How a nurse navigator helps map lung cancer care

Diane Mulligan:

When you're facing a lung cancer diagnosis, you are immediately thrust into a world of tests and procedures, experts, new terms, and lots of doctor's appointments, and that's all before you even begin treatment. I'm Diane Mulligan.

Sarah Beatty:

And I'm Sarah Beatty. Now there's a program that some hospitals have that can help you manage the challenging days after a diagnosis, it's called a patient or nurse navigator.

Ross Camidge:

And she makes them feel like there's a human being who cares. But then on the backside, she has technical expertise to make sure that if you're coming in to see us, there's no missed gaps. All of the data that your report, the scan reports, everything is there so that the doctor and you can have the most useful interaction.

Diane Mulligan:

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers, but first it's a disease that affects people. The Hope With Answers: Living With Lung Cancer podcast brings you stories about people living, truly living with lung cancer, the researchers dedicated to finding new breakthrough treatments and others who are working to bring hope into the lung cancer experience.

Diane Mulligan:

There is so much hope in lung cancer today. So, many new treatment options and ways to help patients live longer and healthier lives. But lung cancer is also inherently very complicated. And the process of getting to a treatment plan takes a lot of expertise, different members of a medical team and lots of tests.

Sarah Beatty:

And one way to make this process easier on patients and more efficient for doctors who are making those treatment plans is to use an expert called a patient or nurse navigator. Now Charity Holien, a patient navigator with the University of Colorado Cancer Center, explains exactly what a patient or nurse navigator does.

Charity Holien:

In the RN nursing world, there's actually a difference between patient navigators and nurse navigators, which I just learned as I come into this role in the last year. But patient navigators are, by definition technically, are non-clinical. They actually are used more in the community setting for patients to get them connected somehow to either a health system or provider.

Charity Holien:

A nurse navigator, which is what I am, is more of a clinical-based provider, in my case a nurse, that actually has some clinical skills to understand and explain the medical jargon for new patients or even patients that already have cancer and trying to get them connected to a provider or health system. So, they're that central person of connecting that gap between their diagnosis and then actually having a specific navigator, which mine would be lung cancer. So, connecting steps for patients.

Diane Mulligan:

Sure. Well, you mentioned that idea of a gap and I think that's such a good way of putting it because there is just this massive gap between I'm so sorry you have lung cancer and okay, here's what we're going to do about it. I mean, that sometimes is days or weeks or even a month or two months sometimes to get all of the information that you need to move into treatment. So, how would someone who is just been diagnosed with lung cancer, get connected with a patient navigator in your case, a nurse navigator and talk about what you help them do.

Charity Holien:

Yeah. So, with patient navigators, I know that you can find them in usually the public health system or a community. And how I've been connected to them, is the patient navigators will usually reach out to us and tell us about a patient that needs a connection to us. So, that's how I coordinate with a patient navigator. Luckily, our facility has the nurse navigator program. So, this has been new for me. We didn't have one until this last year. So, for me, I've developed this myself and in a sense of I've worked in the clinic, my clinic for years. And I knew that there was always this need for a navigator in our clinic. And some of the main reasons why is because of exactly what you said with the gap is there was nobody really to talk to a patient until they came in for that provider visit.

Charity Holien:

So, my main role is to, as soon as I get a referral is to make that connection with the patient right away of let me introduce what I do, who I am, what our team does. And then the big thing, especially for new patients is to explain what things need to be done, what things need to be worked up, why maybe it is a process of, and we can go into this later about those staging workup for a patient and why it takes maybe a few weeks. And it's really just to help anxiety for patients, once they hear they have that diagnosis all these things are going through their head of what stage and what treatment and all that kind of stuff, and there's different treatments for different stages. So, my main thing is to connect with those patients, to give them the information, educate them a little bit more of making a plan and then go through the process of getting them set up with us, for a new patient visit what that's going to look like.

Charity Holien:

Maybe some things we can get in process before they come, if they're comfortable. So that's, how they could get connected. In our facility it's pretty easy, they just have to call and make an appointment and that I'm the navigator that calls them, not every facility has a navigator. So, I think that I'm a big advocate for the navigators because I've seen, I've been in a facility that doesn't have one. And then I've noticed personally what a big difference a navigator can mean to patients.

Diane Mulligan:

What a tremendous difference. I'm thinking of a conversation that I had with Dr. David Carbone, who's with the Ohio State University, but he is a lung cancer expert, thoracic oncologist. And he talks about that sense of this psychological emergency, when you've been told that you have lung cancer and it feels like now I need to do something this minute, I need to start treatment tomorrow. And he, and I know Dr. Camidge and in your facility talk about let's get all of the information and all of the details. And there's so much that goes into it, that someone who's just coming into lung cancer for the first time, wouldn't know, there's no reason that they would know that. So, that's part of your work, but you also provide referrals on some real nuts and bolt stuff like, dietician and financial resources, maybe social work, down to things like parking my goodness. I mean, you drive out to this beautiful facility at CU Anschutz, and it's just like, I don't even know where to go. So, talk about all of those elements of service that you work on and help people navigate.

Charity Holien:

Yeah. Just the parking alone here, or just to physically, where is the building and what floor? I always knew that I needed to incorporate that with what I'm doing with navigating, because of course I got those phone calls in the clinic, but when I start doing it, that little piece is a big anxiety for patients. I come here every day and I see the parking, it's no big deal, but as a new patient, just that little thing makes people go, "Good, thank you for calling." So, what I've done and is for patients is I've developed a map of the campus where I send it to them so they can physically see what the campus looks like, you really only have to come to one building. I specifically have directions of what elevator, how to physically get off the elevator and take a left, and that's our lobby.

Charity Holien:

Like that just already decreases that first time visit. So, something very simple but means a big thing to patients. And a lot of it is like that first, especially that first phone call is I get quite a bit of information and patients just lead into the next thing. The big thing is a lot of people have financial hardships and how am I going to pay for treatment? Or how do I physically get to the clinic? I don't have a car. So, those things are great to have at the beginning. Again, those are a lot of anxiety for patients. So, I will connect them with our social worker, our financial team right away. They make phone calls and start talking to patients about that. Lodging, if they're from out of state, we have some grants at our facility that is the social worker can help with.

Charity Holien:

So, that is a big piece. Dieticians, if I can, especially if they're internal, I can tell that they've lost weight or eating has been an issue. So, I talk to them about like, let's get you looped into those. Some of those people can meet with patients that first day, if they're not too overwhelmed by that new patient visit, or at least a phone call that they're happy to get. So, some of those referrals I can get in place at the beginning, or after I usually meet the patients when they're here at that first visit, and we can talk about that when I close that loop on that of making those referrals and knowing that you might not need this now, but this is what we have. And as time goes on when we get a treatment plan, and you're starting to be more established in a clinic those are always available, so.

Sarah Beatty:

I'm just thinking of you mentioned that idea of just decreasing anxiety and it decreases my anxiety, just thinking about it because you're right. I mean, just from the moment of

like, "I don't even know where to park and I'm going to be late to this, and then I got to navigate this massive building." And all of these things, it's so nice to hear you talking about that. We know that there are so many appointments, so many different people to see, so many different tests, so many different places that information needs to go throughout your facility.

Sarah Beatty:

You mentioned when we were getting prepared for this, how you do things, and this is another one of these things, it seems so simple, but what a major anxiety alleviator to know that you're trying to coordinate appointments on the same day and make sure that, if somebody is coming in, they're going to get the blood draw and they're going to get this and they're going to get that, and it's all on the same day and same thing, and everybody can take care of it. So, what kind of reaction do you get from patients when you help them do that real nuts and bolts and scheduling work?

Charity Holien:

Yeah. When I first started this, I didn't know how patients would react because a lot of it is, they don't know what to expect, they don't know what goes into an appointment. I didn't know if people would want to do this, like some of this testing ahead of time coming from just a nurse. But I have been almost everybody I've talked to have wanted to get things in place before seeing the doctor.

Diane Mulligan:

That was a great conversation with Charity. She's wonderful in helping us understand why someone might want to think about using a patient navigator.

Sarah Beatty:

And she talked about how much of her job is corralling all of the information. So, a thoracic oncologist can make a treatment plan. Charity works with Dr. Ross Camidge at the University of Colorado Cancer Center. And I talked to him about how the patient navigator program helps him in his work. Can you talk to us about from your perspective, how a patient navigator or a nurse navigator helps the patient access the best care?

Ross Camidge:

Well, I should point out that we didn't have a nurse navigator for a long time. So, the absence of a nurse navigator isn't inherently a bad thing, but then when you do get one, you really realize their true values. So, what Charity performs a number of different roles, on the simplistic level. She is the Walmart greater, she introduces herself to the patient, she makes them feel like there's a human being who cares, but then on the backside, she has technical expertise to make sure that if you're coming in to see us, there's no missed gaps. All of the data that pathology report, the scan reports, everything is there, so that the doctor and you can have the most useful interaction. If you're coming from out of town, I mean, she's not the scheduler, but she's going to make sure that if there are things that have to be done, repeat scans, that she's going to try and bundle them together in the time that you have available.

Sarah Beatty:

I think that's such a great point because you do so many second opinions, and I'm thinking of people who come to you from all over the country and they may be fly into Denver and they've got 48 hours or three days, or they're here on a Friday and a Monday or something like that. How, and I think taking into account what you just said, that a patient navigator can help smooth all of those things. It doesn't mean that without a program, that's a problem, but how does a patient navigator help gather up all of this data that you need, or all of the tests or all of the scans, or all of these elements that may be really difficult for someone who's coming into town to think, oh gosh, do I have this? And do I have that? And it's a long checklist. Is that what she's really working on?

Ross Camidge:

I think, once you're in the medical system, you start to generate paper. And I think the challenge is particularly if, you are just the recipient of this medical care, you don't know which stuff's important. And chasing down 15 pages of blood tests, which the doctor doesn't care about isn't useful. Whereas Charity is so experienced. She can say, look, you need this, this and this. And she can also come to me and say, is this enough of information? A few days before the appointment. And I can say, well, everything's there, but this bit's missing. And it's about having a trained set of eyes making sure everything's there. I guess if I was to think of an analogy, you know when you go to the operating room, they always have someone in charge called the scrub nurse and it's their job to make sure that the surgeon goes in there and they're not going where the hell's the scalpel? In the middle of the operation. So, that's what Charity's job is to do the medical oncology equivalent that everything's there.

Sarah Beatty:

All the information that you need. So, she mentioned that you work on a multidisciplinary team. So, can you talk about all of the people that might be involved in a lung cancer, either diagnosis or treatment plan and how she is helping gather data that I would assume everybody on the team needs either the same data or some different piece of data or something like that. I mean, how is she helping get the right information to the right people or even maybe the patient to the right person?

Ross Camidge:

Well, so the great thing is they have electronic medical records. So, she just has to gathering and just get stand in and it's there. But I think what you really want in a navigator is to believe that if you're scared, but you've spoken to this person on the phone, that when you arrive, there is the equivalent of a familiar face there to greet you and that they have your back, that they are not going to let you down until you have a plan and you know where you're going to next. And so Charity doesn't stay with the patient forever, but they will move you on and pass you over to someone. And she's only going to step back when another person is taking you over and you have a plan in place.

Sarah Beatty:

I can imagine what a relief that would be for someone facing that onslaught of a diagnosis or a second opinion where you are trying to figure out who to talk to. And if you're headed in the right direction. Now, what about someone who doesn't have access to a patient navigator? You mentioned, you didn't have a patient navigator program for a number of years, if somebody is walking into a hospital and there's no patient navigator program, is that a problem? Should they be worried?

Ross Camidge:

No. I mean, I think in a good team, you have redundancy. You have people who, I mean, I tend to employ obsessive compulsive people so that everybody has double checking and triple tracking somebody. And so the schedulers performed that role, or the nurses performed that role. And indeed, if you put all your eggs in one basket, what happens if Charity goes away on vacation? You still have to have those other things. So, I think a navigator is a nice to have, it is by no means essential. And if you don't happen to have access to one, it doesn't mean you're getting inadequate care.

Sarah Beatty:

Something just popped into my head. And this is just a definition really, talk about the difference between a scheduler and a patient navigator? Those are two very different positions that work together, and both of them are critical, but they are different.

Ross Camidge:

Yes. I think one of the things that the navigators and even the clinic nurses get most frustrated by is being treated as schedulers. So, the scheduler is literally a person who says, "Okay, you need a CT scan it's going to be on this day and this time, and this is where you go or your chemotherapy." And so they are the logistics person, the nurses and navigators are requesting that information from the schedulers. But a good scheduler, we often make a point of whenever we get new schedulers of carefully integrating them, educating them about the program, they're not just a call center. And so they get to understand that too. So, as I said, there can be some redundancy.

Sarah Beatty:

And so someone like Charity might go to the scheduler and say, "Okay, I've got somebody coming in from out of town. They need this test, this test, this test." How would Charity then interact with the scheduler to make sure that all of those tests are sitting and waiting ready for you, when you walk in the office?

Ross Camidge:

Well, she's a bit of a bulldog. So, she would say I need these things done and tell me when you've done it. And if she doesn't get that that feedback, then she's saying, have you done it? Have you done it?

Sarah Beatty:

The nicest bulldog.

Ross Camidge:

In the nicest possible way, then she passes it on. I mean, that honestly, I think if you had to sum a navigator up in a word it's about trust, you trust the navigator to have your back. And we were just incredibly fortunate to have Charity. We joke, we call her detective Holien because she doesn't miss any detail.

Sarah Beatty:

That's got to be an amazing personality to work with. I'm just thinking of all of the amazing people that you work with and yourself included, and to have somebody there who you can trust to be that very polite, but insistent bulldog. Who's a detail person.

Ross Camidge:

I don't know about you, but I do not believe a team is made up of little uniform individuals who will have the same skills. I think we are all different and we have good points and bad points. And the key thing about a team is you try and emphasize the good points and you de-emphasize bad points, but you tolerate all of it.

Sarah Beatty:

Well, I think that's a great description and a wonderful conversation about this program. And I'm really appreciative of your time today to talk about it, and I hope it's something that more and more hospitals or academic institutions might be putting into place to help people navigate. What is the particularly challenging diagnosis.

Ross Camidge:

I think as the field gets more and more complex, we are going to need this. You can't just plug and play everything these days, and so you are going to need a wing man to help you through these things or woman.

Diane Mulligan:

What a fantastic conversation about the patient navigator program. Thank you so much to Dr. Ross Camidge and Charity Holien with the University of Colorado Cancer Center.

Sarah Beatty:

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Diane Mulligan:

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