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Welcome to Yale Cancer Answers with doctors Howard Hochster, Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers is our way of providing you with the most up-to-date information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week it is a conversation about alternative medicine versus conventional therapy with Dr. Skyler Johnson and Dr. James Yu. Dr. Johnson is a Resident in Therapeutic Radiology and Dr. Yu is an Associate Professor of Therapeutic Radiology at Yale School of Medicine. Dr. Gore is a Professor of Internal Medicine and Hematology and Director of Hematologic Malignancies at Smilow Cancer Hospital.

Gore So, Skyler I understand you are training in therapeutic radiology.

Johnson Yes, that's correct. I have been in radiation oncology for 3 years and did an internship for 1 year. So, I am 4 years deep.

Gore Got it. And James you are an old hat.

Yu Yes, this is my 9th year on faculty, if you can believe it.

Gore Well, I can believe it because I have only been here for four years, so as far as I know you have been here 20 years, but you look too young for that, so that's good. And just to start off, Skyler, I assume that you went into therapeutic radiology because you were interested in offering radiation treatments to the patients. No?

Johnson That is a fair assessment. Actually, I have kind of a personal connection to cancer care. My wife was diagnosed with Hodgkin's lymphoma when I was a second year medical student. So, throughout that process, I realized it was a great field to be in - an opportunity to make a big difference in the care of patients and that is kind of what led me into radiation oncology.

Gore Well, great and certainly we love our radiation oncologists and value you all and refer patients to you, less so in my field than, in which leukemia, where we need you less, but sometimes we do of course. So, Skyler what got you interested in alternative therapies, which seem to be like the antiradiation.

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Johnson Yes, so I think it is something that we were seeing with increasing frequency in the clinic. We were seeing patients who were initially refusing their recommended cancer therapies, and then on the flip side, we were seeing them come in late with more advanced cancers that had spread to lymph nodes or distant sites just based on the fact that they wanted to upfront try something a little bit different or unproven, and this was concerning, we went to the literature

and we said how can we help these patients make an informed decision and there was nothing out there. So, we felt like it was an important question that needed to be studied further.

Gore So, tell me about the subject of your study and what you guys were... what questions you were asking and how you went about that. I mean, from my perspective as a cancer doctor, patients bring in lots of lists of all sorts of supplements they take, turmeric is a big one these days and any number of other things. So, what do you include in alternatives and what was your how to go about it.

Johnson Yes, so basically I do a lot of cancer outcomes research in large databases and found this particular code that I felt was very interesting and it was basically patients who chose unproven medical therapies in lieu of conventional cancer therapy....

Gore Just a minute, I am sure that our audience does not know what a code is or a big data set is because I know that before my wife and I started collaborating, because she is an outcomes health economist, about 10 years ago, I did not know what they were. So, what is a big data set and what is a code.

Johnson So, basically, there is information that is collected about cancer patients nationally within a large database, and every time a patient makes a decision or information about the patient is collected in this data set, and then we can look at this information to evaluate outcomes.

Yu All the data is anonymous.

Gore I was going to say - is the NSA involved? Citizen four? Talking about I have to turn off my cell phone now.

Yu No, no. I mean these data sets were created to provide national information how we are doing as a society in terms of curing folks.

Gore So, they are not spying on Steven Gore, not spying on... they should be reporting that to my employer. Yu Exactly illegal to try and figure out who Steve Gore is, etc.

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Gore I am very relieved now. Okay, so there are these organizations and I guess some of them are like the National Institutes of Health that is agglomerating all this data. I guess the Centers for Medicare and others.

Johnson It is a commission on cancer accredited centers, that is basically a joint venture with

Yu It is College of Surgeons and National Cancer Database.

Johnson So, it is 1500 basically cancer centers, nationwide, academic and both community centers and it captures 70% of cancer diagnoses annually.

Gore So, the patients anonymously get entered into a database, and what information gets collected about them.

Johnson So, it is their age, their diagnosis, their stage, their education, their socioeconomic status, and then their survival, types of treatments that they received, so on and so forth.

Gore Okay, and all of that is in some kind of a code, or is there is a code for different treatments or what?

Johnson Yes. Exactly right.

Gore Okay, you found this unusual code.

Johnson Yes, it was kind of unusually specific and so when we look at the code, we saw that these patients were using unproven medical therapies for the treatment of their cancer and also refused surgery, radiation or chemotherapy.

Gore Does it show that they refused.

Johnson Yes.

Gore Okay. Because like when I have a patient on supplements, I do not like put in a code says that. I wonder how that happened.

Yu Right, so the registrars right, the folks who are abstracting the data will include, 'Mr. So and So refused therapy in favor of vitamins or in favor of baking soda.'

Gore So, we know who you are people. But it is anonymous.

Yu We do not know who you are.

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Gore We do not know you are, but we know what you are doing.

Johnson And it's important distinction as well is if you are seeing a patient, you are likely offering them conventional cancer therapies and they may be doing something on the side or in addition to what you are recommending, you may not think that is of particular interest, you may not put it in your note for registrar to abstract that data, but those patients who refuse those therapies, it stands out a little bit more and it is something that a doctor would know.

Gore At the end, doctor would want to note it because if nothing else from a medical/legal standpoint, he or she wants to document that he offered or she offered an appropriate therapy and explained why it might be the usual recommendation or her recommendation and why the declined that, I mean I think that is what most of us would want to do if nothing else to cover our own butt's right?

Yu Exactly.

Gore Okay. So, you found this code and you went to James and said "James I have got a code," how does that work out.

Johnson It was basically that. It was kind of a Eureka moment, because I think that it is an important question like I said, we have been seeing in clinic and it is an important question that there is really no literature out there to speak off, and basically these are hard patients to follow because usually they say they are going to do this and doctors - they talk to them and they eventually leave and sometimes do not return, so we do not really know what happens to them.

Yu And we were seeing it in the clinic, and we would see patients come in a more advanced stage of cancer than really they should have been in and they would report that they had tried something else before coming in, and we did not know what the impact of that was. Whether maybe they are just as curable as folks who try standard therapy because of all the great things about modern medicine in try and cure these folks, but does it seems like, those patients were doing worse because they were more advanced when they came in.

Gore Yes, but we know you conventional medicine people have this bias against alternative therapies, right. So, you are looking to feel that way.

Yu So, one of the things about looking at the data was that all of the biases seemed to favor alternative medicine patients. They were younger...

Gore Okay, let's just wait a minute on that. So, you got the code, you shared it with James and now what? I mean I have got a pile of patients who have a code that they are using something else, I don't know what to do with that. I would have no idea what to do with that.

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Johnson Well, we basically had 2 questions going into it. We wanted to know who is making this decision and what is the impact of that decision. And so, we started by characterizing the patients who were choosing alternative medicines.

Gore Just describing who they were. Without their names?

Johnson Exactly. And then we compared their survival to patients who were using conventional cancer therapies.

Gore Okay, so who is using alternative therapies. Who are these people? What kind of people are they?

Johnson It is a question and this is a really interesting finding that is kind of being passed over in the lay media quite a bit is that patients who are making this decision are generally younger patients who have higher socioeconomic statuses, they are generally higher educated...

Yu They are healthier, they have fewer comorbidities, they typically live in the mountain west or the west. I mean these are healthy folks going into it, so, you would think that they would be the cohort that does better, all things equal.

Gore You mean, they do better medically.

Yu Do better medically. Exactly, you are younger, you are healthier, you have fewer other problems, you should be doing better in terms of your cancer cure.

Gore It is kind of interesting and maybe we can get into it in the second half, but I think about how this is also potentially the information millennial generation if you will, that has access to how to do research and that might be the least likely, but that is something we can talk about. Okay, so you described who they are, they are not people of a certain age like me, although I got plenty of patients my age who are doing this too, okay. I don't know, it does not seem to me like you can just compare them because maybe one of them has a little ditzel of a lung cancer and the patient is getting chemoradiation of big ol' lung cancers, right? So that is not going to be apples and apples comparison, like what do you with that data.

Johnson So, we actually did a matching comparison. Basically, we matched 2 patients who did conventional cancer therapies to 1 patient who chose alternative medicine therapies on specific characteristics that we thought would impact their survival, so we matched them on their cancer type, we matched them on their age, their stage of disease, we matched them on their insurance type, we matched them on their race, we matched them on the year that they were diagnosed, basically everything that we thought was important in regard to their survival.

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Gore So, basically you are taking patient A who opts out of conventional therapy and you look at the features of this patient and then you find a patient in the same demographic of treated around the same time for the same cancer and all the same features or you find 2 of them, is that...

Johnson Exactly right.

Gore Gotcha. And did you do this across cancers or did you limit yourself to certain cancers?

Johnson We did it for the four most common cancers. We looked at breast, prostate, lung and colorectal cancer and curable stages, I through III.

Gore In both radiation and chemotherapy??

Johnson As well as surgery.

Gore As well as surgery. So, some of these patients are even getting surgery?

Johnson Exactly. None of the patients in the alternative medicine group got surgery.

Gore Really. Wow. How many patients then were in this database you looked at. I mean how many patients did you select?

Johnson So, basically there was 280 patients who chose alternative medicines and then we compared this to the 2 patients who got conventional cancer therapy. Basically, over 800 patients total.

Gore Okay. I do not know what to guess the outcome was. I have no idea. I am going to guess that maybe it turned out that it did matter that it is for these healthy guys and women they can do stuff and they are still healthy enough to get treated so that everything comes out okay.

Johnson Steve, you'd be wrong.

Yu Unfortunately, and you know it was a little sad when we saw the outcomes and we can go into it more.

Gore Well, give us a little hint before the...

Johnson So, basically patients who chose alternative medicines for the treatment of their curable cancer were at 2-1/2 times greater risk of death over the study period than patients who chose conventional cancer therapies.

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Gore Well, that is a sobering thought, but right now we are going to take a short break for a medical minute.

Medical Minute Support for Yale Cancer Answers is provided by AstraZeneca, working to pioneer targeted lung cancer treatments and advanced knowledge of diagnostic testing. More information at astrazeneca-us.com. It is estimated that over 200,000 men in the US will be diagnosed with prostate cancer this year, with almost 3000 new cases in Connecticut alone. One in six American men will develop prostate cancer in the course of his life time. Major advances in the detection and treatment of prostate cancer have dramatically decreased the number of men who will die from this disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using 2 simple tests -- a physical exam and a blood test. Clinical trials are currently underway to test innovative new treatments for prostate cancer. The Artemis machine is a new technology being used at Smilow Cancer Hospital that enables targeted biopsies to be performed as opposed to unnecessarily removing multiple cores from the prostate. More information is available at YaleCancerCenter.org. You are listening to WNPR, Connecticut's public media source for news and ideas.

Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore and I am joined tonight by my guests Dr. Skyler Johnson and Dr. James Yu to discuss patient choices for cancer treatment, in particular what happens to patients who chose less conventional therapies as opposed to recommended more traditional medical therapies. So, Skyler before the break you kind of dropped this bombshell in this big database you looked at, you found 200, almost 300 patients who had opted not to get treated including not getting surgery for their presumably potentially curative cancers I suppose, and compared them to

similar patients who went the usual route, and you said there was a 2-1/2 times likelihood, 2-1/2 increased times risk for patients of death. So, the patients who had alternative therapies had almost 3 times or 2-1/2 times the risk of dying during the study. Is that right?

Johnson Yeah, that is exactly correct. It was really sobering to see that number and we look at these in different ways and we have figures and kind of these graphs and we saw these people who chose alternative medicine, it was kind of sad to think while these people could have been on this other portion of the graph, they could be alive.

Gore You know, just for our audience who may not know the Journal of the National Cancer Institute is really one of the most prestigious medical journals in the United States, and so for them to pick up on this, it is not easy to get an argument to this. They must have really seen this as a really important finding. Was that true across the board for all the cancers or was it more true for certain specific cancers.

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Johnson Yeah, that is a really great question. So, when we looked at this, we separated out the cancers because this was of interest and the interesting thing was that the finding was surprising in a couple of ways. I actually thought that people might have worse survival than the 2-1/2 times greater risk, and when we look at it, because the patients have prostate cancer and breast cancer made up the majority of the data set and the majority of those patients had lower risk of disease, lower stages of disease and sometimes it takes a lot of years for those patients to actually die and in our followup period in our study, the amount of time that we followed these patients, it is only about 5-1/2 years, so it is relatively short. So, when we looked at this by diseases, prostate cancer actually did not make much of a difference, but because I said it is only 5-1/2 years, usually we do not see changes until 10-15 years down the road, but for breast cancer, women were at 5 times greater risk, colorectal cancer is about 4-1/2 times greater risk and for lung cancer, it was 2 times greater risk of death.

Gore And what percentage of these patients, these alternative patients eventually got conventional treatments, would they mostly move onto conventional treatments or did most of them decline or you do not know?

Yu We do not know that. I mean this database captures initial therapy, so it is a snapshot. It is even more sobering then because some of these folks who started out on alternative medicine, then went onto get traditional therapy, we do not know that for sure but some of them probably did and it still impacted their survival.

Gore And so you do not know either then I suppose, like let us somebody had an early stage breast cancer or a lumpectomy with or without radiation might have cured them, you do not know what percentage of them if things went along

presented with a higher stage, they might have been harder to cure, you cannot tell that from your database or can you? In other words, did they start off with an early stage disease and then presented with metastatic disease that could have been prevented.

Johnson No we do not know that, and again this is something that we mentioned in the discussion of the study is that, likely the number that 2-1/2 times greater risk is likely lower than we imagine for some of the reasons I have already stated and because these patients likely got treated later on, but a number of the patients probably showed up after having tried alternative medicines and ended up in our conventional medicine group.

Gore You do not know that for sure, but it is possible.

Yu Right. So, it is obviously not a perfect study, but I think there is a huge signal that it is sending us that initial alternative therapy within the database is matched as well as we possibly could, still gives you a greater risk of dying of your cancer.

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Gore So, what do we do with this information. It goes into a very prestigious journal, it is good for UCVs, it is important information, but obviously these people in Colorado or wherever it is are not reading the Journal of the National Cancer Institute, so they are going on to websites I imagine that are telling them that loco boco berries or whatever else is the way to go or Acai berries or Noni berries from Polynesian Islands was a big deal for a while. How do we get that message across, or is the data secure enough? Or do you have to do randomized study of Noni berries versus radiation? What do you think?

Yu Skyler has been doing a phenomenal job getting the message out and we are trying to do that more and more...

Gore I mean I am not Oprah, allow me to say that.... not even Phil Donahue.

Yu You are now going to make me cry here, Steve.

Johnson But everybody is leaving with a car.

Yu I think we have to get the message out as practitioners through social media, through radio programs like this that if you have a loved one who is considering non-traditional therapy for their cancer, please have them talk to a complimentary- for example - program that can maybe integrate that alternative therapy with standard therapy, or talk to a traditional modern cancer doctor, who can maybe allay their fears about the potential treatment, but please do not just do alternative therapy that you read about online or you heard from unscrupulous practitioners, it is not going to work.

Gore So, tell me about this complimentary approach. How is that different from alternative or...

Johnson Yeah, so the complimentary approach is done in conjunction with conventional cancer therapies. So, it is something that is done with conventional cancer therapies and it is something that we see quite a bit, it is something that needs to be done openly and with your physician because if you use a wrong complimentary therapy, it can affect your conventional cancer therapies, so generally it needs to be done under close supervision and that is entirely different than patients who choose alternative medicines, which was the purpose of this study, which is those patients who choose to forego conventional cancer therapies in favor of some unproven medical therapy.

Yu And not all complimentary and integrative programs are the same. I mean you really should go to one that is attached to a respected medical center. I think there is one here at Yale that will approach it from a scientific standpoint and one that will consider that complimentary therapy in its relationship to standard chemotherapies, radiation and surgery.

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Gore Right. I would like to pick up on that in a minute. One question I have is whether there is a separate code in your database for complimentary therapies, can you look at that?

Johnson Yes. So this is a little bit of a spoiler alert, but this is something that we are currently looking at. So, there are patients who chose unproven medical therapies and then also received conventional cancer therapies as well, which is basically just complimentary.

Gore And you are going to do a similar analysis then?

Johnson In process right now.

Gore Great. That is awesome. So, back to James' comment about while you should do the complimentary thing, that is what do we call the regular medicine, allo medicine or something?

Yu Allopathic.

Gore Allopathic is the conventional thing, is that...homeopathic versus allo?

Yu Yes, I guess depends those say it is western medicine or traditional medicine or allopathic.

Gore Okay, whatever the term might be, patients should use the Yale version or the Columbia version of complementary medicine. Isn't that? Do not you think that this is going to push these people away, who are already very skeptical, you guys are probably the wrong messengers and this is going to be seen a co-opted complimentary medicine, I am just guessing right? I mean why would any major medical center offer that which is really internet vetted and different. Really, I think it is a problem. You guys are in some ways the best messengers for this right?

Yu Yes, it is a huge problem and I do not know what the answer to that problem is in this regard.

Johnson Hopefully, I mean you are right - we are not going to convince the skeptic, but hopefully skeptic's sister can take our paper and show it to them for example, and hopefully we have provided a little ammunition in that war of facts versus faking.

Gore Well, we will not go there. I would have to say that my personal experience not only in cancer but discussing with anti-vaccine people, I am not necessarily the right person to be discussing this with them because I am an allo medicine guy, a western medicine guy and I do not what the answer is. I mean it would be kind of interesting if you could find some spokespeople who are from that group who has realized that that was not necessarily the best decision for them, spokespeople I do not know.

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Yu It is really tough because even the patients that we do see who have come in with more advanced cancers who have tried alternative therapies, they refuse to ever blame the fact that they tried an alternative therapy on the progression of their disease. And so...

Gore You probably do not push that on them either.

Johnson No, not at all, but it is a belief system and it is a strong belief and unfortunately what we know based on other kind of scientific areas and studies that facts and statistics do not necessarily change somebody's beliefs, but I think that there are reasonable individuals who are on the fence about doing this because they may have been misinformed online and we can have really open an honest discussions with them and build strong relationships of trust and I think they can be swayed, I really do.

Gore But that I assume they get to your office in the first place.

Johnson Exactly.

Gore Right. Do you guys pair with any homeopaths or other Asian medicine people in the community that, have you considered some kind of community outreach about this?

Johnson We have clinical trials ongoing in our department looking into Chinese herbal medicines, I think Dr. Higgins has an open study. It is not like we are closed off to the idea that other cultures have something to contribute to medicine, it is just that it needs to be done in a way that generates knowledge and does not place the patients at risk for progression of their disease.

Gore I am thinking more in terms of partnering in terms of getting these alternative practitioners on board to be approaching this more as a complimentary thing. I mean I think this could be a really interesting community model if you

could successfully get them to opt in and decrease the number of patients who are putting themselves at risk. I think...

Yu Skyler, how is your interaction with alternative medicine folks online as have been looking to collaborate with you?

Johnson Not necessarily, I mean it is hard, there seems to be two schools of thought for complimentary practitioners and it is, the schools of thought are generally that you should not offer any alternative therapy, it should always be done in conjunction with conventional cancer therapies, and then there are providers who will treat people without conventional cancer therapies, and it is really these kind of two schools of thought that make it difficult for us, but there is a society of integrative oncology that has been very supportive of the study and mentioned it quite a bit on social media, but the other practitioners, it is hard to know how to reach them.

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Gore It is interesting, I earlier in my career I was studying a drug in leukemias called sodium phenylbutyrate that was actually being studied by the NCI because they had isolated it from something called antineoplastons, it was an alternative therapy, but that people really believed in. And once I had the NCI sponsored study, I heard from a lot of patients who wanted to get the stuff and I became very close to that community interestingly, so So, I know it is a challenge and those people are out there and open the door and they come.

Yu Yeah, while there are still individuals who are offering antineoplaston therapies out there.

Dr. Skyler Johnson is a Resident in Therapeutic Radiology and Dr. James Yu is an Associate Professor of Therapeutic Medicine at Yale School of Medicine. If you have questions, the email address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancer-Center.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer. You are on WNPR, Connecticut's public media source for news and ideas.