



Support for Lung Cancer Patients

Hosted by: Steven Gore, MD

Guest: Brian Jin, MSW

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Welcome to Yale Cancer Answers with doctors Howard Hochster, Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers is our way of providing you with the most up-to-date information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week in honor of lung cancer awareness month, it is a conversation about support for lung cancer patients and their families with Brian Jin. Brian is a Clinical Social Worker, and Dr. Gore is a Professor of Internal Medicine and Hematology and Director of Hematologic Malignancies at Smilow Cancer Hospital.

Gore Brian I have to get just get this off my chest, I have been thinking about this all day. I did a lot of musical theater as a kid and you are probably too young to know West Side Story. When I think of social workers, I think of Gee Officer Krupke:

 Dear kindly social worker,
 They say go earn some dough.
 Like be a soda jerker,
 Which means I'd be a schmo...

...because juvenile delinquency was only a social disease! but that is not what you do. I am sorry I went off subject.

Jin No I appreciate that. I mean it is. Social work is so open ended and so fluid and for a role, I say I am a social worker and then following the question is inevitably 'what do you do?'

Gore Right..

Jin And so for my role within a clinic, within an oncology clinic, surgery clinic, it is really to meet the patient's needs, to join them, to be with them to help explore their concerns in whatever the capacity can be. It can be concrete, it can be questions about disability, it can be questions about transportation with community resources that are available, financial questions. But there also is the emotional side, how are doing? How are coping? How is your family processing this information? How are you processing this information? So, I tell people my basic job is to listen, to hear the questions and try to find support and help.

Gore So what percentage of the patients who are being seen in the thoracic oncology program at Yale get seen by you at least once.

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Jin That's a tough question. We are trying to improve that. We have a tool, a distress screening tool, which patients are given in the beginning, and it really takes down some comments, whether people are feeling anxiety, worry, difficulty sleeping, if they are having financial concerns, and so it is a way of screening patients to really identify those who are struggling in that beginning initial visit. And so, that is one way I am able to reach patients. We have a large volume, so I do not get to see everybody. I would say low teens in terms of percentage-wise. Because there is a lot of people coming in for surgery. The thoracic unit is pulmonary surgery, oncology and lung cancer screening, but the ones that need to be seen, my team really make sure I get to see them and then let me know.

Gore So, who sees this distress screen and who pays attention to it enough to flag it for you?

Jin So, it is either the patient-nurse coordinators or it is the practice nurses. They will give the screen, they will identify the concerns and they will reach out to me to either if I miss them in the clinic, call them and reach out and explore those concerns or I will see them that day. If there is really a lot of concerns, they will page me and I will come and meet the patient and spend time.

Gore That sounds like a kind of haphazard day for you if things are not booked into nice 30-minute units.

Jin Yeah, you got to be on your toes and you have to be willing to go where you are needed the most, it really is.

Gore And some of the people really, I suppose, really have as you said concrete concerns about transportation or housing or finances, right? That is a whole different set of analyses right?

Jin Yeah, it is. And often times, our social work cluster, we look that as a segue to deeper relationship. You know, a lot of times people will come with financial concerns and then later on they will share how difficult it is to talk to their children. So, it is a door opening to meet those concrete needs and allows me to develop a relationship and really let them know all the ways we can help in both as a hospital and a team and in the community as well.

Gore And some social workers do variations of psychotherapy. Is that part of your job?

Jin I often describe this as a brief intervention. Sometimes, it is crisis intervention. We have had the benefit of bringing over a new intervention for cancer patients, meaning centered psychotherapy which offer in a group home and individual, and it was developed to really address the loss of identity that comes with cancer and that cancer is a limitation and it brings a lot of emotional distress, and so it is a way to get people reengage with what is meaningful. It is kind of the ways people go through their treatment and the reasons why. It is for family it is the fact that their dad told them to stand up and those transitions and values that are passed on, those reasons that they connected on family dinners, it is a very heartwarming and enriching intervention.

Gore And is that a one-time thing or is it a?

Jin It is 8-week sessions for group and 7 for individual.

Gore And is it open to patients with all kinds of cancer or this is just for thoracic cancers.

Jin We have opened it to, initially was designed for late-stage cancers, stage III or IV solid tumor, but it is the individuals who created this, Dr. William Breitbart, out of Sloan Kettering, have branched out to bereavement, to early stage breast cancer, there is a lot of different applications for it. So, we have had a social workers to go through the training and have brought it here, and we interweave it in our assessment because it just a strengthening and supportive tool that we can use at anytime as well.

Gore Very interesting. So, sounds like you got to have your hands juggling a lot of things for a lot of patients. You got to be pretty organized in that way?

Jin Yeah. I mean, our team really keeps us on track too. Assessment is ongoing aid, and we are working with people that have brought also a lot of their own issues with the cancer diagnosis. So, we pay special attentions to assess those who are most vulnerable and need extra support as well. So, the team is invaluable for identifying and we work together very well to support people in a variety of different ways.

Gore When you say the team, are you talking about the social services or you are talking about the oncology team.

Jin Both. For the oncology team, I get referrals from the intake coordinator before the person has even set in a foot into Smilow. I get Dr. Gettinger knocking on the door and say come and meet this person. I get the practice nurses reaching out me continuously, I really am worried about this person and I want you to go in and speak with them, or this person is lovely, I think you have a great time talking to them.

Gore You probably like those?

Jin Those are nice.

Gore Right, just kind of a friendly schmooze. So, then there are other, you know I imagine, other branches of service like the people who coordinate home care and stuff which is not exactly you, right?

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Jin No. But I tell patients and family to bring any question. If I don't know the answer I will find out, and we are very lucky because we have a lot of departments and a lot of different ways we can help patients. We have drug assistance, drug replacement, 340B, we have case managers that will go out and get a VNA or help people with equipment at home, so we all communicate and coordinate to meet the needs.

Gore What is a 340B?

Jin 340B is the Yale program, it is the negotiated rate for medication for Yale, and we pass it on with certain pharmacies to patients and families. So, if there is a family that has an extremely high copay for a particular medication, Lovenox jumps to my mind....

Gore That is a blood thinner right?

Jin Yeah. And it is a high copay for some insurances. We are able to get it reduced, it is not completely free, but it is a lot less and I have seen it, you know being 1000s of dollars less than what people are paying.

Gore And that is a federal program, right?

Jin It is a Yale program. The Yale, New Haven. We are very lucky. We have a lot of good diverse programs that support patients. And then it is quite supporting just to ask any questions, and if you do not know and you do not know what to ask, just sit down and talk about what you are worried about and we will try to help.

Gore Gotcha. How many social workers are serving the oncology program if you will...

Jin I know it is over 20, we have just added 2 new members, we are big cluster, Smilow has been great in supporting the social work cluster and really meeting the needs of the patients, but I would say 25, but Bonnie would know, that's my boss.

Gore And how often and in what ways do you guys, if you do, get together and share best practices, share stresses and anxieties, and problems. I mean is the 25 kind of a big team club or is it kind of all disseminated?

Jin Well, we are big unit. We actually also meet once a month with the entire social work department which is over 150. So, clusters meet once a week. We go over recent news, people share stories about good safety catches, they share information on resources, we also have mini clusters, so likewise team clusters meet together and we support each other in that role, but really I am new to Yale New Haven Hospital and I am so grateful for the social workers that are here that have supported me and that have given me the resources, that have me taught me and it is a great and supportive environment.

Gore Where did you come from?

Jin I came from hospice, previous to home health hospice, and a lot of times, you are the only social worker on that team, and so it is pretty unusual to have so many good social workers together working in one location.

Gore Did you find working in hospice particularly difficult? I find that hospice workers, many of them seem to have a calling and find this spiritually enriching, but I know that the lay conception would be that it would be kind of a depressing job.

Jin Yes. Every time how could you do that, thank you for doing that, but I don't know how you do that? and my answer has always been it is a really blessing to be a part of that process and you really get to see how families love each other and how they support each other and how they come together. I have been honored and I have been taught more from the people I have worked with and the families that I have seen than I feel like I have given them, so it is an honor to do that.

Gore How long did you do that for?

Jin About 3-1/2 years.

Gore Wow. Did you always know that you wanted to head towards sort of cancer-focused practice.

Jin Yeah, it's funny. For a social worker, I find myself choosing where I felt like I do the most good and where I could help out. You know, I started off with substance abuse and alcohol and then I heard a lot of times the stories of – the origin of use, that it was a loss of a family member, and then I went to hospice and I worked with families and with a variety of conditions and also my own life has been impacted by cancer, and I think a lot of people have... this was something I wanted to do, this is where I wanted to be, this is where I wanted to help people, and it is kind of branching out to where you feel like you can make the most impact.

Gore What is the transition from end-of-life care exclusively and dealing with grieving and loss to you said even cancer screening, what is, does it require skill sets and how has it impacted you, what has that been like? And why did you choose to change?

Jin Well, primarily my sister was diagnosed with a stage IV cancer and I saw how it impacted myself, my sister's kids, and I saw how much work could be done there. I think it is really one of the hardest things when a parent needs to talk to a child, and that is something that we help with. We have an intervention pact which is parenting at a challenging time and this is something that parents want to ask. It is scary, it is overwhelming. And so, that is one of the reasons I went into oncology.

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Gore Well, thank you for sharing that. Right now, we are going to have to take a short break for a medical minute and we will pick up on this after the break.

Medical

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There are over 13 million cancer survivors in the US and over 100,000 here in Connecticut. Completing treatment for cancer is a very exciting milestone but cancer and its treatment can be a life-changing experience. Following treatment, the return to normal activities and relationships may be difficult and cancer survivors may face other long-term side effects of cancer, including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers such as the Yale Cancer Center and at Smilow Cancer Hospital to keep cancer survivors well and focussed on healthy living. More information is available at YaleCancerCenter.org. You are listening to WNPR, Connecticut's public media source for news and ideas.

Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore and I am joined tonight by my guest Brian Jin who is a social worker for the thoracic oncology program at Yale, and we are discussing support for patients with lung cancer and their families. Brian, before the break we were talking about sort of why you moved from sort of a hospice-oriented, end-of-life oriented practice to a more general oncology practice and you shared with us that part of this was a family experience where your sister had an advanced cancer. How is she doing?

Jin She is doing well. She is in good hands and she is well supported.

Gore I am so glad to hear that, and of course our prayers and thoughts are with her and your family for the best outcome possible. I definitely know many people in oncology who go into areas either because of a family experience and sometimes not, but I also really relate to what you said about learning from our patients because I also feel that when I have been involved with end-of-life care, it is a sacred, holy privileged position to be in where I am learning mostly if I can allow myself to be present, and not everybody, I think it is a challenge for some people to be present there.

Jin Yeah, absolutely, I agree with you. I think for all of us it is something we do not normally talk about or discuss, yet is a part of life and the wisdom that we get from our patients as you made me think as you were talking about the support group, and I keep telling them if I could bottle them and give them to everyone, I would because there are so many comments and statements and ways that they have tackled adversity that I wish I could just give it other people, it is inspiring.

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Gore I can tell you a personal anecdote. My mother at the age of 76 passed away from advanced pancreas cancer. She lived in Chicago, and I kind of knew what the score was going to be from the get-go. She had presented with an advanced cancer and unfortunately that is a bad cancer to have. We hooked her up with a very good academic oncologist-specialist in her area, one of the leading Chicago academic centers who have unfortunately turned out to be kind of a jerk at the end of the day, like some doctors do, and I sort of shopped around for sort of what was the hottest clinical trials since she wanted to be treated more and it turned out that what was the most promising drug was being offered a community oncologist out in one of the suburbs. She lived downtown, so she would go out from the John Hancock Center downtown to kind of a blue collar neighborhood honestly to meet this guy and be treated there, which unfortunately did not work out well, but my mom was a person who would never, like you could not discuss death with her, that was not somewhere she was going to go, and when her cancer was progressing and obviously hospice would have been the appropriate decision, her oncologist was so generous in understanding her, that he hooked her up with a kind of a bridge to hospice thing where they were theoretically going to be giving her some home chemotherapy, which she herself was very happy about it, but by the time, they came out to do so, she was already fading away and so she could be let go without having to make that decision which for her was not possible, and I had to say that I was already a pretty experienced oncologist and I learned so much from that, so people who have that, I do not what that certain thing is, some people have it and I guess more of us can learn it, but it is something special I think.

Jin I think from interacting in the meeting center group, there is a segment where you talk about that, what legacy are leaving and how do you want to be remembered and the people that go there, they make such an impact on the other group members because there is a really courageousness and there is a real ownership and there is a real compassion for those around them. I can tell you that one of the things that comes up in groups sometimes and in the meeting center with individuals is, is that worry for the family around them, how are they going to cope, how are they to do it, and not everybody gets there, not everybody does. It is amazing to see when an individual looks at their life and examines and they make their family the priority and they know what is important, and I think that comes out with cancer. It is sort of a catalyst for examining your life and looking at the priorities and really understanding what is truly important, I kind of rambled on.

Gore No, no I get it. When my mother-in-law passed away last year, she said her regret was not knowing what was - how her grandchildren were going to, you know, what was going to happen to them, she just kind of regretted not being able to see sort of the end of the story for everybody that she cared about. She died with a lot of grace I have to say. I learned a lot from her as well.

Jin I think that is an amazing attribute for somebody to have, I mean it is weird but like you start to develop a concept of what a good death is and that seems odd to talk about, but you know when you have people around you, loving you and telling you the stories and sharing all the memories and I don't know to...it is moving.

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Gore What is special about thoracic oncology from a social worker's point of view. Do you have any particular challenges.

Jin Yeah there are... I mean first and foremost, it has been documented well is the stigma that is attached to lung cancer.

Gore Because of smoking?

Jin Because of smoking, yeah. It comes up in group, it is like people will share that they have lung cancer...

Gore Your fault, you brought this on.

Jin Yeah, then it is makes it safe, it is not going to happen to me, you know it is because you smoked, and that is totally wrong.

Gore First of all, there is a lot of lung cancers nowadays that are nonsmoker's, there is a huge number right?

Jin Yeah, it is a huge number. We encounter that quite a bit and you can do everything. I tell patients you can do everything right and still get cancer, and do everything wrong and never get it.

Gore Even if it is because you smoking, that does not mean that it is a good thing or you deserve it, nobody deserves it right?

Jin Absolutely. So, some of the work is addressing the feelings of guilt that is associated with smoking, but you know we do address and we do try to support people and focus on the present moment and it is not fair, it is not just and it is not right.

Gore And you have patients, I guess it is more head and neck cancer where they would tend to have problems with laryngectomies and things like that. Not so much in lung cancer?

Jin Not so much.

Gore Are there other disfiguring elements, that is not really so much in your bailiwick, right?

Jin I think the symptoms that patients really worry about are like clots and also metastasis to the brain. These are the ones that a lot of the times that have a huge impact.

Gore And how to deal with that?

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Jin Well of course, the doctors handle the treatment and give the options and everybody's experience is different. I have really courageous people in the support group that talk about their experience and some of their fears and what they have regained having gone through some of the treatments. I hesitate to share just because it is not my story, but I think what I have learned from patients is just having that goal, having that motivation, having the reasons to fight, really take you through all these. Even if you lose a little bit of what you like to do, there is always a way around and a way to transcend and get back to the things that are most important.

Gore How much of your work interfaces with physicians, psychiatrists and the rest of the staff?

Jin Well, I go where I am needed, so if a doctor tells me to come...the interface – we do not have psychiatry just yet, I know we have a clinical psychologist, Dr. Fehon, who we do refer to, because he gives that and he has fellows...

Gore He has been on the show.

Jin I saw that...

Gore We had a great show last year with him.

Jin Yeah, he is a wonderful individual, very compassionate and he will sit down and give that one-on-one session and continue care to help people through their cancer treatment, and anything they are also bringing to the table from their past as well.

Gore What about when it is time for patients to consider changing the goals of care from curative or aggressive palliative approaches to maybe strictly palliative, pre-end of life, end-of-life care, are you involved with that now?

Jin Yes we are. A lot of times, I phrase it, after they have had their doctor's input and they are weighing out their options, it is a question of quality of life versus longevity, and that means different things to a lot of people. For some people, it is "I have to be able to ride my bike and go on walks on the beach, and that is very important and I am not going to sacrifice that." For other people, it is fighting it no matter what and that is their journey, and my job is to just listen and to understand and advocate in that way. So, social workers are very involved with that transition and goals of care discussion, you know it is part of our joining with the family and patients, and not everybody in the family system is on the same page, and sometimes that requires time to explore and mediate and bring balance and a chance for everyone to be heard.

Gore Are you sometimes involved with families after the patient passes on? Or is that not really in your bailiwick?

Jin I will have exchanges one-on-one by phone, we have a bereavement service, Andrea Lucibello.

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Gore Yeah, she has been on the show too...

Jin Kelly Ford, and they are wonderful. They offer groups and individual counseling, and so I will guide people to them.

Gore Got it. Well, sounds like you really like your job.

Jin I do. It is very interesting, it is rewarding and I am never bored.

Gore So, since it is lung cancer awareness week, what message would you like to put out there for the audience, should people be is it a screening message, is it a support your loved one message, is it like turn to vaping instead of smoking message...

Jin I get those questions too, about medicinal marijuana and everything. I would say just to ask questions, to advocate for yourself and there are tons of resources out there. There are wonderful local resources, there is Kid's Hugs, there is Ann's Place in Danbury, there is Cancer Cares which will offer online support and telephone support. There is American Cancer Society which will help with lodging and transportation and financial resources, so just speak up and share your concerns, we do not want anyone to go through this alone and we want to support, we do not want it to be hard on you, we want to help in anyway we can and we have a lot of wonderful resources to do that -- we have integrative medicine which will give you Art therapy and Reiki and massage, and talk to you about acupuncture.

Gore I want some of that...

Jin Yeah...that is always good sell when people hear about that. The whole thing is advocate for yourself, be kind to yourself, and help us help you.

Gore And that's true I suppose whether you are at a center like Yale or whether you are at any hospital, everybody should be entitled, every cancer patient should be entitled to a multidisciplinary team, right that includes social services...

Jin Absolutely, I think a lot of cancer centers recognize the need for social work interventions that we will help people navigate the concrete and the emotional side and there are sometimes questions we do not have the answers to and we are used to that, as social workers we get sometimes odd requests and we will research and we will do our best to try to find those answers and so sometimes it is just a matter of being okay with asking for help, and bringing up a concern with anyone on the medical team because we are always going to be looking out to help.

Gore What is the hardest part of your job?

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- Jin Balancing the demands of all the patients needs and triaging the most important needs, I think that is the hardest one, because you want to help everybody and you want to be available and there is sometimes just not enough hours in the day.
- Gore I thought you are going to say balancing work and life, but that said, work-life balance is not a hard thing for you?
- Jin It is okay, I got little ones now, I love Legos, and those things really rejuvenate me. I make sure that the same things I tell patients in terms of it is a dual process of making the space for the difficult emotion and then excellent self-care. you know, doing the things you love, watching the TV show that makes you laugh, being kind to yourself, I try to practice that and I try to make sure I spend time with the kids and watch funny shows and do the things that really heal me and rejuvenate me.

Dr. Brian Jin is a Clinical Social Worker at Smilow Cancer Hospital. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer. You are on WNPR, Connecticut's public media source for news and ideas.