

Cancer Intervention and Decision Making Tools Podcast Transcript

Scott Redding:

Welcome to the 3 Ps of Cancer Podcast where we'll discuss prevention, preparedness, and progress in cancer treatments and research. Brought to you by the University of Michigan Rogel Cancer Center. I'm Scott Redding.

Today, we're going to talk about intervention and decision making tools for cancer prevention in patients. We're here with Michigan Medicine professor of medicine, Doctor Sarah Holley. She is the co-director of the Center for Health Communications Research at the Rogel Cancer Center and Assistant Director of the Cancer Surveillance and Outcomes Research team. Also, she is a research investigator at the Ann Arbor VA Hospital.

Dr. Holley's research focuses on evaluating and improving the quality of cancer care across the continuum from screening through treatment and into survivorship. She's interested in understanding and improving patient and physician decision-making related to cancer prevention and control services. Welcome, Sarah.

Dr. Sarah Holley:

Thank you.

Scott Redding:

As we look at this, what are ways to evaluate a patient's quality of care?

Dr. Sarah Holley:

That's a great question. I think we're, we're always interested in understanding the patient's experience with the care that they receive across the continuum, really. When you think about a cancer patient, from cancer prevention through survivorship care, and there's many ways to think about quality. One is obviously whether or not they simply receive the care that they needed. And that is usually measurable through things like medical records and administrative data to understand receipt of care.

But the work that I do tends to look at quality of care more broadly, and really from a patient reported perspective, and trying to understand how patients feel about that quality. So, we've, as part of my cancer surveillance and outcomes research team group and the center for health communications research, we've been interested in evaluating patient assessments through a variety of measures that we've used both in terms of surveying patients directly, as well as integrating assessments into tools that we deploy to patients in their health setting to try to understand how they feel about the care that they received.

Did they feel positive about the decision making experience and getting the care? Did they feel positive about the coordination of their care? Do they feel positive about their outcomes of care in terms of how they're doing? Symptom management and other issues that they may have at home after receiving care?

Scott Redding:

Can you explain a little bit more about what the Center for Health Communications Research does? I know you just mentioned patient surveillance, but is it do more than just that?

Dr. Sarah Holley:



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Yes, absolutely. So the Center for Health Communications Research, or CHCR as we call ourselves, has really been in business since the mid 1990s. It was originally developed and funded as a center for excellence in cancer communications research under a funding mechanism from the National Cancer Institute. And over time it evolved into working across interventions. It's really an intervention development group.

So interventions for improving patient care and patient outcomes, really across the continuum. Using different formats, anything from print, to computer-based, to app base, to telephone, automated voice response based, to even some newer technologies that we've been using in more recent years. But as we've grown over time, we've also come more recently to focus back on our true mission of cancer specifically. So we're now a center that really serves as a shared resource for the local cancer center to help our members develop tools to really support patients in their care.

Again, using different format. We do interventions focused on cancer prevention, how to help patients obtain screening that they need to prevent cancer, colon cancer screening, breast cancer screening, also more primary prevention, intervention, such as diet and exercise based interventions. We also do quite a bit in the treatment space, which is my own personal area of research, is the treatment decision making that patients have to do when they're faced with a cancer diagnosis.

Trying to navigate what are typically very complex decisions around initial treatment and follow up treatment that they need to obtain and then when they are done with their primary treatment, going back to survivorship care, how to help patients again, monitor any ongoing symptoms, obtain the appropriate surveillance care that they need to again, have high quality outcomes as a cancer survivor. So, we've really done work across the continuum and all of those different topics have been projects using different formats, as I mentioned. Anything from print based to telephone based to app based and beyond.

Scott Redding:

Outside of say, these intervention tools, communications is part of that name. Are there other forms of communication or is it just the different tools to utilize to get the information and/or collect the information from the patients or those that are utilizing them?

Dr. Sarah Holley:

So there's quite a few different types of interventions that the center has embarked on. But what we're really known for is a tailored approach to interventions for improving outcomes for patients and families. So, what I mean by that is how do you take something that is important to an individual patient and collect it from them, whether that be a piece of medical information such as their cancer stage or a comorbidity that they may have that may affect the appropriate treatment that they need to be given, or whether it's something more socially like their cultural background or their language or their literacy level in terms of understanding information.

And so by using assessments that are principally pulled from patients themselves, or the user of the intervention, they answer some questions. But it can also be pulled from a medical record if we have that connection built in place. We're able to tailor information that is most meaningful to that individual. We have a program that was developed as part of that first center that I mentioned started in the nineties called the Michigan Tailoring System that takes this information and then feeds back to the user that information that is most relevant, most salient, most engaging to them and the intervention then feels very personalized.



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And particularly in this era of personalized medicine and precision oncology, having information that feels like it was made for you is something that can be really valuable for users. So, that's sort of an overarching theme of the center. But underneath that theme, again, we've done things that are tailored based on ... We finished a project as part of my VA work that was tailored to the veterans line of service, for example. Because we know that that's something that really resonates with veterans and so we use that information to give them more personalized feedback around that. But I can give many other examples of how we've used tailoring to deliver information.

Scott Redding:

So, the tailoring is the key part. Do you utilize that information for patients maybe that you haven't seen yet, but then could be available to them when they maybe become a patient?

Dr. Sarah Holley:

Well, that's a great question. So, it really depends on the structure of the project that we're working on. And within the center, we do primarily projects that are funded through various funding mechanisms, whether that be the national institutes of health or foundations or internal funds from our own cancer center. But we also have done some work with outside groups such as companies. And so it really depends what we have access to at the initiation of an intervention.

So most of the time when we're working on a study, we have access to what the patient can tell us. So we would build an intake survey that would things that were important to that particular project, who the principle investigator was or whoever was kind of leading that project. If the goal of the project was to have individuals exercise more or eat more fruits and vegetables, we might want to understand at the beginning of the project, what they currently do. Just as an example. We would collect that from them and then we would give tailored information back to them that would address where they were at currently. And perhaps also some of their personal goals in terms of the outcomes.

Scott Redding:

Can you describe a little bit more about some tools that are available? I know on a previous 3 Ps of Cancer podcast I talked with Dr. Larry On about tips for health, which I believe came out of your, your area there. So maybe, can you explain a little bit more about that and other tools that are available?

Dr. Sarah Holley:

Yes, absolutely. So tips for health is a texting based program. We actually partnered with the National Cancer Institute to take what ... The National Cancer Institute had developed some texting libraries. Those are the messages that you get when you might sign up for a texting program. In other areas you might get a regular text every day and somebody would write those messages.

So, these were messages that the national cancer Institute had written related to smoking cessation, diet and healthy eating, and exercising. And so through partnering with them, we were able to take those message libraries to our center and then to refine them somewhat so that they were more appropriate for Michigan patients, particularly Michigan residents. So we had some local tailoring that we applied. And then we also developed our own program, our own tips for health program focused on colon cancer screening, which is a particular area of need in Michigan. We have lower rates of colon cancer screening than some other states nationally and we also have some slightly higher rates of colorectal cancer.



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So we chose that topic as our first additional module to add to our tips for health platform. So now we're able to offer four texting programs out into the community. The three that I mentioned, which are really more focused on primary prevention with the diet and the exercise, and then smoking cessation is something that we always are trying to promote throughout the community.

And then colon cancer screening is the new one that we developed. So how they work is we launched the texting number out into the community, through advertising and local marketing, and by working directly with clinical practices and making the materials available, and then individuals can join by texting into a number or going to our website and answering some questions.

For the colorectal cancer screening version, they do need to answer a few questions so that we can understand their risk for colorectal cancer, which the program is then tailored on as well as any individual barriers that they have to that particular activity, such as concern about the prep or not really thinking it's needed for average risk individuals.

And then we deliver information to them that's tailored to those areas of concern that they indicated that they had. So, that program has been available now for a couple of years. The colorectal cancer screening one only most recently in the last few months. But we've made that available to Michigan Medicine employees. We've also made it available broadly throughout the community, again, by promoting it at community events and through a recent funding endeavor that we undertook with some rural practices in Michigan that were located in the upper part of the state and we made the tips for health program available to them through advertising it in their practices. So, it's been very well received.

We're working now to get the colorectal cancer screening program integrated hopefully into a health system, because we think that's one where it really needs to be paired with a provider's recommendation and with the health system's promoting of colon cancer screening as a priority, rather than something that individuals in the community might be likely to just simply want to do on their own.

So that's one program, which is again, more focused on prevention. Another program which we are working on now is focused on breast cancer treatment decision making. We developed a interactive tailored breast cancer treatment decision tool that runs online. And it's called, I Can Decide. It's designed to help patients with a new diagnosis of breast cancer to really understand and sift through their choices between a lumpectomy with radiotherapy or a mastectomy, and then with or without breast reconstruction and then from there to help them understand their choices with regard to systemic therapy, including chemotherapy and hormone therapy. And that tool went through a large study in many surgical practices, which ended ... In early 2019, we were able to publish the results of the study of that tool and then we were able to get some additional funding to do a next generation version of the tool, which has even more tailoring. And we're working on that currently right now.

Scott Redding:

We've talked about some prevention and what you're doing for some newly diagnosed breast cancer patients, but what other tools are you working on or do you foresee coming down the pike later relating to current health situations that are always going to be around for a bit? Unfortunately the COVID-19, probably be around for quite a while. Although things will be a lot different than they are now. But also as it relates to some of the outcome tools that you've been working on.

Dr. Sarah Holley:



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Yeah. So, I guess starting a little bit more broadly than the current pandemic situation. One of the areas of interest that we've had, and we have a couple of projects in this space, is once cancer patients finish their initial treatment and they are returned to their primary care setting and are in the cancer survivorship space, which is a wonderful space to be, to be a cancer survivor and not undergoing active treatment, that space can be very difficult for patients to navigate and not very well coordinated and cancer survivors can also have ongoing symptoms and needs related to their cancer treatment or simply to the emotional impact of having cancer that often aren't well addressed in that kind of trade off from oncology care to primary care.

So, that veteran's project that I mentioned earlier was a project that was designed to help veterans who were longterm prostate cancer survivors but still experiencing symptoms to manage those symptoms at home because many of the symptoms are easily manageable, but were getting lost in the shuffle of their care. And so we did an automated telephone paired with a tailored newsletter that helped them pick a symptom to manage and focus on that. And that was really well received by veterans.

And the reason that I'm mentioning that now as part of the current situation that we're in is this issue of monitoring at home is becoming so much more important as we're seeing so much of our care shift to telehealth and virtual visits and trying to interact with providers and health system from one's home. Having that ability to do things virtually and to monitor oneself at home is just going to, I think, continue to be important.

So that's something that we're trying to help with as the COVID coronavirus situation is so quickly evolving and the needs are so rapidly changing. But one thing that we're trying to work on currently as part of our center, which is not related to cancer, but to this other issue of monitoring, is could we develop something similar to a tips for health module that could help people with symptoms monitor at home and understand when those symptoms really are getting to the point that they need to go to a health setting versus just an ongoing monitoring and feel more connected to a health system that is rapidly becoming a bit overwhelmed with patients in the hospital.

So, we're trying to join with our health information technology group at Michigan Medicine to do some work in that space and my co-director Larry On, who you spoke with before, is really leading that work. But I think it's critically important.

Another area that we have tried to jump in and help out with in terms of the coronavirus situation is as we have tried to shift more inpatient care to dealing with patients who come in with the coronavirus, that means a lot of patients who are planning to have ongoing care, particularly cancer patients, are having to reschedule that care, postpone it, perhaps go to a different location for surgery than they were originally planning to. And that communication of all of that information can be extremely confusing, unsettling, anxiety inducing to hear that you need to wait a couple of months for a surgery, for example. Even though that is not going to affect your outcome in terms of how well you're going to do following that surgery, for somebody with a new diagnosis that can be very, very unsettling to hear.

So, we've been helping to create some communication tools for providers to use, to really help patients understand better why that's happening and how to settle patient's nerves a bit with regard to some of those shifts in care that's happening currently. And that work launched a week ago and we jumped in and helped with providing some of the communication tips and outline. And now it's being pushed out through our health system and maybe even more broadly nationally for oncology providers to use as a set of tools to help them with those communications.



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Scott Redding:

Outside of what we've just discussed as before the current pandemic situation started And you've been able to jump in with some new tools to be able to address those needs of cancer patients, as well as other patients, I think any time that you could have a symptom checker is valid for everyone. Before all this started, though, what are some tools that you were excited about, looking forward, that you're planning to launch and are looking forward to as things start to change and move forward in the coming weeks and months that are new and exciting?

Dr. Sarah Holley:

Yeah, no, that's a great question. I'll go back to the breast cancer treatment tool because that's a tool that we showed some initial benefit in terms of helping patients to make better quality decisions. They were more informed, they felt more prepared to make those initial decisions. And so we were really excited about that when we tested it originally. But we also identified a couple of areas of gaps where we felt we could continue to meet needs that came forward during the study of that tool. And those two areas are what we're addressing in the next generation, two of which I'm really excited about.

The first is we did a pretty good job of helping patients cognitively understand risks and benefits associated with treatment options. But we did not really address the emotional response that goes along with a cancer diagnosis that can be ever present throughout a decision making process and if we don't address and help to manage worry and anxiety, sometimes decisions for more intensive or snap decisions are made that patients may regret down the road a little bit more than if they really had been able to kind of go through that with a little bit of a less anxious hat on, so to speak.

So, we have developed a module for the I Can Decide tool that helps to address worry and anxiety as patients go through their breast cancer treatment decisions. And I'm very excited for us to launch that as part of a new study, hopefully at the end of this year. We also paired that with something that's missing from a lot of decision tools, which is the physician piece. So, a lot of decision making tools are developed to put in the hands of patients and give them information and then ask the patient to bring that information or bring your questions back to your provider.

And that puts a lot of onus and burden on patients, particularly in this context of anxiety and worry. So, we've linked it to their physician, through a physician facing dashboard that will test at the same time as we test out the patient anxiety and emotional support regulation module that we've developed. So, that is something that hopefully will be in the field at the end of 2020 and we're really excited to test it out and compare it against traditional patient facing cognitive based tools.

We have a couple other projects that we're working on currently that are really exciting. One is what we're calling a menu based chatbot project that we're doing in partnership with the cancer support community. We're taking their evidence based program called open to options, which is primarily delivered by a trained counselor over the telephone, helping a newly diagnosed cancer patients come up with a list of priorities and values as they go into their first appointment or an appointment with an oncology provider.

The cancer support community wanted a version that could be more widely deployed and utilized, not necessarily by a person on the other end of the phone. So, we're working with them to develop a chat bot version one that's menu based using the experience of the counselors to work with us to pre-populate some of the responses that patients get to again, help them develop this question list and values lists. We hope to test that out eventually on enough users that we can actually develop a real time chat bot.



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So, that technology is very exciting to me, as well as the focus on getting something out there in front of patients. Usually, it's easier to get something that could be used on a phone rather than having to always make a phone call to a person on the other end of the line. So we were hoping to have a broader reach by that partnership.

And a third exciting project that we're working on currently is a partnership with Google, which is also being spearheaded by my colleague, Larry On. But it's helping patients and their family members to really end a visit with an oncology provider with a transcribed audio text of that conversation with that provider that can be then searched to find additional information. So, what we know is patients often go into a visit and they're a little bit of a deer in headlights hearing all of the information about their cancer diagnosis for the first time and their treatment options and they may leave the visit and not really remember what was said.

So we are developing an application that they can, again with Google and with support from Google, putting it on their own smartphone or their own device that can then be transcribed and searched to revisit and really spend some time looking over that visit later at home to understand more about their treatment options and to return to the provider with any questions, should they have any. And we're hoping to also expand that more broadly as we get further into that project.

So, those are a couple of exciting ones that we have going on right now.

Scott Redding:

Yeah. That one sounds really exciting. I know when my dad was diagnosed with cancer, I recorded it so I would remember. But trying to skim through a recording for something that, "Did they say that or not?" Can be difficult. But being able to have it turned into a text to be able to type in what I'm looking for would have been very helpful.

Dr. Sarah Holley:

Yeah, absolutely. And obviously Google is known for search. That's what they're known for. So, that's where we're really benefiting that collaboration. And again, hopefully down the road, the idea would be if we can get enough people using it and have enough transcripts, something like natural language processing or AI could even be used to feed people that more nuanced search.

We're definitely not there yet, but we're hoping that those types of methodologies can be applied in the future as we continue this work with them. But it is something that people have really resonated with in terms of being able to have something tangible that they can then take back and then share securely with family members and other areas. If they weren't able to attend a visit with you as the patient that's another benefit of something like this.

Scott Redding:

You've talked about some of these new exciting tools and specific cancers and some prevention. Are they focused only on existing patients? Are there any tools or anything that you guys are working on geared towards maybe an underserved population as well?

Dr. Sarah Holley:

Yeah. I would say most of the things that we work on, we have an eye toward ensuring that the use is across individuals of various diverse backgrounds. Whatever that might be, whether it's rural, urban, racial, ethnic minority, whether it's digital literacy. That's something that we're always kind of having an



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eye to and we try to make versions of things that are easily accessible and don't require the most new version of a iPhone, for example.

We try to make mobile applications that are mobile optimized so that they can be used not only on an iPhone, but also on an Android, which there is a digital divide in terms of the use of Android versus iPhone that we kind of always have attention to so that they're not always having to be used on a desktop. For example.

With that said, we are limited somewhat by the goal of the project and whether that project has a specific focus on reaching underserved populations, which many of our projects do. The breast cancer treatment study that I just mentioned will have a Spanish version developed and we'll have attempts to particularly over-recruit patients who are Spanish speaking. But after that, we're limited by funds to do other languages at this point. But that would be the hope down the road. If you can show effectiveness that you can obtain additional resources to do those translations, to make them work for anybody.

We do have a version Tips for Health at this current time that we're translating into Arabic. We are really wanting to reach that population in the Dearborn area, which is, I think, the second largest Middle Eastern, North African population nationally. And so we're attentive to that and want to make sure that our program, which is a prevention program primarily, so it's designed to be used by people who don't have cancer and if used well to hopefully help towards cancer prevention.

So, that program will be done hopefully this summer and launched and we can do some evaluation of whether it was well received in that population. So, we're always thinking that way, how to reach the most people, what are the issues that need to be surmounted in order to get tools to all types of people, even something as simple as Tips for Health, which is probably one of the easiest programs to use because it's simply text messages that can be delivered on any type of phone. You do not need a smartphone to do the Tips for Health suite of prevention programs.

But even that we found, for instance, in some areas of rural Michigan, data use plans become an issue. So while most people have a phone that can receive texts, whether they want to use their data plan for a smoking cessation program is something that we're trying to understand and come up with some ideas about how to meet that. Could we pair that with some minutes or could we pair that with something that would make it easier for individuals with that particular problem to use the programs?

Scott Redding:

As things move along, you're evaluating the tools and updating them to make sure that they are meeting the end users needs?

Dr. Sarah Holley:

Yes, absolutely. That's a challenge because as I said, we are funded by grants that are given to members of the Royal Oak Cancer Center and individuals that want to work with our center to develop goals. So when the grant is done, then the money is done to help us continue its dissemination or its updating. So we're always trying to think ahead about how to do that when we get to that point with the end goal really being tools that work should be publicly available and they should be hopefully integrated into health systems that have interest in using them.

And so the more that we can connect with groups that can promote tools nationally, whether that be national organizations, national foundations, health systems, the better. Because then when we can do that handoff at the end of our study, and somebody would be willing to take on that tool, but it is



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an ongoing question as to the ongoing updating needed to make sure that a tool is current and that will continue to evolve and probably be a challenge, but it's always something that we're thinking about.

Scott Redding:

So I really appreciate the time today. Can you leave us with a key point that you want to make sure that we can walk away with?

Dr. Sarah Holley:

I think what I would want to walk away with is that we're an ever-changing society and technology is also ever-changing and rapidly changing. But it offers us what technology as simple as something like an automated phone call to something as complicated as using artificial intelligence to run through a big data set and give tailored feedback and anything in between.

It gives us opportunities to improve care for patients to make them feel more connected with the health system, with their providers, with evidence that we know would be useful for them to understand. And we can use technology to deliver it in a way that, like I started by talking about the tailoring, that feels very personalized and that can be comprehensible because a lot of times what we as health providers tell people doesn't always kind of make it to them in terms of the literacy and understanding terminology and that can be confusing and complicated. But technology offers a way to make that bridge.

So, I think there'll be a continued need for a group like the Center for Health Communications Research to rapidly meet the needs of not just cancer patients, but as you said, people who don't yet have cancer and then people who have survived cancer and other people as well as we think about how to improve their health outcomes. And then the question that you started with, the quality of care, I think these types of technologies and tools can be a big part of that.

Scott Redding:

Well, again, thank you for the time. Thank you.

Dr. Sarah Holley:

You're welcome. Thank you so much.

Scott Redding:

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