Supportive Care for Cancer Patients

Hosted by: Steven Gore, MD
Guest: Laura Donnelly, LCSW, Oncology, Smilow Cancer Hospital

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Welcome to Yale Cancer Answers with doctors Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week it is a conversation about supportive care for cancer patients with Laura Donnelly. Laura is a Clinical Social Worker in Oncology at Smilow Cancer Hospital and Dr. Gore is a Professor of Internal Medicine and Hematology at Yale School of Medicine and Director of Hematologic Malignancies at Smilow.

Gore I am an old music theater guy and so when I think of social workers, I immediately think of West Side Story and ‘dear kindly social worker, They say go earn a buck, Like be a soda jerker, Which means like be a schmuck.’ Those are the lyrics, Steven Sondheim wrote that, and I think many people's experience about social workers is that they work with difficult youth and people who need assistance, how does that fit into oncology, and of course I have totally the wrong stereotype going on.

Donnelly I think that is a stereotype that maybe a lot of people have about social work, and when I started in the field, it was really only when I started in graduate school that I realized how vast and how broad it is. And my first experience with social work as an intern was at a hospice agency in graduate school, and it was a wonderful experience. It was an amazing experience.

Gore Is that something you sought out or just kind of fell in your lap?

Donnelly It really did fall into my lap. It was a matter of placement that worked with my schedule and was close by.

Gore Serendipity?

Donnelly Right, and I thought, am I going to be able to do this? Working with people who are dying.

Gore It’s scary.

Donnelly Right. And instead, I found it to be actually very life affirming and very uplifting and really an honor and a privilege to be allowed into someone's life at the very end of their life when they are really trying to find some peace and acceptance and closure and a lot of things all at once. So, that was my first experience, which is a little bit different, but social workers certainly do work with marginalized youth and people with very difficult issues.

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Gore: It is really important work also.

Donnelly: Absolutely, and people with cancer sometimes come from those backgrounds; so it is not that we do not see those issues, they are part of our society, they are part of our world. I think in oncology, it is a very collaborative environment and I really love that about it, that every person on the team has a different perspective as to how to care best for that patient and we all work together and inform each other based on our profession and our background. So, that is I think one of the things I enjoy the most about the environment.

Gore: How long have you been an oncology social worker?

Donnelly: For the last 6 years I have been in just oncology.

Gore: I see. And you focus on a couple areas particularly, disease wise?

Donnelly: Yes. I work on an outpatient floor at the Smilow Cancer Hospital, and the clinics that are on my floor are gastrointestinal cancers, neuro-oncology which is brain tumor primarily, and melanoma.

Gore: I see. So, you are sort of geographically assigned and whichever patients are in that area are under your purview or catchment?

Donnelly: Right. And it is also an infusion area, so sometimes there are patients with other diagnoses – head and neck cancers, or primarily solid tumor cancers come to my floor – the area that I work in.

Gore: How much have you had to learn about the actual diseases or is that kind of just a by the way and it is all about the people and their emotions?

Donnelly: Actually quite a bit, I have learned quite a bit about the types of cancers and I actually find that very fascinating even though I am a social worker and I love the psychosocial support and emotional support that we provide. I find the science very fascinating and very interesting and I sometimes I have the opportunity to be in an appointment with a patient when a doctor is talking and I am very fascinated by how they describe the disease process and how the treatments work and why certain ones do not work and what is the best way to approach the disease and manage it, what the side effects will be, etc., I find all of that very interesting. So, I have acquired quite a bit of knowledge over the years working in the field with no formal medical training at all.

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And do patients ever rely on you or use you as a sounding board to help sort through what they have heard from the doctor in terms of choices or is that not really in your practice perimeter?

They certainly do ask these sometimes. Sometimes, they have been given 2 different options and I cannot give any medical advise for sure, and certainly if it starts to go that way, I refer them back to the physician for some clarification perhaps, but I would say what I try to get to is what is your understanding of these treatments and how are they going to impact you and what matters to you if the treatment is going to have a lot of side effects, is it very important for them to continue working or it is very important for them to get to a wedding say, and these treatments might preclude them from doing that, how can they weigh that. So helping them kind of navigate what matters to them the most or is really what matters to them most long-term survival. What I work with is what matters to a person and also it is nice to see them get to a place of feeling at peace with that decision; whatever it is, you need to feel comfortable with it -- you need to be able to go to sleep at night with it, wake up in the morning and feel good about it, what is going to bring you to that place.

It is so interesting that we are talking about this, just yesterday I was giving a scientific talk about some very bad leukemias and I was showing some survival statistics for certain subsets where there is very little chance of long-term survival, and I mentioned ethical discussions that my wife, who is an economist but thinks a lot about ethics, and I have had over the years about how one approaches discussing treatment options to healthy patients who do not have a lot of good choices, and how to present their choices in a way that they can feel good about making a choice without taking away hope and really giving the patient autonomy without smothering them in depression, it is really, really tough. We got home last night and my wife, Amy, says I do not remember any conversation about that, and I told her about an experience I had when I was either a young attending or a fellow in training about such a thing, and she remembered the conversation, but it changed my life when she gave me the patient's perspective and I felt that I was not giving that patient enough information to make a really informed decision, so I think it is so important because I think as doctors we tend to be, well I do not know, we want to do our best. We like to do stuff and I think it is a challenge for us to really give the no-treatment option fair play, we always talk about it. I think you guys are much better at that.

I think that speaks to the team environment that we have, and I have had the privilege of working closely with some physicians who struggle with that.

You have patients with pancreas cancer for example which is pretty tough?
Donnelly: Sure, and also oncologists sometimes work with the patients over a period of years, and people are living longer with diagnoses, even very difficult diagnoses, I think there are 15.5 million cancer survivors in our country right now, so it is natural that physicians get to know their patients and they get to really care about them and know them, and when the time comes where it seems like doing more treatment is maybe going to be more harmful to the person, having that discussion can be really, really hard and I think it is important that physicians have a place to share how they are feeling about that.

Gore: Do you think the physician who has had that longstanding relationship is more likely to be forthright at that time, do you have any experience with that or is that person at some point so bonded with the patient, he or she starts to delude themselves a little bit? I think we can go either way.

Donnelly: I think it can and I think it really depends on the physician. People go into this profession to help and to heal and to cure and to save lives, and so that is wonderful, we are so grateful for our physicians that they can do that, and I think some have an easier time of being able and sometimes that relationship does help, and they can say, I care about this person so much and it is really not in their best interest, they are not going to have a peaceful death if we continue with treatment. And other physicians just really want to keep going forward and I can empathize with both sides for sure.

Gore: I know when my patients are in that kind of position and state, it is very important for me that I be the one who deliver that news. I feel really awful if they are hearing it from someone else, that is just my feeling. It does not mean that it is easy for me or that I am happy about it, and I think I am probably sometimes a little blinded as well, maybe I should I have thought about that a month or two ago, I do not know.

Donnelly: No, I agree with you 100%. I think sometimes patients intuitively know when things are not going well, they intuitively know, but they maybe do not want to say anything, am I jinxing myself if I say it and it happen, but they intuit — they say things are really not going well, I know this is my fourth treatment or my fourth line of treatments, I know the options are running out, but until sometimes they really hear that and they need to hear from their doctor, it really is not real or they really cannot take the steps that they need to really prepare.

Gore: If patients are expressing those kinds of things to you, I assume you ask that the doctors talk to them about it, do you kind of push them to ask the doctor or do you talk to the doctor on the side, how does that work?

Donnelly: A little bit of both sometimes, it depends. Our clinic and practices are very busy and they move very fast and so some of it is timing, do I have a few minutes to pull a 12:57 into mp3 file https://cdn1.medicine.yale.edu/cancer/2018-YCA-0930-Podcast-Donnelly_343419_5_v1.mp3
physician aside and mention, this patient is really wondering about this or this, or this
patient is really worried about this and sometimes the patient might be worried about
something when there really are a lot more options. It is amazing to see some patients
be so, so sick and then see them a few months or a year later when they have stopped
treatment and they are so much better. So, it really can kind of go either way too. But
I do try to facilitate that communication and encourage patients to advocate for
themselves too.

Gore  Do all patients have scheduled appointments with you or do you kind of circulate and
pop-in, how does that work?

Donnelly  We attempt to meet every patient on the first day of treatment and in my area, it is the
first treatment because they are typically getting treatment in the outpatient setting.
There is screening that is done with every patient at the very first appointment and it is
a scale of 1-10, it is called the distress thermometer. It is a scale of 1-10. Patients
report on distress and various aspects of their life. Those who score towards the top
are really a priority for us to connect with, whether it is by phone or in person to really
help to see how we can help them cope better, how we can relieve that distress, what
we can do together as a team, as a social worker and the community.

Gore  We need to take a short break for a medical minute. Please stay tuned to learn more
about supportive care for cancer patients and the help that social workers provide with
Laura Donnelly.

Medical Minute

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for women living with advanced ovarian cancer. Learn more at astrazeneca-us.com.

This is a medical minute about pancreatic cancer, which represents about 3% of all cancers in the US
and about 7% of cancer deaths. Clinical trials are currently being offered at federally designated
comprehensive cancer centers for the treatment of advanced stage and metastatic pancreatic cancer
using chemotherapy and other novel therapies. FOLFIRINOX, a combination of 5 different
chemotherapies is the latest advance in the treatment of metastatic pancreatic cancer and research
continues at centers around the world looking into targeted therapies and a recently discovered
marker – HENT-1. This has been a medical minute brought to you as a public service by Yale Cancer
Center. More information is available at YaleCancerCenter.org. You are listening to Connecticut
Public Radio.

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Donnelly_343419_5_v1.mp3
Welcome back to Yale Cancer Answers. This is Dr. Steven Gore. I am joined tonight by my guest Laura Donnelly. We have been discussing supportive care for cancer patients and in particular the role that social workers play. Laura, I would like to come back to one of the very first things you mentioned, which was during this internship you had during your social work training at a hospice, and you said you found the work life affirming, could you elaborate on that? I think that is just a fascinating comment.

I think when people are approaching their own mortality and also the family members that are around them, I think it leads a person to really focus on what is most meaningful in their life and what has been most meaningful, and perhaps sometimes there is regret or perhaps somebody felt like they spent a lot of their life maybe doing a job they did not really like or did not really love and that maybe some of that time was not as meaningful, but what can I do now to sort of make every day more meaningful and incorporate more of that into my life. And I think it is a time in which a person really reflects and reviews their whole life and the adversity and the difficulty and what the value was in those difficult experiences and the joy and the good moments that they have experienced in the life, so it is like the culmination of a really good book or something, and I think to see people make progress and grow and change is also just very rewarding.

Is there any kind of, the word that comes to my mind is curriculum or process, kind of formal process for helping people negotiate that kind of existential review or is this just something that you get skilled at, it is really interesting to me.

That is a good question.

Somebody must write about that kind of stuff I would think.

I think it was when I look back on my training, I did not learn those skills specifically in the classroom, but more from the people – my mentors and my people in the field who were doing it and there were many educational opportunities just in that hospice year and ongoing now in my current career for continued education for conferences, for experts in the fields, and so, I always took advantage of those opportunities to learn more because it would help me understand my patients better and it would help me help them more. So, I would say not really a curriculum, it really was like learning from those who were doing it.

It seems it would be nice for patients if they have even a work book, a guide, what to expect when you are expecting... like how to put your life in order or something, I do not know, it just seems like there is so much opportunity because probably not everyone has access to thoughtful people like you and your time is limited I assume?
Donnelly: Again, a good point and I do not think that there is a manual out there like that.

Gore: Here is the future, you can be even more famous.

Donnelly: And some people are a little more resourceful and a little bit more proactive in their own initiatives to seek out those kinds of things, and other people are not. It does not mean that they do not get there, there are other people that help them or they come to a place of acceptance without a lot of that.

Gore: That is interesting. When my mom was dying of pancreas cancer, she was a woman who was never going to discuss the D word, and my siblings and I have regret about not being able to really discuss the anxiety she must have had, but that was her choice and we respected it. My mother-in-law was a little more open and she kind of discussed some existential thoughts she had had with her daughters, not deeply again, and then I have some patients who really just exhibit and I call it grace, and I do not mean it really in a religious sense but I mean really an amazing sense of peace and insight or acceptance that I am not sure I would ever be able to have, I mean it is really fascinating, I so respect it and in some ways envy those patients and I would like to bottle it and learn from them, I try to but it is so different from patient to patient.

Donnelly: Absolutely, and I think it is very important like even in your own family, respecting where the person is at. I try to think of it as a story book and they really get to write that last chapter and if that last chapter is to continue to protect family members by not talking about, that is okay. And I think as a social worker, a lot of times it is our job to maybe open the door for some discussion if that door gets shut quickly.

Gore: I often find that our medical staff, particularly in the hospital, that is medical, I mean the entire health staff, patient care staff, is very focused on making sure people have a ‘good death’, but what is good death in our eyes and we address resuscitation issues immediately. I think it is the most important thing. God forbid if somebody is put on a ventilator, and of course we want to respect those wishes, but I think that many of us cannot step back and say, first of all we do not know how we would feel in their shoes and we are not in their shoes and we are not that person. So, we have to watch out for own hubris I think.

Donnelly: Sure and I think as social workers we have to be really aware of how we are feeling and really not project that onto the person, but to be aware of it.

Gore: Where do you process those feelings?

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Donnelly: I think it is really important to collaborate and connect with other social workers who are doing the same kind of work. We have opportunities together as a team to do that and to really get some input from our colleagues, that are a little bit more objective to help us with that.

Gore: Nice, at least you are well supported that way.

Donnelly: Yes, definitely.

Gore: You do not want to have be home stewing about some bad interaction or some patient you are really unhappy about I would think?

Donnelly: No, as social workers, a part of our job is our own self-care.

Gore: I would think so, yeah.

Donnelly: And we really try to learn from patients a lot, especially those at end of life. How do I make my days more meaningful, so I think it is something that has to be intentional, you have to really carve out time to do, but getting that energy and that reinvigoration helps me to be able to give more to my patients the next day.

Gore: What happens to the patients who, either the patient or family member have a difficult problem that might either need some kind of more intensive therapy or medication, what happens to those patients, how do we get them support?

Donnelly: We collaborate with a lot of partners in the community too. We collaborate with mental health practitioners who are in private practice, with cancer-specific organizations, with psychiatrists at times. When we do an assessment with a person, we really look at their entire social contacts and their history and maybe some issues that were there prior to diagnosis and really collaborate with and connect them with people, encourage them to get connected, talk about the ways that they can cope with this but also giving a space to allow some of that; for example, some people I think can go through a period of time of being angry, and that anger can certainly come out towards the medical professionals when they present in clinic and sometimes the first reaction is to take that personally. I am trying to help this person and they do not appreciate it, but I think it is taking a step back and realizing this is a part of the process, this is the part of their grief process and I can be available and I can listen to that and I can validate that and then I can help them try to move beyond that, and say, I can see you are in a lot of distress, how can we help you with this, these are some things that have helped other people in the past because I want you to feel good every day, even living with this difficult illness or your family member’s difficult illness, what
can we do to make this better? And I say to the patients too, how you are going to get through this is not going to be one thing, it is going to be a variety of things – a variety of coping skills that you already have that you are going to acquire, it is going to be support from your family, from perhaps a faith community, it is going to be a multitude of things. It is really not going to just be counseling or just a support group, it is going to be a lot of things. I think that is what I see, and the more things you can avail yourself to, I think the better you are going to feel.

Gore And what about the physician, the physician who is being attacked? Are you available for her as well?

Donnelly Absolutely, I am. I am available to talk about it, I am available to problem solve with them, how can we mitigate this situation in the future, is there a way to kind of prepare the patient ahead of time, are they angry about wait time or are they just angry about the news they got or did the plan have to change for some reason, perhaps a really good reason and they were not expecting it and that set off a reaction, how can we be proactive and plan for that ahead of time, or sometimes it is really just giving a physician an opportunity to say gosh that was really awful I did not know what I could do, they were so angry and just kind of giving a moment to sort of de-brief before you move onto the next patient.

Gore Recoup?

Donnelly Yeah.

Gore That is interesting. I used to work in Maryland, and in Maryland, the social workers I think had a lot more I am not sure what the word is, case responsibilities for helping with paperwork and getting durable supplies and beds and things like that, it seems like that is not so much the case in Connecticut or at least here in our medical center that there are other professionals who kind of deal with a lot of that more practical stuff, am I right about that?

Donnelly I would say that that is the case at Smilow. There is a care management department that does a lot of those practical things, setting up visiting nurses, getting durable medical equipment and things like that. We as social workers though, we do provide a lot of community resources. So, that is a part of our job too, there is sometimes some paperwork involved and forms and things like that, but I would say our top priority is really helping patients cope with the illness.

Laura Donnelly is a Clinical Social Worker in Oncology 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 here on Connecticut Public Radio.