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WEBINAR 8-7-14_TRICIA STRUSOWSKI

00:00:00 CHELSEA PROUGH: My name is Chelsea Prough and I will be moderating today's webinar. I'd like to introduce this afternoon's speaker, Tricia Strusowski, Senior Consultant Oncology Solutions, LLC. Ms. Strusowski will discuss her personal experience as a practitioner and what she identifies as the most challenging issues in cancer prevention and treatment.

00:00:27 At this time all participants will be in listen only mode. Please note that this webinar is being recorded. If you have any technical difficulties or questions, please enter your question in the chat window so we may help you. I will now turn the call over to Ms. Strusowski.

00:00:45 TRICIA STRUSOWSKI: Great. Thank you so much Chelsea, and I really appreciate all of your help getting ready for this webinar. And I really want to thank everyone today for this opportunity. I really always enjoyed working with NCI [inaud.], it's always been a wonderful experience and so I really appreciate that.

00:01:08 Next slide, Chelsea. So, what I'm going to review today is basically some of my background, education,

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and career path and then we'll kind of give it a good understanding of where I've been and what I've been up to over the last several years.

00:01:24 Just to review some of my publications, presentations, and National Committee work, again, so that you can kind of see my background and what I've been involved with and some of my passions. Some of my core strengths and then really getting into where I know the meat of this webinar needs to be in regards to discussions with our pivotal decision making challenges for patients and their families, which I'm very passionate about and have always been throughout my career.

00:01:49 Next slide. So, my humble beginning started at Nursing School [inaud.], so I've been a nurse a little bit over 30 years, 31 to be exact. I then went on to get my business degree in business administration and then I went on to get my healthcare administration from [inaud.] University, and finished up in 2008.

00:02:13 I started my career on a hematology bone marrow transplant unit, which I wasn't really sure if that

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was the right place I was going to be in my career as a brand new nurse, but absolutely fell in love with the patients. So, therefore the rest of my career ended up being in oncology, so you can kind of see that.

00:02:34 So, I stayed on that same unit, the hematology bone marrow transplant unit as a nurse, became assistant head nurse and then became the nurse manager, where we actually did open the bone marrow transplant unit, it was an eight bed unit at [inaud.].

00:02:49 From there I worked in the hospital for 10 years. I did leave for a brief period of time and I went into oncology home care. And again there I learned a whole new set of skills kind of being out in the patient's home and assessing their needs, which was very different, because I had to learn how to really spice up my assessment skills, because I was out in the patient's home solo, and not necessarily around other nurses that could help and provide additional background.

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00:03:20 So, I learned a tremendous amount about the oncology patient in the home setting. From there I actually got recruited back to [inaud.], at that time they had their own insurance agency for private insurance as well as the Medicaid program. So, it was Mid-Atlantic and First [inaud.] and they asked me to create their case management program.

00:03:43 So it was really chronic disease management, what we're calling now population management or population health. I help them set up those departments back within the Christiana [ph.] Care Health System. Insurance really wasn't my thing at the time, so again I was very fortunate as a nurse, I had plenty of opportunities again, and my vice president at the actually asked me if I had any oncology experience and I jokingly said, yes, I have a little bit.

00:04:10 And from them she actually asked me to coordinate the opening of the Helen F. Graham Cancer Center and several departments starting in the 2000. So, with Christiana Care and the Helen F. Graham Cancer Center, I was responsible, number one for first of all the cancer care management department, and that was

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primarily the support services, which did include for example the navigators, the social workers, the dietitians, genetic counseling, health psychology, the clerical staff, the in-patient discharge planners also reported to me.

00:04:44 So in 2000, you know, navigation programs were pretty new, you know, there was a little bit of information out there, but we had to figure out very quickly how we needed to coordinate care for the patients across the continuum and I think we did a fabulous job throughout the years. So, that was one area.

00:05:04 The I also was - would create with under the direction of my medical director Dr. [inaud.], our multi-disciplinary centers. And we actually, before I left, we were up to 16 multi-disciplinary centers and this is where the patient and their family would meet with the medical oncologist, the radiation oncologist, and the surgeon, at least, as well as other appropriate disciplines as needed for the disease site, they would meet all in one visit to review the treatment options for their patient and their family.

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00:05:39 Access them for eligibility for clinical trials, let them introduce themselves to the navigators and the other support staff, and actually at that point in time if the patient was prepared to sit down and actually put together their treatment plan, the physicians actually would meet with the patient, then go back to the team room, discuss the case, and then actually return back to the patient, with what they felt were the best options, and then again allowing the patient to participate in the treatment discussion.

00:06:08 That treatment discussion was actually facilitated and the templates were actually put together by the nurse navigator, reviewed with the patient and then that's where the beginning of the follow-up would occur with the nurse navigator to make sure that there was no breaks in treatment for what the treatment plan outlined.

00:06:25 So, we were very proud of this, and, you know, we had to work very quickly to make sure the process was working, number one for the patients and their family, and number two, for the physicians. Because I was

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working with a handful of private physicians as well as employed physicians, so, it was a lot of fixing and cleaning up immediately.

00:06:49 But it was very successful, and by the time I left Helen F. Graham last year our patients actually ended up being our best marketing for our multi-disciplinary center, so it's something that we're very, very proud of.

00:07:02 So, I also had our pharmacy and our chemotherapy infusion suite, our pain and symptom management program, thoracic surgery, our bone marrow transplant program, and [inaud.] accreditation, and one of my last programs was rehab, and then the last piece I was putting together right before I left, was creating an oncology medical home.

00:07:23 So, needless to say it was quite fulfilling, it was a tremendous amount of program development, which I actually loved, it's my biggest passion, and everything was truly patient centered. That's a big part of my background as well too.

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00:07:36 So, from that I was actually recruited to Oncology Solutions, November of 2013, and I'm going to review a little bit what I do with Oncology Solutions in a couple additional slides. Next slide, Chelsea.

00:07:55 So, I'm going to review some of my background [inaud.], publications and presentations. Next. Next slide. So, my most - the way I put this together was the most recent. So, hot off the press, was something we're very proud of, it took over a year to create is the [inaud.] oncology nurse navigation workbook and I co-authored chapter 8, examples of successful navigation programs and actually I just got my complimentary copy last week and so I was very excited to see that.

00:08:26 I was also very fortunate to work with oncology nursing solution, in regards to nurse navigator for [inaud.] in 13. A little off navigation topic is I actually, we received the state and international healthy workplace award from the American Psychological Association. And I actually did presentations for them as well too.

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- 00:08:50 I was on the Academy of Oncology Nurse Navigators conference present circuit from 2009 and '13 and I'll actually be at their conference again this year, I just had a poster abstract accepted, surprise, surprise on navigation. And I was actually on their leadership committee for a few years as well too.
- 00:09:09 And then I was also - I initiated the NCCCP Navigation Network Committee in 2009. It was actually a need that spun out of the quality of care committee which was started with NCCCP of course in 2007, I was co-chair. Next slide.
- 00:09:32 I guess one of my more challenging projects was when I was on working with the [inaud.] experience survey, it was a very complicated few years in regards to putting the survey together. I think it turned out beautifully, I was on the expert panel and then we are actually one of the sites to test the actual survey itself, and we were extremely pleased with the results.
- 00:09:57 I've been interviewed by NCI Cancer Bulletin as the patient navigation programs expanded and involved.

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Nursing excellence award, again I was NCCCP co-chair for the quality of care committee, which I thoroughly enjoyed especially with my background with the [inaud.] and multi-disciplinary centers and of course navigation.

00:10:18 I had a wonderful couple years working with the association of community cancer centers. What we actually did was we actually chose out of hundreds of applications six sites that I went out and taught the navigation process to over a two day period of time. And then we actually did some outcome studies and wanted to make sure that they were benefiting from the information that I provided.

00:10:41 And then I've done some miscellaneous articles on multi-disciplinary centers, care management models and of course navigation. Next slide. So, we're going to get into my core strengths. Next slide. Again my passion is all about program planning, development, and implementation.

00:11:04 Truly my passion since day one. What I actually do now as well, which is something I really enjoy is when

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I do go out to a site visit, I actually go to a cancer center, and I will do a site assessment on whichever clinical program that they're interested in. Most recently it's been survivorship and navigation.

00:11:28 I will do a gap analysis, I will make program recommendations and observations. So, I've done this for survivorship, navigation, [inaud.] care, and [inaud.], research, patient [inaud.] care, advisory programs, and cultural competency as well.

00:11:44 I also work very closely in regards to the support staff, making sure they're working within their roles and their scope of licensure and their job descriptions as well. I like to help them always - I'm real big in developing tools, so that they're utilizing evidence based tools for their assessments and their performance improvement activities.

00:12:07 And then I've also worked in regards to the new commission on cancer standards for chapter three continuum of care in regards to the patient navigation, psycho-social distress screening, and

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survivorship. I go out and we do that, and I'm very passionate about the Institute of Medicine report.

00:12:25 I've also worked very closely in regards to development [inaud.] improvement and optimization as I reviewed in regards to the tumor site multi-disciplinary consults or the multi-disciplinary centers. Next slide.

00:12:41 So, we're going to get into my what I feel is pivotal decision making challenges for patients and their families. Next slide. I think a major pivotal decision making challenge for patients, actually I think there is a lot out there for patients and their families, and again they are the unit.

00:13:01 There is no way you can have them separated in any way, shape, or form. So, the patient, family, and/or caregiver, whatever's appropriate, there is a lot of treatment options out there. You know, balancing these critical decisions, straight from prognosis to their outcomes and the finances.

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00:13:17 I think this is absolutely huge right now, more so than ever, especially in regards to the finance piece. Next slide. So, again I want to share with you some of the additional challenge of this, because I said I think there's definitely more than one. Next slide.

00:13:40 So, I think, again, I love the Institute of Medicine slides that came out and I think the most powerful ones to me was slide 16, when we're hearing information directly from the patients. Number one, listen to me. If I have done anything in my role as leadership, I have always tried to teach my staff throughout the cancer center and anywhere else I go, number one, it's all about the patient.

00:14:07 The patient comes first, take care of the patient, and everything else can be fixed later. I think that's huge. Especially for an oncology patient, of course that's where my whole career has been. We actually received a lot of this information when we were doing the patient experience survey.

00:14:26 Patients just want to be heard. And I think another very important piece that I took out of the IOM [ph.]

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report that I share when I go and do site visits or do presentations that ask tell, ask model. Meaning, ask the patient what they know about their cancer, ask what them what they've been told from the doctor about their treatment, their treatment options, the side effects.

00:14:49 Then it's for the healthcare provider, for example, myself just say, okay let's review this, let's review your cancer, let's review your treatment. And then again asking the patient again, please tell me what you understood.

00:15:05 And then going back and forth and making sure that they truly, truly understand what is being relayed to them. Again, firsthand there's so many times that I've seen either physicians, or even nurses explaining things to a patient using medical terminology and I can just see the patient glaze over and I think they're almost too scared to ask a question, or to appear stupid with the question that they're asking.

00:15:34 And that is something that I try to relay to my staff as I teach them about ways to communicate with their

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patient. So, in my programs right now I tend to always incorporate these type of questions, open-ended questions, very basic questions.

00:15:52 I also utilize different modalities for asking the questions. I'll ask the patients do they actually understand, you know, a preferred language, do they prefer to look at more visual type educational tools, please tell me how I can help this discussion succeed.

00:16:09 Again, tell me the truth about my diagnosis. There are so many times, and I know there's research that's been out there that I've actually read through, that the patients, they might be a late stage patient and they still believe, or actually they've never been told their true prognosis in whether it be months, or several months, they're still assuming that there is a cure going on.

00:16:36 It might not be that it was never shared, but obviously the patient did not understand what was going on. And tell me about the risks, I think that's huge as well too. When you're sitting with the patient, you know, they have these one hour

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chemotherapy sessions with their nurse in the chemotherapy setting.

00:16:57 You know, do they really understand, you know, again I try to always create again tools, I create what they're called frequently asked question tools. I also create, we're calling them now decision aide tools for the patient and their family.

00:17:09 And again research has been shown the patient will use these tools. Because they really don't even know what to ask, so if we're helping them with creating these questions to ask their healthcare providers it's setting them up to succeed, so that's always been my goal.

00:17:27 And let alone cost, cost concerns are a major worry. I've seen this first hand, of course overseeing the chemotherapy infusion suite. I worked very closely with the office to make sure they're providing financial information right up front with the patient and their family so that they can make decisions, not necessarily that they're not going to receive their care, but, you know, how can we help them.

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- 00:17:52 Can we help them with the terrible application up front, can we have them meet with a social worker right up front, to look for other financial alternatives. Is there better ways that we can move forward, can we put them in the hospital out-patient setting for their chemo verses the private doctor's offices where we have more flexibility to help with financial planning for their chemotherapy.
- 00:18:14 I've seen families actually mortgage their homes for their treatment or not get treatment because they couldn't afford it. So, again from the IOM report, cancer care is often not patient centered. I think a lot of people it is patient centered but I know firsthand as hard as we try, I still think we can go to a whole different level.
- 00:18:37 I actually teach the IOM report, one of the first things that I do is teach [inaud.] cancer standard and the Institute of Medicine report when I'm going to a new site visit. I cannot assume that they know this information. A lot of times they're not even aware of

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it and it creates a tremendous, wonderful foundation for moving with any program development.

00:19:00 Next slide. So, again I'm not telling you anything you haven't seen before or shared or heard before, but again, the demands for cancer services, your population is aging. You know, the number of medical oncologists in the future is going to dwindle, we're going to have to utilize, you know, advanced practitioners.

00:19:23 We're going to have to have staff working to the highest of their licensure for their state regulation. You know, in a fragmented system. We're not [inaud.] base guidelines or quality of measures. We're not creating the correct matrix when we put together some of our programs.

00:19:40 Cost is rising tremendously and poor clinician patient communication. And I said, you know, I'm going to give you a perfect example. I have an older mother and she will do whatever the doctor tells her to do. You know, we have to encourage even our older

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populations that, you know, what are your goals of care and explaining what goals of care are.

00:20:04 What do you want, you know, if you're 85 years old, and this is what's going on and this is what condition you have with your heart or your lungs and this is what the treatment is going to do to those vital organs. You know, what do you want to do, what are your goals of care as you go through treatment, if you even want to go through treatment, these are some really important discussions that we need to have with our patients and their families no matter how old they are.

00:20:30 And I tend to worry about our elderly population, because they already have, you know, so many things going on with them anyway. You know, very rarely will a patient just have cancer. Of course they may have cardiac disease or diabetes, which causes tremendous amount of complications.

00:20:48 You almost need to have a gerontologist onboard in your cancer center to help these patients, and it's just vital and they're so fragile to begin with. And

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of course, IT, that is a challenge, everywhere I've gone for my entire career and the challenges, I can see how they're getting better, but they still exist.

00:21:10 And again using novel framework and foreign vocabulary. So, again we have all our new accountable care organizations, value based modifiers, [inaud.], research [inaud.], survivorship plans, and of course one I'm much more familiar with, of course the oncology medical home.

00:21:29 Next slide. Again, my area, which I truly enjoy is creating patient centered cancer care. So, again right before I left, I had a patient advisory group that was eight years old, I had a patient advisory committee for patients and caregivers.

00:21:51 My safety committee actually had a patient on there and I was - any other committee that I started to created, we always had patients or family members. When we were doing walk-through for our safety measures for - we actually had a patient and a family member and actually one of the elderly patients who walked through the cancer center with me, so we could

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really evaluate our cancer center or facility, which was not very elderly patient friendly at all.

00:22:20 So, we actually did some very creative interventions to really help keep our patients safer from the time they entered the door, straight through to whatever department that they were going to. And actually we started to encourage our patients to even call us if there was any specific needs prior to their visit so that we could meet them at the front door to keep them safe.

00:22:41 So, again that's just one example of patient centered care. So, we should be looking, you know, at the oncology supportive care, standardization of protocol pathway, definitely quality. When I look at quality, I'm looking at three pieces. I have three buckets, patient experience, quality outcomes, and business performance.

00:23:00 And that's how I try again. Go to a site visit and help outline their matrix. Multi-[inaud.] participation, is so important anymore. You know, if we were fortunate enough at my cancer to be able to

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have face-to-face multi-disciplinary centers, but there's other options, we could have virtual multi-disciplinary centers.

00:23:21 We can utilize the tumor conferences and share that information and feedback with the patients and their families. As long as that discussion occurs, that's the main thing and of course communicate it back to the patient so that they understand.

00:23:33 So, of course from the supported program infrastructure, multi-disciplinary physician teams, evidence based clinical pathways, which is extremely important, I've seen again through my career, tests and procedures being order that are being inappropriate.

00:23:47 You know, now we're very fortunate, I think just about everybody follows [inaud.] guidelines and it creates pathways extremely similar to those guidelines. Service line leadership I think is extremely important. That was my background at the Helen F. Graham Cancer Center, so pretty much anything related

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to oncology either reported to me or was a matrix report to me.

00:24:13 Cost transparency, which I know a lot of sites and cancer centers are having a tremendous difficulty to be able to provide this information and I know personally when we tried to pull this information from our finance department, it was somewhat difficult for us, we could get there, but it wasn't an easy process.

00:24:30 Data driven program development and clinical decision making, full complimentary support services and again when I'm at a site or when I work with different cancer centers, I say listen, all the support services do not need to report to the cancer center or the cancer program.

00:24:50 Be creative, look at the other support services within your hospital system, you know, your dieticians, your pastoral care, your finance department, utilize their expertise to help you create the services needed for the cancer patient.

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- 00:25:04 Also, I created a lot of programs for my volunteer department. I looked at the background, actually created a financial literacy program with a retired CPA that was a volunteer, I found a couple of retired social workers that I actually volunteer mentor training and they actually became outreach for my patients to actually help with my navigation program to reach out to the patients.
- 00:25:29 So, there's a lot of ways to be creative within your hospital setting. I also say look into your community. You know, look at the American Cancer Society, look at the YMCA, look at your Cancer Consortium, reach out see what they're up to, do not reinvent the wheel, if there's already successful programs going on partner with them. Invite them into your cancer center.
- 00:25:51 Utilize as many of your resources for your patients as possible. Because especially in this economy, you know, we're not going to be able to have all these additional [inaud.] for our programs. And then again metrics. Everything I shared with my staff as we did

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program development, it turned into a performance improvement activity.

00:26:10 It did not have to be grand projects but we did always incorporate some metrics in regards to that. Next slide. So, I think you can see by now it's all about the patient and their family. It has been that way for me through my entire career. They have been my biggest gift throughout my nursing career is just listening to them.

00:26:37 And it's I always say, boy listen to the patients and families, ask them what they want and you know what they'll tell you. If you truly listen to what they want and try what they're telling you to do with the program development, it really does work.

00:26:51 And that is really, I think some of the basics of my program success at the Helen F. Graham Cancer Center and I really try to incorporate everywhere I go. Again, coordinated multi-disciplinary care across the continuum.

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00:27:05 You know, I keep things short and sweet and easy. You just increase communication amongst the healthcare team, it's almost impossible to over communicate but make sure any way possible you're decreasing duplication for that patient and their family.

00:27:16 You know, so many times when we opened our cancer center, you know, there was one office alone that had five different medical oncologist and there were five different medical history forms and it was - and then they would have to go to maybe our multi-disciplinary center which had another medical history form.

00:27:33 So, you know, it took about a year, but we did get down to one medical history form. And that medical history form was actually forwarded to anywhere else that patient was going to go within our cancer center and we also gave the patient a copy so that they did not have to repeat that information again.

00:27:52 Same thing for registration, the patient could have lab work and then maybe go down and have some imaging studies, in the past the patient would have to have two different registrations, so we worked very hard

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again, pulled the information forward, re-verify the information, yes, but don't make the patient go through that again.

00:28:08 And it was very obvious and the patients appreciated it so much. You know, even if our patients were admitted to the hospital, my staff would share information between the in-patient and out-patient setting and it was very polished, as my discharge planners went into the patient's room and they already knew who their caregiver was, what equipment they had in their room, what homecare agency was already set up, what your financial concerns were.

00:28:30 It sounds easy to do and it really is easy to do, but those concepts actually need to be shared amongst your team so that they really understand the benefits of sharing the information across the continuum. Again, evidence based guidelines is extremely important, high quality, research driven oncology programs, competent staff, which I did share with you before, functioning at the highest level of their licensure is going to more important than ever.

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00:29:00 It's a little devastating to me when I do go to some of these cancer centers and I see a registered nurse functioning as a clerical staff member, meaning, doing authorizations for insurance, or for coordinating appointments. I understand some appointments may need to be coordinated and might be a little bit more clinical that is needed, but with some of the specifics, maybe a CAT scan or a PET scan, these are pretty easy procedures to be scheduled and a clerical person could do that process at a much, much lower rate, therefore leaving the registered nurse to function at the highest level of her licensure.

00:29:42 And again awareness and use of national standards and guideline, I think is essential. They're out there, there is no reason why people should not be utilizing them. Teams have worked on them, national experts have worked on them for many, many years and it's just high quality information. So, you know, that's where I always turn in regards to my program development. Next slide. And that is my presentation. I truly thank you again for this opportunity.

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00:30:15 CHELSEA PROUGH: Thank you, Ms. Strusowski. At this time I will turn the call over to Dr. Jerry Suls, Senior Scientist at the Behavioral Research Program. As a reminder this webinar is being recorded. All lines will now be unmuted.

00:30:34 DR. JERRY SULS: Thank you very much for that very thorough presentation, covering a lot of bases. I wanted to ask you just a definitional question first, mostly for some of the folks who might be listening or listening in the future certainly. And that would be would you give us just a brief description of what you mean by navigation and then I have a follow-up to that.

00:31:04 TRICIA STRUSOWSKI: Yes. Yes. Navigation is, and I specifically when I speak about navigation I was fortunate to have nurse navigators that reported to me, however, I have helped create lay social work and even more creative bi-lingual or [inaud.] navigators, so really what the navigators role is is to coordinate resources removing barriers of care across the continuum, providing psycho-social assessment, distress screening for the patient and their family

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across the continuum and I am talking from outreach screening straight through survivorship and end of life.

00:31:53 DR. JERRY SULS: Okay, thank you. So, there's a wide range of ways and places where decision making is going to play a role and one of the things you raised that is actually novel and has not been something that anybody has raised in any of the webinars previously, so I want to get back to it, but and that has to with the [inaud.] set of - physical issues which is an important one as you observed.

00:32:27 But I guess my question is there's a general recognition that the multi-disciplinary team is needed, there needs to be a lot of participation, I'm trying to understand how that would work in the context of shared decision making, which not always, but sometimes in terms of the patient, maybe the family as well, and the oncologist, but I think you're making the case that there's really a variety of professionals that could be involved.

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00:33:03 Practitioners that could be involved and probably should, but there's not a lot of familiarity with that in practice, I think. So, I wonder if you could say something about that and how that interacts with decision making by the patient?

00:33:18 TRICIA STRUSOWSKI: I know the way that we moved forward with it, so for example when we had our multi-disciplinary centers and that is like I said, when medical oncologist, radiation oncologist, and the surgeon were reviewing the patient's treatment options with the treatment, the patient and their family with the navigator and a clinical trial nurse all in the same room, it usually initiated with the physician explaining the treatment plan.

00:33:46 And the physician, I'll be honest, some were very good at it and some needed a little bit of help or needed a little bit more follow-up from the navigator after the meeting, would do to the best of their ability to explain the treatment options, which are extremely complicated.

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00:34:02 I mean it is very hard information to really kind of get down to the bare bones with the patient. I know, because I've witnessed I believe from a patient's standpoint there can be a lot more of the incorporation of the ask tell, ask model. However that does take a little bit more time. What we tended to do is we would allow the physician to review the information, yes the physician did always ask the patient if they understood.

00:34:34 I could tell by observation that maybe sometimes the patients did understand, maybe they didn't because if maybe I was covering for one of my navigators, but what I would always ensure is that even after that multi-disciplinary center team meeting occurred with the patient and their family, that navigator was key.

00:34:55 She would either stay after the visit with the patient and their family and say, you know, what let's look at this, let's review this again. Let's discuss this in more detail or there could even be a follow-up call, or two follow-up calls to make sure that the patient understood and that they truly felt comfortable with their decision.

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00:35:13 The other piece of it too, is that we did not make the patient have a decision by the end of our multi-disciplinary centers. If they felt that they needed a second or even a third opinion, we actually helped them coordinate that.

00:35:28 We would get all of their films and their information together on a CD, we would actually, you know, Delaware, we're very close to Philadelphia, I'm sorry, Newark, we are very close to Philadelphia, or actually if they wanted to go to [inaud.] or Hopkins we actually knew the contacts there, we would help the patient with that.

00:35:47 Our big thing was to make them feel that they were making the right decision. Some patients felt that they shouldn't be making a second opinion. And we said absolutely not, you need to feel comfortable with the care that you're receiving no matter where it is. So, you know, it's still a process. We were still - I know a lot of centers are still working on that, making sure that the patients feel comfortable and are

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a part of the decisions, you know, our life in oncology is getting faster and faster.

00:36:19 The patient volume and case loads are getting higher and higher because as we lose maybe a medical oncologist or a navigator, they might not be replaced or they take a little bit of time to replace. So, we again need to make sure to the best of our ability for each time, you know, I'm thinking one doctor in particular, he may run a little bit later with his schedule but I know when he is with his patients he is giving his patients 200 percent of his time and making sure that they are a part of this decision. So, it's a very hard, it's a very big challenge. I hope I answered your question.

00:37:01 DR. JERRY SULS: Yes, no you did. I would assume and I think you eluded to this, that this idea that the whole team is there or all the specialists are there and then there is also the possibility for a repeat and the navigator may very well stay around and wait and make sure all of this information has actually been processed.

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00:37:26 That's probably the exception right now in oncology treatment, would you say that's true or could I be wrong about that?

00:37:38 TRICIA STRUSOWSKI: Well, I - it's a different model. It's a very high functioning model and I have to, I always have to say, listen [inaud.] tip to tip we're two hours, there's only three counties in Delaware. All of our physicians were housed in one cancer center. However, there's ways around this, I know what we started to do is do some telemedicine, you know, where we were starting to pull up the information, whether it be on a PACS system or on I-Sight system so that the different teams could look, be in different places, to actually at the films and the pathology, have a discussion, you know, and then that physician who was solo at his practice in his office, could then say, you know what I did review your information this is the recommendations from my team.

00:38:27 You know, as I was exposed to [inaud.] I realized I wasn't in Delaware anymore, as I met teams from Billings, Montana. You know, one physician actually

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said you fly or you die, they had to live by telemedicine, they had to utilize different resources, so that was a real eye opener for me.

00:38:49 As long as the information gets back to the patient in a form that they can process and understand, I know firsthand again, the patients appreciate when they said, your information has been [inaud.], even at a tumor conference, your information has been discussed with several physicians in the specialty of surgical oncology, radiation oncology, medical oncology, this was the recommendations, let's talk about it.

00:39:15 I think there are ways around it. But I do know what I'm starting to see is the navigator is taking a much more intense role to be - to facilitate some of these discussions after these patient appointments actually occur.

00:39:33 DR. JERRY SULS: Okay. Just a concrete question, very concrete question, the options are presented verbally, but I'm assuming there is also written materials that the patient takes away or reads along with, or how does that work?

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00:39:49 TRICIA STRUSOWSKI: We actually created a treatment plan, a preliminary treatment plan. So, this was the responsibility of the nurse navigator to complete. So, for example if the impression was, you know, an early stage lung cancer so we're going to have surgery followed by, you know, different things, she would actually outline the specific plan.

00:40:17 So it would be surgery and she would actually have - be responsible to make sure that she got from the clerks what the surgical date would be. Maybe next would be chemotherapy, when is that first appointment with the medical oncologist in their office with a target date.

00:40:34 That might be followed by radiation, when is that initial consult going to be, when is simulation going to occur, when will they start their first treatment, what's a target date. So the patient actually would receive a copy of this. We also send a copy of the treatment plan to every single physician that was involved in that patient's care.

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00:40:53 So, for example their primary care physician, should they have endocrinologist, a pulmonologist, everybody received a copy of that because we do not want it to turn into a black hole, and we wanted them to be aware of all of the physicians, and of course all of the consulting physicians meet [inaud.] surgery, received a copy.

00:41:09 And then this was pretty much the marching orders for the nurse navigator to make sure, we actually would create continuum care spreadsheet electronically so we knew when the patient hit surgery we shared information with the in-patient unit, we knew when the patient hit [inaud.] that the visit did occur, that the chemo did start.

00:41:26 We knew key times to be calling the patient when they're in their [inaud.] or whatever else is going on based on psycho-social distress screening and then also maybe also when they hit the radiation therapy. So, we knew there were no breaks in care. That was a huge role of the navigators and that's really what I taught, navigators really need to be following these patients across the entire continuum to decrease the

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breaks in care and constantly providing a comprehensive assessment of their needs for themselves and their family members.

00:41:55 DR. JERRY SULS: Okay. You talked a bit about - I'm sorry.

00:42:11 STEPHANIE LAN: Yes, so I have a quick question if I can jump in, this is Stephanie Lan [ph.] and my question for the speaker is, what sticky decision making issues have you seen patients face where their reasoning or their psychological processes that they're undertaking are not obvious and where you think decision making researchers are coming from, more of a basic psychological perspective, could perhaps be helpful for clinicians to better understand the process and how to help.

00:42:44 TRICIA STRUSOWSKI: So in regards to specific decision making treatment, for treatments? Treatment decisions, is that what you mean specifically?

00:42:58 DR. JERRY SULS: I think that's what she means.

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00:43:02 STEPHANIE LAN: Not necessarily, any of the decisions that you're working with patients on, whether it's treatment decisions, financial decisions, and I suppose there must be decisions about what they do in their occupational life and whether they move to another place to receive treatment, any of the decision that you're helping patients navigate.

00:43:23 TRICIA STRUSOWSKI: Okay. Well, there are times when patients will specifically ask the team, a well informed patient will research their surgery and the number of procedures they've completed. I'm going to give you a real-life example. Originally we started, we didn't take care of a lot of sarcoma patients originally and so those patients actually asked, they said how many surgeries have you done for sarcoma.

00:43:50 There was a physician out of Philadelphia doing a tremendous amount of these surgeries and patients were informed, we shared with them, we actually had information on our website in regards to the physician's specialty. We tried to be very transparent in regards to the services that we had

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available and therefore patients actually decided they were going to go up to Philadelphia.

00:44:14 Now of course we wanted to actually take back that market share and we actually did recruit a physician that did a tremendous amount of work with sarcomas and we went from seeing only 70 patients a year to two years later up to 140 patients a year through our sarcoma multi-disciplinary center. So, we tried to be very transparent. What also -

00:44:38 STEPHANIE LAN: Can I jump in?

00:44:38 TRICIA STRUSOWSKI: Sure.

00:44:40 STEPHANIE LAN: I'm sorry. So, let me try to ask the question again, because I'm not sure I was clear. What I'm asking is what decision making scenarios have you witnessed where you don't really understand why patients are making the decisions the way they are or where in some other respect decision making research might help answer questions that you've encountered. So a situation where you don't really know the answer

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and you're perhaps hoping that someone will do some research that may help.

00:45:14 TRICIA STRUSOWSKI: That's a really good question. There are so many pieces to this big oncology - wow. I think just - you know, what I shared with you in regards to decision making tools is probably an extremely basic tool to use for patients because patients don't even know what to ask, that's why I'm kind of challenged with your question.

00:45:57 I tend to provide patients with the information or the questions that may prompt the decision that they want to have with their providers. So I think a tremendous amount research, that could be evidence based, frequently asked questions created by particular cancer disease sites might be a pretty unique opportunity for research.

00:46:26 Again, you know, a lot of times I would tend to want to go back and ask the patients that have been through treatment, where were your challenges, where did you feel you didn't even know the right questions to ask, I think would be a great way to start.

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00:46:44 I think, I'll be honest that question is going to require a little more than a couple minutes to answer, but it's a fantastic question, but I tend to think that we need to look at some of the information we provide the patient that is really beneficial to ensure appropriate communication when it comes to decision making with their healthcare provider.

00:47:12 DR. JERRY SULS: To sort of follow-up on Stephanie's question, maybe this an appropriate follow-up. When physicians, when the physician team provides a recommended plan, I'm sure some patients, I assume some patients asks what the likelihood of success are associated with this and of course those are really delicate - that's a delicate question and very frequently the answer is, it's always probabilistic and sometimes very inexact and are those places where patients frequently - does that come up or no?

00:47:59 TRICIA STRUSOWSKI: No, it comes up. It comes up. I'm thinking of one particular example where the patient thought she had a different stage of disease. The physician started talking about chemo and

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radiation and she was like whoa I didn't know, and so I just saw her whole life shatter in front of her.

00:48:19 She was a little bit more educated. There are, you know, some patients that are really not even aware of again what to ask or what to do but I have seen physician actually say, per the literature this is the survival rate. Per the information that's been researched to date this is the prognosis.

00:48:51 A lot of times the patients aren't really asking maybe so much about prognosis but like you said success rates they're using different terminology. A lot of times what I've again started to incorporate and again it's very delicate conversations, it's what information do you want to know.

00:49:14 What specifically - because sometimes we're even providing too much information and then the patients are like why even bother with any of this, you know, they just shot down everything I ever thought was going to be - again it's a real balance.

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00:49:26 Every single patient is an individual and some people can handle front up truth of what's going to happen, this is your stage, this is the prognosis, this is the treatment, these are the side effects. Some people do very well with the facts and then some patients crumble with all of that information.

00:49:42 So, again it's, sorry, it's not an easy question for me to answer, but does that help a little bit?

00:49:50 DR. JERRY SULS: Yeah, well I guess, Stephanie did you want to follow-up. Go ahead.

00:50:02 [Cross-talk]

00:50:22 STEPHANIE LAN: That was me Wendy, but if you wanted to go ahead that's fine.

00:50:24 WENDY: I just had a question, it seems as though geriatric oncology of patients kind of get [inaud.] and I would think that they would have special needs, not just special medical needs but also cognitive as well, and I was just wondering, you know, from your experience is there any kinds of special decision

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making needs of geriatric patients or a different approach to management that you find helpful for elderly patients?

00:51:01 TRICIA STRUSOWSKI: Yes, I believe so, and I think gerontology really needs to be forefront in regards to, actually before I left, this is how strongly I feel about gerontology. We actually created a medical home with a gerontologist who actually had oncology experience as well too. That's how important I thought it was.

00:51:22 Again everything evolves the other comorbidities that that individual has, and again I think the decision of goals of care which they don't understand you actually have to say this is what the chemotherapy will do to your heart and you already have a heart condition, let's talk about this.

00:51:45 Maybe there's a different chemotherapy or maybe something that won't be so strong on your heart and then explaining to the ability so that they can make their own decisions. Again I think the older population they tend to agree with whatever the

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physician will tell them, and that's a hard mindset to get through.

00:52:03 It's just a sign of their times but it's really important and a lot of times that's where the navigator spends a little bit more time just to say I really want to make sure that you understand when you're getting your chemotherapy.

00:52:18 It's really important that you do take this medicine because it's going to make you feel a little bit better. Because a lot of the times they're scared to take different meds or meds may interfere, I mean it's just a very complicated. I mean I'll be honest our whole cancer center wasn't even physically set up for an older population.

00:52:35 Our halls were very long, the floors were slippery, we really had to relook at everything, we were having - you know, from a very basic standpoint of your facility set up, not - let alone the conversations that you have about these extremely complicated treatments that are going to interfere with their other co-morbidities.

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00:52:55 I think that's why I think the majority of patients that we started to see in our medical home initially were actually the elderly because we would have diabetics that were having problems because of their steroids and what that was doing their side effects and being dehydrated because they were having so much diarrhea and not knowing what to do and being at home or nauseated beyond any scope and not taking meds because they didn't understand how to take the medicine.

00:53:24 So I think our older population, we are definitely - maybe if we looked at some research maybe that's definitely an area that we need to look at.

00:53:38 WENDY: When do you introduce the notion of Hospice? Is that introduced kind of toward the beginning or because I mentioned the decision making process around that is very different for every individual. But there's some discussion of Hospice even in kind of the initial discussions?

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00:54:06 TRICIA STRUSOWSKI: Again, it depends where the patient is, whether the type of diagnosis prognosis -

00:54:17 WENDY: Well just the notion of [inaud.] care.

00:54:18 TRICIA STRUSOWSKI: Well, [inaud.] care and Hospice are two different things. [inaud.] care really should be introduced right up front. Now again I had a patient advisory group that associated [inaud.] care with Hospice, which is not correct.

00:54:29 So what we did is we changed the name, we changed it to pain and symptom management and we incorporated that discussion with our patients right up front. We did share information about Hospice in our patient treatment journal and the number one thing, get that out of my journal I don't want to be seeing that information right up front, and we removed it immediately. That was a pilot that we did.

00:54:54 That it was loud and clear they did not want to have that Hospice information. However, what we also did was, and what we did and again it was another grant project that we worked with some of our late stage

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[inaud.] cancer patients and I actually assigned them a social worker, because we knew of these prognosis.

00:55:09 We knew what was, you know, potentially going to happen and they actually were extremely, they were just wonderful about how to start these conversations about next steps and, you know, have you ever thought about this and of course it was all under the direction of a physician, that was our [inaud.] that actually oversaw the grant, but those very delicate questions in regards to Hospice and not like pain and symptom management or [inaud.] care. It's very delicate and very time sensitive, you guys know that, very time sensitive discussion.

00:55:47 WENDY: Thank you.

00:55:52 TRICIA STRUSOWSKI: Absolutely.

00:55:56 DR. JERRY SULS: So, we don't have a whole lot of time, is there somebody else that would like to ask a question or has a comment? Okay, let me ask one final thing, I'm not sure whether there is enough time for this one, but, I wondered what your reflections on

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this would be. On the one hand the multi-disciplinary team approach, there's all kinds of reasons why that sounds like a great idea, but I wonder how patient respond to that when they're in a room with a group of docs and they have a navigator and they have family there too of course, but nonetheless that could become a pretty intimidating situation with somebody giving you a recommendation in that kind of context and I wonder if you have notice any dynamic that goes on there that is a problematic one for the folks making decisions and asking questions.

00:57:09 TRICIA STRUSOWSKI: Well, first of all they are 100 percent intimidating meetings. And I'm going to give you, you know, I like to always share the good, bad, and the ugly. So, for example our head and neck team, there was 11 members on our head and neck team, that multi-disciplinary team, because it was the physicians, you know, we had a dentist, all the other support staff, we had therapy, we had a speech therapist, we had our dietician.

00:57:33 So for example we initially did not prepare our patients very well for that visit and here I am coming

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down as the manager, saying, oh I'm sorry, you know, the patient is say wow I didn't know everybody was going to be there.

00:57:43 So, we fixed that immediately, what we did is that we would have a call before they came with a letter to say listen this is the team you're going to be meeting with, it's a large group, however this is the reason why we're doing this. We are going to be coordinating your care, right up front.

00:57:59 You know, the patient, by the time they got there, first of all they showed up and they knew that there was going to be a large team. That didn't - they were still overwhelmed, however once they realized that we probably saved them close to six or eight weeks at least going from specialist to specialist for their treatment plan and maybe or maybe not that treatment plan was discussed between the different physician specialist, which usually it wasn't saved them a tremendous amount of time, and all of their care was coordinated right up front, being introduced to a navigator that was going to make sure everything was going to happen in its proper sequence.

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00:58:38 After a while, our patients that went through the multi-disciplinary center they would still - I had focus groups on that and they would still say to this day it was very overwhelming, however I would not have done it any other way. And so, you know, we'll try to tell the patient listen it is going to be overwhelming, there's going to be a lot of information reviewed, you know, I would teach my navigators to say you know what Mrs. Smith, I'm here for you, you're stuck with me, I'm here to help you across the whole continuum, you know, across your whole cancer journey, but it was a very overwhelming experience.

00:59:14 But like I said, once the patient realized that wow I had the whole team meeting with me in one visit, because if anybody - I mean everybody has a family member with a chronic disease, you go from doctor to doctor. So, a lot of these cancer patients get it very quickly and say wow my whole team was in one room with me.

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00:59:37 Or they took it to the tumor conference shared information to the team and brought it back to me, they realize the benefits.

00:59:42 DR. JERRY SULS: Okay.

00:59:45 TRICIA STRUSOWSKI: But it is overwhelming for them, absolutely.

00:59:47 DR. JERRY SULS: Thank you. Well, thank you very for sharing your insights and your experience and answering your questions, some of which are pretty challenging, I know, and difficult, but we much appreciate it.

01:00:07 TRICIA STRUSOWSKI: Well, thank you.

01:00:08 CHELSEA PROUGH: Thank you Ms. Strusowski for providing today's information. If you have questions after today's program please email NCI.brpwebinars@ICIF.com or call 301-407-6608. Thank you for joining us. This concludes today's webinar, you may disconnect at this time.

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