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Welcome to Yale Cancer Answers with doctors Anees Chapgar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest 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 access to cancer care with Dr. Amy Davidoff. Dr. Davidoff is a Senior Research Scientist in the Department of Health Policy and Management at the Yale School of Public Health, and Dr. Gore is a Professor of Internal Medicine and Hematology at Yale and Director of Hematologic Malignancies at Smilow Cancer Hospital.

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Gore Dr. Davidoff, you think of yourself, I think, as a health economist. Can you explain what that is?

00:56.300 --> 01:50.300

Davidoff Well, as an economist, I am interested in how incentives that are built into systems in healthcare, particularly healthcare delivery system, so those incentives might be how providers are paid for the care they deliver or how insurers are paid or how the kind of out-of-pocket payments that patients have to pay and how the way that these incentives that people face influence whether they seek care, the kind of care that people receive and then ultimately it has an impact on the outcomes of care and also has an impact on individuals in terms of their out-of-pocket spending and the kind of burdens that they and their family face associated with that treatment.

01:50.300 --> 02:12.200

Gore Hmm... So, how do you study the impact... first of all, how do you measure the incentives and how do you measure how that makes people behave, I mean I guess I could guess that if I have had a high out-of-pocket cost, I might not want to see a doctor for certainly something minor, but how does that work?

02:12.200 --> 05:00.500

Davidoff Well, okay, how do we study it: So, there are various ways that somebody might study incentives. First, how do we figure out what those incentives look like. That is based pretty much by keeping tabs on the way that policies are designed. So, when sort of out-of-pocket cost sharing is capped or co-payments are changed or the Medicare program changes the way that it pays doctors or something, those are policy changes that my colleagues and I try to keep tabs on as they are happening and then over time, I work very closely with various clinicians who may give me insights into how some of these policies actually

affect the care that they provide on a day-to-day basis, and so that helps us to identify question areas that should be addressed. Now, how do we actually study the impacts, that is done on a number of levels. One can be very, sort of, micro, small kinds of studies where you are actually interviewing clinicians or patients on their experience with out-of-pocket costs, so sometimes people will do small surveys of patients or do focus groups and interview them in depth. The kind of work that I have tended to do uses larger data sets, so there are a large number of surveys that the federal government undertakes of populations or of certain sub-groups where they ask questions about the individual and their family, their insurance coverage, their health status, kinds of care that they receive and out-of-pocket burdens that they face. And then, we might use that survey data to analyze some of these questions. We might look at changes in the responses to those questions over time, so as a new policy is implemented, how that affects people's responses or we might look at different subgroups of patients depending on how we think that might affected. We also do a lot of work with what we call administrative data, which is data that is collected for some other purpose - like paying insurance claims, and we use insurance claims a lot in our research. They give us a lot of information on patient's characteristics, health status which we get from diagnosis codes that are on the claims.

05:00.500 --> 05:06.400

Gore A claim is like the hospital bills and insurance company for a procedure like an MRI or something, is that a claim?

05:06.400 --> 05:31.500

Davidoff Yes, yes. And for all services that are paid by insurers, some provider is submitting a claim to the insurer so that they can pay it. In the old days, it used to be paper claims, now it is all electronic and so those electronic claims can be sort of assembled in a big research database that we researchers can use.

05:31.500 --> 05:38.100

Gore So, there is a big tally for each patient of all the claims that have been made on their insurance?

05:38.100 --> 06:52.200

Davidoff It can be at the tally level, but it is actually for each individual service that patients receive there would be a claim that is issued and paid or not paid, but we can use that detailed information. So, we have information for cancer patients when they receive a diagnostic test, when they receive cancer screening first I guess, a diagnostic test when they have surgery, we know what kind of surgical procedure it was, we know how long they stayed in the hospital if it was inpatient, we know where it was provided, by what type of provider. When they get chemotherapy, we know what kind of drugs they are getting, how much they are getting, how long they are getting, what dates of service. I should stress though that the research data that we have tends to be totally stripped of all identifiers for individual patients. So, we are never looking at what happens

to an individual and we also have a lot of protections in place to protect the confidentiality of individuals whose data might be in that data set.

06:52.200 --> 07:02.400

Gore So, we do not have to worry about turning off our cell phones when we go into the office because Big Brother is soaking up stuff about us, it is not like that?

07:02.400 --> 07:04.000

Davidoff That is correct, that is correct.

07:04.000 --> 07:09.500

Gore Yeah. You know, there is so much paranoia nowadays about these big data things in Facebook and so on, but this is not like that at all right?

07:09.500 --> 07:26.600

Davidoff We try to make sure that it is not. We and the institution and the federal government all work very hard to make sure that all of that information is kept confidential.

07:26.600 --> 07:43.100

Gore So, could you give us an example of some policy change or policy consideration that might affect the cancer patients that you either would like to study or have studied and how you, sort of, went about that or would go about that?

07:43.100 --> 08:27.000

Davidoff Well, a big focus is on the cost of prescription medications. In cancer care, traditionally a lot of the chemotherapy was IV or injected chemotherapy, and it was all covered usually under the medical benefit that someone might have in their insurance plan, but prescription drugs, oral chemotherapies would be covered under a different mechanism; for example, if anyone has Medicare, any IV chemotherapy would be covered under their part B benefit which covers doctor's visits, office visits, diagnostic testing, all the outpatient things.

08:27.000 --> 08:29.500

Gore Part A is hospitalization?

08:29.500 --> 09:37.700

Davidoff For the most part, yes. But if their physician wants to prescribe an oral chemotherapy, they would have to have prescription drug coverage to cover that to help pay for that particularly if it is an expensive drug, which many of them are now. So, people with Medicare might have purchased a part D plan, which is the prescription drug benefit through Medicare. That has been available since 2006, and now covers probably about 65% of all people with Medicare. If you do not have part D, you may not have it because you were lucky enough to have an employer who provided health insurance for you when

you were actively working and then when you retired, there might be a retiree plan that would cover both supplement what Medicare provides on the inpatient and outpatient side, but also includes prescription drug coverage and so that you do not need to buy a part D plan.

09:37.700 --> 09:45.100

Gore And some people have things like AARP or other kind of insurance right, secondary insurance that sometimes has prescription plan?

09:45.100 --> 10:13.500

Davidoff Well, AARP has both what is called Medigap which provides sort of that supplement on the part A and B side, but no longer covers any outpatient prescription drugs, they used to before 2006 and now if you want that, you have to also have a part D plan. Now, many of the part D plans actually also come through AARP, so they have got you coming and going.

10:13.500 --> 10:33.700

Gore Okay. So, your point is that people may be prescribed this expensive oral chemotherapy, which is now coming under this part D or prescription plan, and so what does one look at there, is it an out-of-pocket there or...?

10:33.700 --> 10:40.800

Davidoff Yes, yes that has been one of the big issues, particularly with the part D program.

10:40.800 --> 10:43.300

Gore There used to be those donut holes that people would fall into?

10:43.300 --> 13:33.700

Davidoff Yes, yes. So, when part D was designed, it was designed with sort of a small deductible and then some co-payment or co-insurance for the first part of your spending during a year and that was several thousand dollars. But then when you got to a certain limit, which they thought that very few people would get to, there was something called the donut hole or coverage gap where there was basically no coverage from the part D plan and you had to pay out of pocket for another several thousand dollars. Then, if you reach what was called the catastrophic limit, you had already paid so much out of pocket, then you would only have to pay 5% of the cost of your drugs going forward until you reach the end of December and then as well all know with insurance, you get to a new insurance year and all the deductibles and everything starts over. So, the donut hole was not a problem for most people when part D started, but over the last decade certainly and more so increasingly so in the past few years, there are now some oral chemotherapy drugs that can be very effective for some people and are drugs that in some cases may need to be taken for the rest of someone's life. And these can be very expensive and if you start out in January and you have got a part D coverage and you fill a prescription for one of these drugs, it may

actually bring you all the way through your initial coverage zone, your coverage gap and into the catastrophic zone where you continue to have to pay quite a bit each month out of pocket until December and then start all over again in January. So, one of the things that people have looked at is just how the fact that there is this donut hole when you have very expensive cancer drugs, how that affects whether people initiate a certain drug that is recommended or how long it takes before they line up their in-home or internal financing to be able to start affording it, and then how that affects their ability to persist with the therapy over time and even whether they sort of delay refills or split pills or skip doses, something that we call cost-related non-adherence. So, there have been a lot of studies, some that I have been involved in where we have looked at how the fact that there is that donut hole affects use of cancer medications and then how it also affects the out-of-pocket spending that someone with cancer faces at the end of the year.

13:33.700 --> 13:49.300

Gore Wow! This is really fascinating Dr. Davidoff and I want to take this up in the second half of the show, but right now we need to take a short break for a medical minute. Please stay tuned to learn more about access to cancer care with Dr. Amy Davidoff.

13:49.300 --> 14:04.800 Medical Minute Support for Yale Cancer Answers comes from AstraZeneca, a biopharmaceutical business with a deep-rooted heritage in oncology and a commitment to developing cancer medicines for patients. Learn more at astrazeneca-us.com. 14:04.800 --> 14:56.000 This is a medical minute about pancreatic cancer, which represents about 3% of all cancers in the US and about 7% of cancer deaths. Clinical trials are currently being offered at federally designated comprehensive cancer centers for the treatment of advanced stage and metastatic pancreatic cancer using chemotherapy and other novel therapies. FOLFIRINOX, a combination of 5 different chemotherapies, is the latest advance in the treatment of metastatic pancreatic cancer and research continues at centers around the world looking into targeted therapies and a recently discovered marker HENT-1. This has been a medical minute brought to you as a public service by Yale Cancer Center. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio. 14:56.000 --> 15:24.000

Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore. I am joined tonight by my guest Dr. Amy Davidoff. We have been discussing access to cancer care and how health economists can understand, if I am getting this right, how various policy changes the way people use their medical coverage because of the financial incentives. Do I have that more or less right?

15:24.000 --> 15:24.100

Davidoff More or less, yes.

15:24.100 --> 16:49.800

Gore It is a little complicated for me and in the spirit of disclosure, I have to say that I am probably one of the few people who graduated with a bachelor's degree from Yale College without having ever in high school or college taking any social sciences, so you will excuse my relative ignorance about this. But I do know from my patients that just at bedside that these seem to be real problems and we prescribe for my leukemia patients some rather expensive oral antibiotics, let's just not even leave aside the issue of oral chemotherapy, but oral antibiotics which are very important to protect these patients from fungal infections, and when patients hear about their co-pay, they really believe they cannot manage it and yet if they do not take them, they are likely to die of a fungal infection, and this is a, it is almost unconscionable the hoops that we seem to make patients jump through that they never, I do not think any of them ever expected that their insurance. These are insured patients, you know their insurance would not prove adequate for something that is really essential for them to fight their cancer, I mean, it is a little crazy!!

16:49.800 --> 17:32.300

Davidoff It is crazy. It is crazy. I think it is important to say at some point in our discussion that the cost of prescription drugs has escalated dramatically and as economists, we sort of one of the fundamental principles is that the price of something should be a function of, should be set to the actual cost of producing whatever it is you are producing now. So, the cost of producing a pill is probably really, really, really tiny relative to the price that the drug companies assign to it.

17:32.300 --> 17:35.000

Gore But they are saying that we are recouping the research cost, right?

17:35.000 --> 19:10.200

Davidoff So, they are saying they are recouping their research costs, but the other piece of it is that they first of all have a lot of protection from our patent system. So, they have monopoly power. They are the only ones who have a particular drug, and if a clinician decides that that is the drug a patient needs, then either the patient is going to have to pay the price and it is usually a negotiated price, not the actual list price, it is usually a price that is negotiated down by the insurance company or there is a pharmacy benefit manager in there, but some high price that someone might have to pay or they are not going to get the drug. And what the drug companies have done is really price the drugs at a level not based on the cost of producing it, even if they wrapped in the cost of research and development, but they have been sort of setting the prices at what they think the market will bear, what people with their insurance with patient assistance would be willing to pay for another month of life or to not get a fungal infection in the case that you cite. And this makes sense for them as they are for-profit companies, they have shareholders, they have boards of directors, so their goal is to make profit.

19:10.200 --> 19:10.800

Gore Little cynical.

19:10.800 --> 19:43.800

Davidoff But it's the truth. It is the truth. And so, with the current system, these prices that people face are going to be high and are going to continue to be high until we find some alternative non-market, not competition based strategy, and I do not know that that is going to happen anytime in the future, but that is some of what is driving the cost growths in cancer drugs, not the cost of producing them but rather the fact that the market will bear very high prices.

19:43.800--> 20:01.100

Gore And yet we hear that the same, very same drugs are much cheaper in Canada or Europe or that there are generics being made perhaps illegally in India, that are very much, much cheaper. Why is it so different in our country or am I wrong?

20:01.100 --> 20:52.300

Davidoff Well, so in terms of the, no you are not wrong, you are not wrong. In other western countries, the governments allow, or the governments actually maybe providing some kind of National Health Insurance or in the case of Canada Provincial Regional Health Insurance and they negotiate prices with the drug companies and because of that, they have a lot of market power and they can say if you want us to make your drug available, we will only pay x amount for you. And so they have much lower prices. And they use various approaches to actually setting what that value will be, but it will not be the drug company setting the price. Then, the drug company will have to decide whether or not it wants its drug to be sold in that country.

20:52.300 --> 20:57.500

Gore Hmm. So are there examples where the drug company pulls out?

20:57.500 --> 21:31.600

Davidoff Very, I cannot think of any specific, but they certainly complain a lot. And it has an affect. I mean, this is getting a little maybe off-topic, but it certainly affects the way drug companies deal with -- Australia which has a very tight control on the price it is willing to pay for drugs and that probably had an impact on whether our country stayed in the trans-pacific partnership.

21:31.600 --> 21:49.200

Gore Really? Interesting. So, it is different for the patients depending on whether they have private insurance or Medicare or Medicaid, you know, you talk about policy and I think of policy is being made by Congress, which should not affect private insurance right or am I wrong?

21:49.200 --> 22:24.300

Davidoff Well, I think the biggest impact is probably on private insurance has been the affordable care act. So, you are right that for the most part, the federal policy would not affect what private insurers do. But the affordable care act has required that private insurance now has an upper cap on the out-of-pocket requirements. Now, it might be quite high but there is an absolute cap on the out-of-pocket spending.

22:24.300 --> 22:26.000

Gore Including on prescription drugs?

22:26.000 --> 22:49.400

Davidoff Yes. It would be the total that a family would have to face. So, that has been a potentially important change. I think that in the Medicaid program, that is different because people's out of pocket is really pretty minimal.

22:49.400 --> 22:52.800

Gore This is usually for lower income people, right?

22:52.800 --> 23:21.100

Davidoff

Medicaid is for, historically, for people who are on what we used to call welfare, now we call temporary assistance for needy families, so quite poor individuals. With the affordable care act, many states expanded their Medicaid program to higher incomes individuals but still only up to what we say is a 138% of the federal poverty level.

23:21.100 --> 23:23.700

Gore So, the near poor?

23:23.700 --> 23:56.400

Davidoff The near poor, the near poor. But it also expanded it to adults who did not have young children. That was a previous requirement for adults to be covered. So, now, you might have more near poor who are getting into their 40s, 50s, do not have young children. In the past, they might have been uninsured and now they will have Medicaid coverage, and Medicaid tends to have very limited out-of-pocket if any. So, you might have to pay 6 dollars to fill a prescription.

23:56.400 --> 24:09.800

Gore That's amazing and I know that in Connecticut we have a very robust, it seems that we have a very robust Medicaid and medical support system compared to some other states which I am aware.

24:09.800 --> 24:12.900

Davidoff I think that's true.

24:12.900 --> 24:30.400

Gore So, how has the affordable care act impacted access to cancer care or the care for cancer survivors for example. I mean, have there been measurable changes because that has been a big, pretty big change in our insurance system?

24:30.400 --> 25:58.900

Davidoff Well, it has had an impact on insurance coverage for people with a cancer history, say cancer survivors, so people who were newly made eligible for Medicaid have enrolled to a large extent. Individuals who maybe were previously eligible for Medicaid and did not know it, have also enrolled in Medicaid now that there have been so much publicity about insurance coverage, and there is still in place an individual mandate for everyone to have coverage even though there is no longer a penalty that is being enforced. Other changes, other really important changes is that people who have a preexisting condition can no longer be excluded by private insurers, and so that actually potentially had a big impact on being able to access insurance for people who previously might have been denied insurance if they went to a private individual insurance market, not through their employer, then they might have been turned down or they might have been offered a policy where the premium was really exorbitant, and under the affordable care act, these people can now get access to insurance with a premium that does not reflect a cancer history.

25:58.900 --> 26:07.900

Gore Some people who have had breast cancer in remission or colon cancer or any of the above, you are saying they might have been excluded from private insurance before?

26:07.900 --> 26:09.500

Davidoff Yes. Absolutely.

26:09.500 --> 26:10.600

Gore And now, they cannot be?

26:10.600 --> 26:12.200

Davidoff Now they cannot be.

26:12.200 --> 26:20.900

Gore Wow! So, has anybody tried to measure the uptake or the impact that that has had on cancer patients or do we know that more patients have enrolled?

26:20.900 --> 27:33.600

Davidoff We know that more patients have insurance coverage and we know that it has happened across the board for people who are eligible for either Medicaid or people who previously could not get insurance in the private market and

particularly people who are what we would call low income where the affordable care act subsidizes their purchase of insurance premiums. There have been a lot of issues with overall premiums going up because now there are many sicker people who are buying insurance and so healthier people may be facing higher prices and people who are above a cutoff of 400% of the federal poverty line do not get any subsidies to buy insurance and so they are faced with the higher premiums that are now in these private insurance markets. So, that has been a big problem. It is a problem that could be fixed if Congress are willing to tackle this issue, but it has not been something that they have been willing to tackle.

27:33.600 --> 27:40.700

Gore Right then we hear about this death spiral that people warn us about the affordable care act, but hopefully that is not going to happen?

27:40.700 --> 27:45.200

Davidoff Hopefully, that is not going to happen.

27:45.200 --> 28:23.500

Gore No, it is really very interesting and I have to say again I see it every day in my practice how these insurance issues really impact, you know, people's decision making, but I have to say as a consumer, I do not think that I am particularly aware of what my insurance will cover and what my co-pay is not it? Do you have a general idea, seems very complicated what we are asking people to sort of keep track of and manage, do not you think?

28:23.500 --> 28:45.700

Davidoff I think it is true. I think that our system is quite complicated and there have been surveys done asking people whether they know what a deductible is or what their insurance covers, and people tend to have very limited understanding of that until they get faced with a serious illness.

28:45.700 --> 28:51.900

Gore What do you mean I have to pay a \$1,000 dollars for that pill, right? Yeah. It is unbelievable.

28:51.900 --> 29:37.100

Davidoff Right. So, it is problematic. I think that it could be resolved to some extent if we had sort of a National Health System. I am one of those leftie people who supports that. I am not sure though that Medicare for all given how Medicare is now is the actual solution to that problem because as I am sure you find in clinical practice, the Medicare system is sufficiently complicated as I was describing with the part D benefit that even though 50 million people are enrolled in Medicare, it is still very difficult for each of them to understand what is and what is not covered by Medicare.

29:37.100 --> 30:05.900

Dr. Amy Davidoff is a Senior Research Scientist in the Department of Health Policy and Management at the Yale School of Public Health. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.