

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



Hosts

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**Peer Services and Cancer
Survivorship**

**Guest Expert:
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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week, Dr. Chagpar welcomes Dr. David Sells. Dr. Sells is Associate Research Scientist in Psychiatry at the Yale School of Medicine. Here is Anees Chagpar.

Chagpar Dave why don't we start off by having you tell us a little bit about yourself and about what you do and how psychiatry intersects with cancer?

Sells First about myself and how I got into this, was two ways, one was professional, and the other was personal, which would you like to hear about first?

Chagpar I want to hear about everything.

Sells You want to hear it all.

Chagpar Yeah.

Sells Professionally I do a lot of work in recovery from severe mental illness and around 2005 I was looking at folks who were utilizing primary care services at high utilization rates and learning more about their lives through qualitative interviews which essentially means that we asked them about their lives and their interactions and their illness. What we found out was that the psychiatric difficulties went hand in hand with the physical ones and over time I was quite struck by sort of the vast array of physical difficulties that they were dealing with and how that interacted with the psychiatric difficulties and made things worse. So that was one area that I sensitized to at that point. Personally around that time several loved ones had been diagnosed with cancer of various forms and various prognoses and I would go to meetings and appointments with them, part of their primary support circle, and learned a lot about it that way and it occurred to me that the work that I was doing in recovery, in psychiatry, a lot of those principles would apply equally well to how people recover from a cancer experience.

Chagpar Tell me more about that, because certainly people when they are diagnosed with cancer have a great deal of physical things that they need to recover from, but I would think that just the mental shock of getting that diagnosis of cancer and what that means to your life, your world, has a significant impact. Talk more about how that intersects with psychiatry and where you have taken that.

Sells A profound effect on identity and understanding of self, self in context of your significant relationships with your spouse, your children, employers, that is an excellent point.

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- Chagpar Tell me more about those personal interactions you had with people with cancer and how you felt much of the work that you had been doing in psychiatry would play a role.
- Sells The idea of identifying what sort of remains in the chaos that is kicked up through diagnosis, through the effect of the illness, through the effects of treatment and what remains in terms of your identified strengths, what you know you can do. Who is there for you that you can rally support from? What are the activities that you cherish that you can still do? All these things contribute to your sense of self and ultimately to the recovery of a psychiatric illness, but also when you are dealing with something as devastating as a diagnosis of cancer, and by natural extension, it seemed like if this held true then peer services, which were used quite frequently and with more regularity in psychiatry might apply equally well to people who are recovering from cancer.
- Chagpar Tell us more about what you mean by peer services. Is this kind of like cancer survivors helping other cancer survivors through what was possibly a devastating diagnosis?
- Sells Essentially, folks who have cancer or who have had it, can reach out to folks who are currently going through it, the rigors of diagnosis of treatment of the illness itself of how to navigate other aspects of their lives within that context. Somebody who has been there helping somebody out who is there now.
- Chagpar How does this work? I know that there are many people who have had cancer, who go to support groups, many who go to social work, is this the same kind of thing that you are talking about or is there a slightly different bend to the kind of work that you are looking at?
- Sells Slightly different bend to it insofar it is one-on-one where the relationship counts the most, but different from other sources of support like group meetings and such because it is one-on-one and different from speaking with a therapist because it is somebody who has been there and in that respect the notions of provider and receiver are a little bit more fluid, so somebody who is receiving the services can say “you know I discovered along the way that such and such thing really helps and you should try that out too” and it becomes a collaborative.
- Chagpar How do you bridge the whole notion of sometimes it is really great to hear what people have gone through and it kind of helps you to realize that while right now this seems to be completely turning my world upside down and I just think, how I can ever possibly get over this, getting to the point of not only can I get over it but I can actually turn this into a strength. How do you differentiate that from peers giving each other medical advice or information that may be in fact potentially harmful?
- Sells The folks who provide these services receive training and the roles are defined in the sense that they know that they are not there to provide medical advice but they are there to speak from their own experience from their heart and minds and offer that with that level of as to what worked for them and the person who is the “receiver” can accept that kind of advice, or they can reject it, can

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say “well that worked for you because of XYZ, but it would not work for me because of these other things and how can we adapt it in ways that will work for me?” But the notion of providing medical advice it is not part of the scene.

Chagpar How much of this peer support do you find is emotional support, in other words rallying around people to say you know what you are going to be okay, it is fine I got through this so can you versus giving people tangible tools to use in terms of reframing how they may see the world.

Sells It is both, it depends on where they both are in terms of their relationship. If the relationship is strong they can take some risks and say, enough is enough, you have got to do this, and don't you want to feel better? And that is the way it is and I know because I have been there, is the message. Starting out certainly you do not necessarily challenge the person in that way, you work on building a relationship and you generally work on building a relationship through providing support and understanding and things like unconditional positive regard, acceptance, all that stuff to build that foundation. Later on you can be more challenging and certainly along the way at each point you can offer practical types of guidance depending on what the receiver is asking for.

Chagpar One of the things that you said that I found particularly interesting and intriguing was that in these dyads of peer support that the giver has had some prior training as to how to do this in a way in which it will be helpful. I can imagine that there are many people who are sitting there thinking, “I have just been diagnosed with cancer, or I have a friend or relative or colleague who was just diagnosed, and they could really benefit from this.” How do they get that training to provide that support and/or how do they connect their friend, loved one, colleague into this kind of peer support?

Sells As to how they get the training, first of all if they want to be peer providers it would depend on the program that is out there in the community, such as Gardner's House up in Hartford, or the program here at Yale or through person to person, each has a particularly different way of approaching training and so which is your question about?

Chagpar I think that you have answered it in part by saying that there are a number of places where if you have had cancer and you want to be able to provide that kind to peer to peer support that you can get this kind of training because I can imagine that there are people who feel like they want to be part of that process, and would really benefit from that training. So you're saying there are a variety of avenues that people can use, and similarly, if there are people out there who want to receive support, one would presume that they go through the same kinds of networks, is that right?

Sells Yes, the same kind of networks. You can find these resources online. I do not have the websites handy, but they are out there.

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Chagpar That's okay, people can Google it, that is the benefit of search engines these days. I realize that you cannot speak for all of these various programs that are different in terms of training people to provide this peer support, but give us a flavor of how it works at your program at Yale.

Sells Actually I have not initiated the program at Yale yet. I was working more at Gardner's House in Hartford, but I can speak about that.

Chagpar Great, what we will do is we will take a short break for a Medical Minute and then as soon as we get back after the break we can learn more about training to provide peer support. Please stay tuned to learn more information about psychiatry and cancer with Dr. David Sells.

Medical Minute

There are over 12 million cancer survivors in the US right now and the numbers keep growing. Completing treatment for cancer is a very exciting milestone but cancer and its treatment can be a life changing experience. 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 like the one at Yale Cancer Center to keep cancer survivors well and focused on healthy living. 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 the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guest, David Sells. We are talking about psychiatry and cancer and right before the break Dave you were talking to us about peer support and how this is a one-on-one interaction that cancer survivors could have to help other cancer survivors get through the mental anguish that comes with getting a cancer diagnosis, and one of the things that I thought was particularly intriguing was the fact that in this peer support dyads that those who are giving the support can get actual training in how to do this. Tell us a little bit more about how that training process actually occurs?

Sells Once the person enrolls or contacts a particular program they are brought in to discuss their motivations and interests, their own personal experiences and what they feel that they can draw from it. This information is generally used ultimately to match based on aspects like personality and so on that are very important.

Chagpar One would think that this is beneficial not only for the receiver who would benefit from the wealth of information and the previous experience of the person giving this information, but have you also noticed in looking at cancer survivors who are on the giving side that they also benefit from that interaction?

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- Sells Yes, profoundly. In fact, the effects that we found in our research suggest that they ultimately have as much benefit as the folks who are receiving the care and this is a very interesting part of it because what folks are doing essentially is in providing the care, they are creating a transformation of meaning for themselves. What I am saying is you start off with the diagnosis, you experience the effects of illness, the effects of treatment, and all of it hurts and it is painful psychologically as well and it feels relatively meaningless, or you cannot find meaning, and it might not be immediately apparent what this is useful for, if anything. That is a tough thing. It might be the toughest thing. People generally do not mind the suffering as much if there is a meaning attached to suffering, and when there is not, it is just terrible. So, these folks go into cancer initially thinking of cancer solely as a liability, an endless trial of physical and psychological challenges that have also affected their families and caretakers. When they provide services and they see that the trials they have gone through are applicable to helping this person who is going through it now, there is this interesting shift from liability to asset which forms a kernel of meaning associated with these past experiences and it fosters recovery in a very profound way.
- Chagpar I can imagine, I think that that would help them as they kind of conquer this and say, I turned that liability into helping others and not only did I get over this, but now I am moving forward myself and helping others at the same time.
- Sells Yes, the sense of emotional suffering that they went through and that it was not for naught and certainly there are an infinite number of meanings you can attach to something like this, however, this is one way that peer services can help.
- Chagpar Tell us a little bit about recovery and how people go through recovery, is it that you go from cancer diagnosis, treatment, to I am over it, this is done and behind me? It seems to me that this is really a process. Can you talk a little bit about that?
- Sells In term of the process, Davidson and Strauss have an interesting paradigm in psychiatry that would apply pretty well to this and it is a stage-wise approach and has four different stages and they are not always sequential and overlap on themselves sometimes, but the first stage would be discovering a more active sense of self in the midst of the chaos and the pain, the realization that at least some part of the self is retained and some ability to act as well. This could be as simple as feeling exhausted from all the trials of illness and treatment, but recalling the simple pleasure of taking a walk on a spring day. The next stage often is taking stock, sort of like a status check. Okay, what are my existing strengths, what are my limitations? And thinking about them before taking further action on potential new activities. You could volunteer as a peer provider, you could return to other projects that had been placed on hold when you learned you had the illness. This stage might go on for a while as you meditate all the possibilities the advice the people offer you. So here you might think well, I am not up to doing a marathon, but I could take a walk down the block. Putting self into action and you get to that reflecting and incorporating the results

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of this action are also an important part of this stage. Start a daily walk routine, maybe you do not go far but the point is you initiated it, it is yours, and it has grown from your vision whether it is a block or a mile and finally there is appealing to the self which means that this new or renewed sense of your own agency to do things makes it easier for you to do other things, you have to go to your three or six months check-up which isn't pleasant but it is easier knowing that tomorrow you can go back to your routine. You can take another walk around the block. You have this as a counter point to the rigors of ongoing treatment and focus on illness when you have to do those things.

- Chagpar One of the things as you reach that fourth stage that struck me was that I have had many patients who are cancer survivors who at the end of the day really transform into doing things that they never thought they could, and they use that getting over cancer as a springboard to do any number of things, take a vacation that they never used to, spend time with kids, quit smoking, get into a good relationship or out of a bad relationship, go skydiving, take educated and informed risks that they always wanted to do because now they reached that kind of mindset of, I have got this.
- Sells Life is real, yeah, this is one of the benefits that participants have identified from time-to-time, this is it and I am going to do the things that I love or was always dreaming about.
- Chagpar Yeah.
- Sells And that gets lost in our daily routines.
- Chagpar I think that is so critical and it is something that as you say either things get lost in the daily routine that all of us take for granted, and sometimes for cancer survivors particularly it is that lens that all of a sudden makes everything really clear as to what is important. And they think, I am going to get out there and live my life and that is something that is a unique perspective in terms of recovery.
- Sells It is beautiful to see when that happens and it is different for everybody, it can take a while to get to that place but it is a remarkable thing to witness and I always feel privileged when I get to see that.
- Chagpar That is terrific, I want to turn to how we can move this field forward? I know that you have done a fair amount of research. Tell us a little bit about your research in the area of psychiatry and the intersection with cancer and recovery?
- Sells It is relatively new, where should I start. The research that is most typical I think is quantitative research, when you talk about cancer treatments and cures and therapies, and the key point in that research is how well these things generalize. Hopefully there are positive things, but ultimately the question of internal validity, generalization, will this work for everybody, or as many people as possible, is at the heart of it and that is profoundly important, however, we take a little bit of a

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different tract as qualitative researchers. We incorporate quantitative research, but the question in quantitative and qualitative research is less of how well things generalize and more the consideration of what is possible and that happens on a very individual level, so the research that we do focuses on people's stories, focuses on how they got to this particular point and what we do is we put together these narrative interviews with people who generally have been quite upfront and frank with us about their experiences, depending on how far they feel they have gotten in their recoveries. From that we map out a set of stages that they seem to go through that I referred to earlier and then what we do is we do several, maybe 20 qualitative interviews and we condense them. We take out the themes that are salient, and we put them together in ways that are sequential because usually in interviews they are broken up and you have to take those fractures of meaning and put them together in a way that flows. So you end up with maybe 20, 1-page narratives and you put them together and then you start looking across them and you say, what is it that everybody seems to identify with? And in that sense it is an elegant way of putting together a kind of general aspect to specific paths of recovery as identified through qualitative means. Ultimately the best way to do it is to put the two sources of data, qualitative and quantitative, and everything in between, narrative through members I like to call it, and put it together and see what it has to tell you.

Chagpar Terrific, in our last minute, can you give us a sense of whether this has been looked at in terms of what we talked a lot about, peer support? Does either the qualitative or quantitative data suggest that this is really helpful to cancer survivors?

Sells Yeah, absolutely, from both perspectives, from the perspective of the provider and from the perspective of the receiver, they get different things out of it to be sure, and they both feel better.

Dr. David Sells is Associate Research Scientist in Psychiatry at Yale School of Medicine. If you have questions or would like to add your comments, visit yalecancercenter.org where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.