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Ellen Kelsay
That's Dr. Robin Mendelson, co-director of Memorial Sloan Kettering Center for Young Onset Colorectal and Gastrointestinal Cancers, a clinic dedicated to the specific needs of people under 50 with these types of cancer. As a practicing gastroenterologist, Dr. Mendelsohn focuses on taking care of gastrointestinal issues in people with cancer. She's also involved in the center's research efforts to better understand why we're seeing a rise in colorectal cancer among those 50 or younger.

I'm Ellen Kelsay, and this is the Business Group on Health podcast, conversations with experts on the most relevant health and well-being issues facing employers.

Colorectal cancer diagnosis and deaths have been increasing in adults under age 50, bucking the trend we've seen in older adults, and many are asking why. Today, Dr. Mendelsohn and I do a deep dive into this topic, including the research she and her colleagues are doing to understand what's behind this global phenomenon, as well as what employers and employees need to know when it comes to prevention and treatment.

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Dr. Mendelsohn, welcome. We're thrilled to have you with us today.

Dr. Robin Mendelsohn
Thanks so much for having me.

Ellen Kelsay
All right, well, let's dive right in. Just recently, I had the opportunity to speak with Dr. Bill Dahut from the American Cancer Society about their annual report, *Cancer Facts and Figures*. During that conversation, I was struck by a number of things, but really by the increasing rates of colon and rectal cancer among the younger population, specifically those aged 55 or younger. I would love for maybe us to start our conversation there. Can you recap for the audience what you're seeing in terms of the rising rates of colorectal cancer diagnosis and mortality?

Dr.Robin Mendelsohn
Yes, absolutely. We have been seeing this increase in the younger patients. Those patients 50 and over have been in our traditional screening group, so they've been screened for colon cancer. We've seen a decrease in that group. But in the same time period since the 1990s, we've seen an increase in those under 50 and it's been increasing about 1 to 2% per year over that time period. We've been noticing this throughout the last few decades, and really, really has been coming to the attention of the media and society over the last few years. We are excited that it is hitting the media and that we're doing podcasts like this to really increase awareness so that we can get people in to be evaluated and promptly treated if necessary.

Ellen Kelsay
Let's talk about your work and the organization and center you're affiliated with. What's that all about?

Dr. Robin Mendelsohn
Yes, so we had been seeing this increase in this younger group and the patients would tell us, you know, you guys do a great job at taking care of my cancer, but I feel like nobody is taking care of me. That really hit home because, you know, at Memorial Sloan Kettering, we treat a lot of patients with cancer and the average age of developing colon and rectal cancer is still in the 60s and 70s. But this younger group, and as we said it's been going up in those under 50, but the biggest increase has actually been in the youngest age group in the 20 to 29 group and they have different needs - looking at sexual health, at fertility. You know, a lot of people in their 20s and 30s don't have wills. It was just a whole new ballgame for these younger patients. So we opened our center in March of 2018, with two main goals. One is the patient care side where we really want to give coordinated care to this unique group. Everybody that comes in under 50 is enrolled in our center and they all get the same medical care that they would get, you know, seeing GI, surgery, oncology, radiation, oncology. Then we have dedicated social workers that reach out to the patients and assess their needs and everyone is offered referrals to nutrition, sexual health, integrative medicine, fertility, psychology, psychiatry, to really give them the coordinated care that we felt was lacking. Then the second part is really the research side of things, which I'm sure we'll delve into, and really trying to understand why this is happening and how best to take care of these patients throughout treatment and then hopefully to survivorship.

Ellen Kelsay
Wow, so this center is really comprehensive. You talked about coordinated care, you talked about the social workers really helping to make all these referrals to so many different types of specialists. Are these specialists also a part of the center or these referrals outside of the center?

Dr. Robin Mendelsohn
Everybody is really within the center. We have all these specialized care teams. If people actually undergo fertility treatments, that's not done at the cancer center, but we do have experts to discuss with them at the center.

Ellen Kelsay
In your role, you are a gastroenterologist. What is your role in the center, and almost maybe more importantly, what brought you to your work with the center?

Dr. Robin Mendelsohn
Yes, so as a gastroenterologist, a lot of times we're doing the diagnosis. They're coming to us with symptoms and the most common presenting symptom is rectal bleeding. Traditionally, you would always think, oh, you're young, you have rectal bleeding, you don't have a family history of cancer, you're too young, it can't be cancer, it has to be hemorrhoids. Over time, we really saw that though the majority of time when you're younger and you're having rectal bleeding, it will not be cancer, that it is not impossible and that we are seeing this increase. So as a gastroenterologist, I was making these diagnoses in these younger and younger patients. It was coming to my attention that we were making these diagnoses that we needed to really figure out how to take care of these patients, and even more importantly, why this is happening, because we have such great screening tests for this. When caught early, it is so potentially curable that if we could either find out why this is happening and intervene, find a higher risk group that needs screening, we could really, really, really make a difference.

Ellen Kelsay
That's great. I wanted to go back to, you know, the comment you made about the coordinated care and the role of the social workers and I would imagine just the mental load, the feeling of overwhelm that a patient has upon receiving a diagnosis. Speak to a little bit of the continuum of how does a social worker work with a patient who may not be ready to talk about their mental health needs or may not be quite ready to explore their fertility needs. How do you kind of keep them within the center and help them navigate all the different needs that they're going to have, but they don't all hit at the same time. So what's kind of the interaction that the social worker has throughout the continuum of evolving needs across all of those different array of services?

Dr. Robin Mendelsohn
That's a really great point. When we first started the center, we really thought everybody was going to want to have referrals to each one of these services right away. Actually, over time, and we did publish on this after our first two years, we did find that not everybody wanted all of these at once. For each one, there was sort of a sweet spot as to when to ask. So we have a clinic coordinator who is really the heart and soul of the center and he reaches out periodically throughout treatment to reassess and see where they are and if they want more referrals. The social worker reaches out at the beginning and then makes a therapeutic relationship and decides how often to follow up and when to follow up. That has been so integral to our program. We actually started off with one, and now we have two because of our increased needs. You mentioned feeling alone, not an earth-shattering diagnosis, obviously. That was also part of the center was really so that they don't feel alone, because that was another thing we kept on hearing over and over again. A lot of people in their 60s or 70s know someone who has cancer, knew someone who went through it, knew people getting colonoscopies. But people in their 20s and 30s were going to happy hours and just starting their lives and these weren't things that were routinely spoken about at dinner. Part of this center was really, you're not alone, that there are other people going through this. We have webinars, and we have chat groups, and everybody gets a letter when they come, basically welcoming them, telling them about our services, and really getting that feeling out there that you're not alone, that if you want to be alone, we're here for you if and when you need us.

Ellen Kelsay
So impressive. You mentioned previously the research that is the other side of what the center is all about. Please describe the research and what have you learned so far.

Dr. Robin Mendelsohn
Yes, so we really, really want to figure out why this is happening. Everybody that comes to the center is given a questionnaire, and asking about risk factors and exposures, family history. We're also collecting stool on everybody to look at microbiome, we have their tissue, we have blood. We retrospectively looked back at about 4,000 of our patients. When you think about young people, like I said, you always think, oh, they have to have a family history or a genetic predisposition. What we found is that the majority of these patients don't have a family history, don't have a genetic predisposition, that only about 10 to 20% will have a genetic mutation, even in this young group. The caveat to that is that you can't really predict who will have a genetic mutation. So we do recommend that all these young patients do get genetic testing, but the majority of them will not have a genetic mutation. Then we thought about the traditional risk factors for colorectal cancer, so obesity, and we do know that obesity rates are going up. When we did look back at our patients, they were more likely to be overweight and obese, but when we compare them to a national cohort without cancer, they were actually less likely to be overweight and obese. So though obesity may play a role, it's clearly not the entire answer. Anecdotally, a lot of these patients are healthy, marathon runners, vegetarians, and really don't fit the obesity mold. Smoking is a risk factor. Smoking rates have gone down. There's diabetes that's been thinking about as a trigger and our patients were more likely to have diabetes, but these numbers were small. That's something that we are actively looking into. The microbiome is a very hot topic. We actually just presented our data at our GI meeting in May and it does look that our younger patients do have changes in microbiome that are different than the average onset patients. The question is, is it something that is exposing their microbiome to that's changing it or is the microbiome causing these changes? Our data are preliminary and something that we are taking a deeper delve into now. It's not going to be one thing in the end, because I think if it was one thing, we probably would have found it already. I think it's probably going to be a multiple hit, but these are things that we are so actively looking into and really trying to figure out.

Ellen Kelsay
It is certainly not linear, lots of factors. The work around the microbiome is fascinating. Are there other areas of research that you have on the docket for future that maybe you haven't delved into, but are kind of hypotheses that you want to explore?

Dr. Robin Mendelsohn
It seems that the change really happened in the 1950s and 1960s. So, the question is really, what has changed over these last decades? Things like breastfeeding patterns, and age of parents at birth, and C-section patterns, and plastic use, and ultra-processed foods, and all these things that have changed. And these are all things that we're trying to capture with a questionnaire, which is not that easy, because we're asking people in their 20s, 30s, and 40s what happened when they were kids and teens. It's hard for me to remember what I ate for breakfast yesterday, so to try to remember this is difficult. We're trying to capture this with questionnaires. We're trying to work together throughout the city, and throughout the country, and throughout the world, because this is really an international phenomenon. It's not unique to the United States. A lot of people think it's the way people eat in the United States, people live in the United States, but we're seeing it in all the continents. We're seeing it in Africa. It's really an international phenomenon. These are things that we're looking into and we're always interested to hear more hypotheses. I will get emails and calls and letters and really take them seriously, because clearly we need to figure this out.

Ellen Kelsay
I'm speaking with Dr. Robin Mendelsohn, co-director of Memorial Sloan Kettering's Center for Young Onset Colorectal and Gastrointestinal Cancers. We'll be right back.

Ellen Kelsay
You mentioned this earlier in your own practice, in younger, you know, these are the 20 to 29 cohort and rectal bleeding and sometimes for this younger population, the path of diagnosis is significantly delayed, often because they don't think that it's cancer. They might dismiss it as something else or because their clinician isn't thinking cancer and might dismiss it as something else. How do you as a clinician think about that and how should patients maybe advocate more effectively for themselves?

Dr. Robin Mendelsohn
Yes, absolutely. You hear it from both sides. You hear patients saying that they had to see four or five doctors before making the diagnosis. But then you also hear that younger patients, they are busy, and they otherwise feel well, and their heart and their lungs are healthy, so they're able to compensate. So they wait a long time before they see the doctor, because again, young, you know, I can't have cancer. I think that podcasts like this, and there have been a few unfortunate tragic stories in the media, though the stories are tragic, they have brought to light that this is happening. I think that it is so important from both the patient side and the provider side to understand that this is happening, to recognize the most common symptoms, which the most common symptom is rectal bleeding, but there can also be a change in bowel habits. So, it's not somebody who's been constipated their whole life, but somebody who, you know, has never been constipated, and now is constipated, or abdominal pain or distension, unexplained weight loss. These are all symptoms that should be checked out, especially if you have rectal bleeding once, and that's entirely it, it's unlikely to be anything. But anything that's persistent should really be checked out. The more and more we're able, you know, the first line people that are seeing these patients are primary care physicians, OBGYNs, ER, and just getting the word out there that this is a phenomenon, this is happening, and that as a patient, be your advocate, and providers understand that if this is the case, that they should be evaluated promptly.

Ellen Kelsay
Anything that you would offer in terms of patients thinking differently about screening and prevention and treatment? We just talked about so many of these younger people aren't even probably of age for a recommended screening, so they've got to be paying attention to their symptoms. But is there anything

more you'd want them to know about what the treatment path looks like, what the screening path would be for this younger group?

Dr. Robin Mendelsohn
Because of this increase, we did decrease the recommended age to start screening from 50 to 45. That's important to know. And it's important to start the conversations earlier, because you're supposed to start screening at 45, so you need to start the story earlier so that people do get screened at 45. But I think it's important to know that there are groups that do get screened earlier. The majority of them, you know, people with inflammatory bowel disease or history of radiation, they're followed by physicians that will recommend it. But the biggest one is a family history. Not all families like to discuss family history, but anyone who has a first-degree relative, so parents, sibling, child who is diagnosed with colorectal cancer, you do start screening earlier. So you either start at 40 or 10 years younger than the youngest person in the family was diagnosed. If the youngest family member was diagnosed at 45, you start at 35. It's so important for people to know their family history, to know whether you should start earlier. So those are the people that we start earlier. Otherwise, now, those under 45, we don't have great data to do generalized screening in everybody, but symptoms definitely, definitely get evaluated and encourage your family members to get screened if they haven't, because if they have findings, that implicates you to start screening earlier as well.

Ellen Kelsay
You mentioned earlier the risk factors, obesity, smoking, diabetes, potentially some genetic family history there. Is there any sort of, you know, kind of decision matrix that you as a clinician use if you've got two or more of these risk factors, you should be screened, if you've got five or more risk factors. To a lay person, if they're sitting here listening to this, and they're both a smoker with diabetes, should they get screened even if there's no family history? How should they think about that?

Dr. Robin Mendelsohn
Yes, so right now our guidelines don't incorporate those risk factors for screening earlier. Really, the only indications for screening earlier are family history, a known genetic mutation, history of inflammatory bowel disease, or history of radiation to the abdomen pelvis. Those are really the only, right now, part of our guidelines to start screening earlier. The other risk factors for colorectal cancer, like we spoke about - obesity, alcohol, smoking, diets that are high in red and processed meats, low in fruits and vegetables, low physical activity - those are all things that are associated with an increased risk of colorectal cancer. We don't recommend screening earlier, but these are all, you know, healthy lifestyle changes, no matter what. When people ask me, what can I do to decrease my risk of colorectal cancer - the number one is to get screened when you should get screened, and the second one is to really adhere to these lifestyle modifications that will be good for you overall. They're good for your heart, they're good for your lungs, so that even if you do get diagnosed with this and the treatment is surgery, or chemotherapy, or radiation, your best shot of getting through it is to be as healthy as you possibly can. The CDC now recommends actually no alcohol, no smoking, increased physical activity. We recommend a plant-based diet where the majority of your plate is fruits and vegetables, and a third or less is lean meats, and really adhering to this will decrease your risk, but also give you the best chance of beating it if you do get diagnosed.

Ellen Kelsay
For sure. All right, that's really helpful. Anything you would call out for employers or those who are providing health and well-being benefits to patients, to the general workforce, anything that they should think about or be aware of?

Dr. Robin Mendelsohn
Yes, I think it's also important to know that there are multiple screening methods and we broadly break them up into stool-based tests and then colonoscopy, basically. The stool-based tests are pretty good at finding cancer. They usually find cancer in over 90% of the time. They're not as good at finding polyps. It's usually under 50% of the time. So, you know, polyps are precancerous growths in the colon that if left over time, we do believe that the majority do progress to cancer. Colonoscopy, when we do these, we use a camera, we take a look, and if we identify polyps, we can remove them. It's actually a cancer prevention

technique. If we do find cancer, because by definition, when you're getting screened, you have no symptoms; if we do find cancer, the majority of times it's at the earliest stages when it is extremely, extremely curable. We consider the colonoscopy to be cancer prevention and early detection, whereas for the stool-based tests, it's really mostly early detection because it doesn't really find polyps at the same rate and any positive stool tests does lead to a colonoscopy. Many people do consider colonoscopy to be the gold standard, because you're able to have this cancer prevention part as well. But really, the best test is the one that gets done. So for people who are worried about a colonoscopy, you know, there's a lot of barriers - people don't want to take the preparation, people are worried about anesthesia, you have to take a day off of work, you need someone to pick you up - there's a lot of barriers to it. For some people, it takes effort to get to their colonoscopy, but if they're willing to do a stool test, understanding, you know, I think it's so important to understand what these tests mean, their pros and cons, and really get the test that will get done and get done well. It's been shown that screening saves lives and though the majority of it is attributed to polyp removal, really, it is the overall screening process. So whatever test the patient is willing to do is really the one that we should recommend.

Ellen Kelsay
Well, Dr. Mendelsohn, you've covered so much ground so succinctly in this conversation already. Before I ask you, maybe my last question, I've got one more question for you. Is anything else about the center, the research, what you're seeing in practice that you would like to share with the audience that I haven't asked you about?

Dr. Robin Mendelsohn
Yes, we mostly focused on colon and rectal cancer, but even though the numbers are smaller because the cancers aren't as common, we really are seeing an increase in all GI cancers. They don't have the same great screening tests that we do for colon, but we're seeing this increase. That's why we expanded to all GI cancers in 2021. You know, unfortunately, the numbers are going up. Since we started in 2018, we've had over 2,500 patients come through for colorectal cancer. So unfortunately, our numbers are going up, but we're hopeful that we're able to treat these patients well, to give them coordinated care, and to try to figure this out together so we can really try to decrease these numbers in these younger patients.

Ellen Kelsay
Well, you might have already just beat me to the punch with my last question. It's about what gives you hope for the future and you just mentioned a number of things right there. But anything else you would offer as you look to the future what is a glimmer of hope that you are looking forward to?

Dr. Robin Mendelsohn
The glimmer of hope is one that we talked about, the ACS study at the beginning. The glimmer of hope is that overall colorectal cancer rates are decreasing, so that is a glimmer of hope. The increases in these younger patients, but the glimmer of hope is that we used to think that the younger patients have poorer survival, but when we looked at our patients, they did not and the younger patients do just as well as the average onset patients. We're learning more and more every day and each step brings us a little bit closer and I do think that we are going to at least find some risk factors that we could either change or hopefully put people into earlier screening, so that we can decrease the incidence and mortality from this disease.

Ellen Kelsay
Well, Dr. Mendelsohn, thank you so much. It's a troubling but fascinating field, so much research underway and really keen to see what you learn through it over the next several years. Thank you for sharing your insight, perspective and knowledge with us today. We're grateful for your time and expertise.

Dr. Robin Mendelsohn
Thank you so much.

Ellen Kelsay
I've been speaking with Dr. Robin Mendelsohn, who treats patients under age 50 with colorectal and gastrointestinal cancers and is part of a research effort to better understand these increasing rates of

cancers among that age group. For more information on cancer, check out our recent episodes, *By the Numbers: Cancer Facts & Figures 2024*, and *Cancer and Careers: Moving Forward Without Fear*.

I'm Ellen Kelsay, and this podcast is produced by Business Group on Health, with Connected Social Media. If you like this episode, please rate us and consider leaving a review.